

The moments we meet:

Lived experiences of rapport for nurses, patients and families in palliative care

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Abstract

Background: Nurses are charged with making rapport and connection with every patient, every shift, every day. Rapport and relationship are considered foundational to palliative nursing with its focus on the patient and their family. Yet the meaning and understanding of this rapport has received little research attention in palliative care.

Aim: To describe the lived experience of rapport and connection with nurses, patients and their families in palliative care.

Methodology: This is a phenomenological study informed by Max van Manen's approach to research. Twelve in-depth interviews were undertaken with nurses, patients and families. These were transcribed and thematically analysed and interpreted.

Findings: In-depth descriptions of rapport and connection come under two main themes of "Being Connected" and "Being Disconnected".

Being connected has sub-themes of connection to self and connection to other. Due to the context of Hospice there were also connection to place, and connection to spirit as subthemes. Associated with being connected were feelings of peace, ease, love, comfort and satisfaction. There was a sense that connection makes things easier and rapport was experienced.

While being disconnected has sub-themes of disconnection from self or disconnection from other. When disconnection was present there were feelings like sadness, anger, anxiety, frustration, and dissatisfaction. There was a sense that disconnection makes things uncomfortable and rapport was not experienced.

Key conclusions: Rapport is important and gives meaning and fulfilment in palliative care nursing. There are different levels of care given, related to the quality of connection created. Rapport and connection are linked to holistic care. An absence of rapport is linked to holistic care being unlikely. Rapport is the preferred way of connecting for all participants and a lack of rapport was considered unsafe and uncomfortable. There are implications for practice relating to kindness, safety and belittlement and rethinking rapport. This study has potential implications for all nursing where the nurse-patient-family relationships are a cornerstone of care.

Chapter 1: Introduction

There had seemed some mysterious rapport between her soul and mine

- Devil's Dice, William le Queux

He was blind. The nurse sat beside him and held his hand. His daughter holding his other hand, said "Dad, this is your nurse, she seems really lovely." He opened his unseeing eyes, glistening with tears and said, "I know, I can tell by how she is holding my hand". The nurse and daughter also had moist eyes, and all smiled in silence for some moments.

This is an experience of rapport from my own practice as a palliative care nurse meeting someone for the first time. It is demonstrating a rapport established and trust bestowed without having to say a word. This was in some ways an extra-ordinary meeting and in other ways an everyday occurrence. It demonstrates the power of open-hearted intention, non-verbal communication and a willingness to connect. This study is entitled, "The moments we meet" in recognition that in the field of palliative care as nurses we are only really in someone's life for moments in the totality of their whole life, we are only there for moments in a given day in hospice or community. We are only there for moments as a person dies or prepares to die. These moments can be of much consequence or not to the patient family or nurse.

This research project has emerged from a curiosity to know how rapport is created, what it is like and how important rapport is to care, particularly when someone is dying. There is curiosity to know how important rapport is to nurses in their everyday practice; is it conscious and intentional, is it unconscious and habitual? The New Zealand Nursing Council (2012), asks nurses to "establish rapport" as part of being a nurse. It is a nursing responsibility to commence maintain and complete the nurse-patient relationship of which rapport is considered an important part (Bryant, 2009, Dunne,2005). This study explores rapport and connection by interviewing nurses, patients and families about their experiences in interaction with each other. This is to discover the possible nurse-patient-family connections and rapport, ranging from platitudes and politeness to something transformative and healing. The main focus of the study is to discover more about the phenomenon of rapport as it is experienced in clinical practice. This study is guided by this the overarching research question:

What are the lived experiences of rapport for nurses, patients and families in palliative care?

The Purpose of the study is to explore the research question using a Phenomenological approach with the three main aims being:

1. To develop an understanding and in-depth description of the lived experiences of rapport from the viewpoint of the nurse, the patient and the family in palliative care.

2. To explore rapport and connection in relation to the quality of care given and received in palliative care.
3. To report findings and their implications for improving nursing communication practices in palliative care.

Palliative care is a growing and changing part of the healthcare sector, as the awareness of the needs and challenges of how to care for people as they are dying is spreading throughout our communities. Providers face the impact of our increasing aging populations and the impact of chronicity of illnesses and its effect on current resources and systems of care (Lancet, 2010). The parameters of how this care is being delivered are widening into primary care and the speculation of the numbers needing this care in the future is unprecedented (Ministry of Health, 2017). With so much tension between growth of need and finite resources there is perhaps a risk of communication being sacrificed before the gods of business and efficiency. The need to have awareness when creating rapport becomes important, especially if we are to maintain, let alone improve quality of care for dying people. This study will add to the existing body of knowledge about the type of nursing communication that best serves patients and their families during the universal human experience of dying. It also gives a reason to pause, to check in with what is driving nursing communication and is a reminder to take care of the most fundamental aspect of human connections in healthcare; that is how we meet and connect with each other as nurses and patients. This study has potential implications for all nursing where the nurse-patient-family relationships are a cornerstone of care.

Overview of this study:

This study is presented in seven Chapters.

Chapter 1 is a brief introduction into the background of the study, the research question and its stated aims and its relevance to palliative care communication.

Chapter 2 is a review of the literature in three parts. Part One looks at how rapport and connection are defined and described, what the components and characteristics are, with examples of how rapport has been researched in observed settings. There are sections on verbal and non-verbal components and acknowledging silence and its place in rapport. Part Two is more clinically focused, with the first meeting of nurse and patient, the recognition of rapport as part of effective communication, and the link to rapport and trust. There are sections that look at aspects of patient-nurse-family relationships and whole person care. Part Three examines the barriers to connection and rapport, and also looks at quality outcomes of rapport and future research needs identified in the literature.

Chapter 3 supports Phenomenology as both the methodology and the method used to explore the research question about the lived experiences of rapport in palliative care. Part One gives a background to the philosophy of phenomenology and the methodology applied in this research. Part Two outlines the research design, which includes researcher preparedness, the methods for collecting data, the sample size and selection of participants. The research design also

includes sections on interview questions and style, thematic analysis and phenomenological writing. To ensure research integrity there are also sections on other research considerations, ethics and consultation with Māori.

Chapter 4 focuses on “Being Connected” as a presentation of what is revealed in detail from the interviews of the nurses, patients and family members. “Being connected” has two main dimensions. Firstly, connection to self, with sub-themes of safeness and self-awareness, and being real and present. Secondly, connection to other, with sub-themes of safety and confidence, being conscious and deliberate, genuine personness, acceptance and inclusion, lightness, kindness and friendliness or being like family. Connection to place (as hospice) and connection to spirit are also sub-themes. With a section on the finding that rapport and connection make things easier.

Chapter 5 is a presentation of what is revealed in detail from the interviews of the nurses, patients and family members with the theme of Being Disconnected. Under “Being disconnected” there are two dimensions. Firstly, disconnection from self which is described with two sections: feeling unsafe and vulnerable and being not present or partially present. While being disconnected from other is described in the sections: separateness, belittlement, a sense of uncertainty or not known-ness and one-sidedness. With a section at the end on the finding that disconnection and lack of rapport make things uncomfortable

Chapter 6 includes discussion of significant findings, implications for clinical practice and recommendations for action. The themes and findings from Chapter 4 and 5 are further explored to offer understanding of the meanings of being connected and being disconnected. These are discussed under the headings of rapport and links to care, and between-ness and separateness. This understanding of meanings was then applied to the clinical implications of rapport in palliative care with headings: kindness and rapport, safety and rapport, belittlement has no place in nursing, and rethinking rapport as moments and micro-relationships. This is followed by recommendations for action in nursing practice.

Chapter 7 is the concluding chapter and includes a review of strengths and limitations of the study, researcher rapport reflection, suggestions for further research and concluding thoughts.

Chapter 2: Literature Review

Introduction:

Nurses use rapport of some sort every day. It is a requirement of each nurse's registration to achieve the indicator that they can "Establish rapport and trust with the health consumer" as part of the Interpersonal Competency (3.1) of the Nursing Council NZ, (2012). It is expected that nurses can do this, and it is expected they provide evidence that they can do this. Exemplars are given by individual nurses for portfolios and for appraisals of how they establish rapport. Good examples might be brought forth and fine communication work is probably being done, but this focus on rapport is sporadic. It is also unlikely to include the examples of when rapport is challenging or not achieved, with examples of lack of rapport scarce in the literature (Canning, Rosenberg & Yates, 2007; Duke & Bailey, 2008; Stein-Parbury, 2014). Rapport and the connections made with nurses, patients and families, and the clinical importance of these connections is what drives this review; with an aim to place this study under the palliative care communication umbrella.

Communication occurs as a constant dynamic process in all relationships whether we are conscious of this process or not, this follows the maxim that we cannot not communicate (Watzlawski, 1967). From this we can presume the same is true for all healthcare relationships too. There is much written about how important communication is for nurse-patient relationship (Dahlin, 2016; McCormack & McCance, 2010; Stein-Parbury, 2016) and there are good studies on the nurse-patient relationship in palliative care (Johnston & Smith, 2006; Mok & Chiu, 2004; Seccareccia, et al., 2015). With little written about rapport for nurse, patient and families, and the impact on care. The general tone of information found in the literature was generally of how rapport and connection *should* be and not how it is actually experienced. This is the gap that gave the original impulse for this research: to learn more about rapport as a lived-experience in palliative care.

To give a cohesive structure, this literature review has three parts. The first part is grouping the literature that helps define and describe rapport and connection, details the components and characteristics of rapport and connection, reports what rapport is like as observed in research projects, places verbal and nonverbal behaviours in making connections, and makes links with silence, holding space and rapport. The second part of the review is more focused on the nurse or patient literature found: the first meeting of a patient, establishing the role of rapport in effective communication, the link between trust and rapport, the dynamics of nurse patient and families relating, and the link with rapport and whole person caring. The third part of the review looks at the potential/actual barriers to creating rapport and connection, the links with rapport and quality outcomes, and considers further research needs.

Key Words:

Rapport. Connection. Nurse. Patient. Family. Palliative Care. Phenomenology.

Searches:

There were two main literature searches undertaken. One at the time of writing the proposal and another a few months later prior to interviews being conducted. Searches were made using CINAHL and SAGE Research Methods, Google Scholar and the University of Canterbury Library search algorithms were consistently productive. There were multiple combinations of the key words used on all data-bases. Interestingly during searches, it was difficult to access in-depth information using 'rapport' as a key word. It was when the word 'connection' was mentioned here and there in articles and books that access to literature changed. For this review it proved useful to expand search horizons by using both rapport and connection. The resulting literature found, use the words rapport and connection seemingly interchangeably or at least in very similar contexts. Another benefit for adding "connection" into literature searches was that it broadened the disciplines mined to include counselling and psychology, teaching, medicine and research, which provides other world views into similar therapeutic relationships.

Part One

Rapport and Connection

In this section of the literature review, both rapport and connection will be defined with etymology and examples from literature to show their relationship and how they are used in the context of this study. The meanings of rapport and connection in the dictionary are different but do have a level of relatedness. According to Merriam-Webster online dictionary (2017), rapport is a friendly, harmonious relationship; especially a relationship characterized by agreement, mutual understanding, or empathy that makes communication possible or easy. The online etymology dictionary has rapport meaning "intense harmonious accord," as between therapist and patient, is first attested in 1894. The same Merriam-Webster online dictionary (2017), was used to look at the word "connection" from Middle English, and from Latin, connectere, to become joined, to have or establish rapport. Connect and connection have several other meanings not related to this study, the following one was chosen: Connection: a binding or joining together which developed to include "to establish relationship" 1881 and to "awaken meaningful emotions or to establish rapport" from 1942, (online etymology dictionary, 2001-2018). Rapport is therefore linked to connection in meaning and for this review there is an overlap with connection where it can mean "to establish rapport and relationship". Connection can be used to describe a relationship, "they have a connection" which is neutral, or "they have an amazing connection" or a "poor connection" which is charged positively or negatively by the adjective. Whereas rapport has a more specific meaning implicit; rapport is harmonious and characterised by empathy trust and mutual responsiveness that makes communication easier.

In some literature the word rapport is not used at all, in Brene Brown's book connection is used throughout and defines connection "as the energy that exists between people when they feel seen heard and valued; when they can give and receive without judgement; and when they derive sustenance and strength from the relationship" (2010, p. 19). This definition could also

be a description of rapport. Whereas in their chapter “The power of high-quality connections” Dutton and Heaphy (2003), describe a connection as a dynamic living tissue between two people who share social interaction and awareness. Still other writers use neither rapport nor connection, for example, Jean Watson (2008), wrote, “Authentic caring relationship building... is about human presence, authentic listening and hearing, being present for another in the moment” (p.72). This is undoubtedly akin to rapport. There is other literature that blends the two terms of rapport and connection together. Epstein and Street (2007), write, “Rapport is a perception of connection with another person based on respect, acceptance empathy and a mutual commitment to the relationship” (p.19). Connecting is one of the dimensions of care in the model developed by Davies and Oberle (1990), where making a connection is described as getting to know each other in a deeper sense, spending time together, finding a common bond and establishing rapport. The title of Raine and Ewing’s book (2006), “The art of connecting: How to overcome differences, build rapport and communicate effectively with anyone”, is implying that a connection comes before the rapport. From these examples it can be seen that both rapport and connection are occupying a similar space in research and literature around relating. There is also a sense that rapport and connection are beneficial and important aspects of relationships.

Components or characteristics of rapport

Rapport is essential for effective communication (Antic, 2006). It is a concept of communication that has been described by Tickle-Degnen and Rosenthal (1990), as gestalt in nature (or perceived as more than the sum of its parts), and that “almost everyone has a rough-and-ready working definition of it”. This section seeks to better understand what constitutes rapport and connection, and what the components and characteristics are to help flesh out these working definitions.

In their landmark work, Tickle-Degnen and Rosenthal (1990), found that three components are needed for rapport to be present: mutual attentiveness, positivity and coordination. Mutual attentiveness is cohesiveness from the involvement with one another. Positivity is the feeling of caring warmth and friendliness. Coordination is when the participants have balance, harmony or are in sync with one another (Tickle-Degnen & Rosenthal, 1990). They noted that feelings of rapport emerge more readily when both a high degree of mutual attention and positivity are present at least initially (Tickle-Degnen & Rosenthal, 1990). These three components of rapport are echoed in Hall et al. (2009), Epstein and Street (2007), Goleman (2006), and Lakin (2009). In a similar vein, Dutton and Heaphy (2003), in their work on the quality of connections in corporate workplaces, found High Quality Connections (HQC) have three defining characteristics. 1. Higher Emotional carrying capacity. 2. The Tensility of the connection. 3. The Degree of connectivity. They suggest that the people in these HQCs are also likely to share three subjective experiences: feelings of vitality and aliveness, a heightened sense of positive regard, and feelings of mutuality (Dutton & Heaphy, 2003). They also referred to Low Quality Connections (LQC) which were found to be weak and unsatisfying and had the opposite characteristics (Dutton & Heaphy, 2003). Raines and Ewing (2006), studied people they call

Masters of connection who excel at creating rapport. Their mastery was documented into core principles and activities. These included: putting the focus on the other person, being present and unobtrusive, being unhurried in conversation, listening respectfully and being accepting of different beliefs and values. These masters of connection shared: looking for the common ground, not expecting reciprocity and having curiosity about people, as it is difficult to be both curious and judgemental at the same time (Raines & Ewing, 2006).

Rapport promotes communication, collaboration and a shared understanding of the patient's perspective and it requires good intentions, words and actions (Ross, 2013). It is recognised when a connection feels pleasant engaged and smooth but Goleman (2006), also says that rapport "matters far beyond these fleeting pleasant moments" (p. 29). The lists of other reported benefits of rapport include better compliance, care planning and with less complaints, Leach (2005), and that rapport enhances the strength of clinical relationships and leads to more satisfactory interactions; including job satisfaction (Mok & Chiu, 2004; Epstein & Street, 2007). Intentionally establishing and maintaining rapport may go a long way towards accomplishing more accurate diagnoses, higher levels of patient satisfaction, better patient compliance, and lower incidences of malpractice complaints (Buckman et al., 2011; Ross, 2013). There are also physiological benefits cited to experiencing a high-quality connection (HQC) such as a lower allostatic load with a stronger immune system and lower blood pressure (Dutton & Heaphy, 2003).

In the realm of neuro linguistic programming (NLP) rapport is thought of as "eliciting and holding the willing attention of another person or persons with a view to facilitating communication". (Collingwood & Collingwood 2001, p.5). It is considered so important that NLP practitioners are reminded to include rapport in every interaction. Rapport has verbal and nonverbal components and is understood to be conscious and unconscious (Antic, 2006; Lakin, 2009). As rapport between people may be evident when they unconsciously move similarly, talk at the same speed or tone, and even having the same breathing or heart rate, (Collingwood & Collingwood, 2001). Although mirroring and matching behaviours can deepen rapport, Lakin (2009), suggests conscious mimicry can also feel stilted and provoke negative response.

The observed nature of rapport

Ideally, rapport is measured from the standpoint of the participants themselves (Hall, Roter, Blanch & Frankel, 2009) but this can be difficult to achieve when researching from an external point of view. Observing rapport externally though does shed some light on what is happening when a dyad come together. The following are research findings where rapport has been observed.

Recognising the importance of rapport as a component of interaction, Puccinelli, Tickle-Dengen and Rosenthal (2003), looked at the context of non-verbal cues and how they affect rapport. Their results showed female observers perceived more rapport-facilitating behaviour under headings like responsiveness, friendliness polite sympathy, than the male observers. The activity the dyad is engaged in also affected the perceived quality of rapport, such as having a

discussion scored higher than a doing a puzzle together. Hall et al., (2009) used trained research assistants to rate rapport in a dyad, on a 1-9 scale from no rapport to high rapport. They defined high rapport as a relationship that was pleasant and engaging, a high degree of liking or positive affect, mutual attention, harmonious relation, easy/smooth communication, and synchrony in the interaction. Higher rapport ratings were associated with giving less information and providing more positive statements (Hall et al., 2009). Not directly observing, Ross, (2013) conducted a literature review of “real patient” encounters as training for rapport building skills with medical students. The focus was on using real patients not standardised patients as actors in a study. Conclusions drawn indicate this is both achievable and beneficial as a training method for health care professionals to gain skills with rapport.

Researcher rapport is the rapport needed when conducting research with individuals, as in interviewing. This rapport is recognised by Pitts and Miller-Day (2007) who say it is “potentially the most important” early steps a researcher takes in the field. Their work details relational turning points in the researcher-participant rapport of experienced researchers using a retrospective interview technique. The pattern of rapport building that was uncovered had five phases: Other orientation, self-in-relation to other, self and other linking, interpersonal connection and partnership. These are key relational turning points that move the researcher-participant from merely connected to developing a relationship (Pitts & Miller-Day, 2007).

There is increasing evidence to link neurobiology with first meetings (Hill, 2010) and beyond. Brown (2010), states we are wired for connection in our very biology, and that studies in neuro science show that our relationships affect our brain development. The amygdala has been recently credited with a social role as it heightens alertness to emotional cues in other people and creates what he calls an emotional contagion, where we can ‘catch” emotions from other people. (Goleman, 2006). Being with someone you like raises what is known as positivity resonance which raises oxytocin levels and results in calmer, friendlier more connecting behaviours (Fredrickson, 2014; Ricard, 2015). Brain “coupling” was found in 2010 by Stephens, Silbert and Hasson when they recorded brain activity of speakers and listeners. This neural coupling is what underlies successful communication (Stephens et al., 2010). Liben, (2009) refers to mirror neurons and their impact on empathy, with an example of someone smiling at you and the effect of this on the mirror neurons “creating a reflected smile on your own face without having conscious thought”. (p. 61). This supports the idea of interconnectedness. Buckman Tulskey and Rodin (2011), cite evidence of a neurobiologic substrate seen on MRI indicates acts of kindness toward another person may activate reward centres in the brain, and suggest being empathetic and kind may benefit both the donor and the recipient. The experiments with psychiatrists and the clients in session had each person attached to fingertip wires measuring sweat responses while being videoed (Goleman, 2006). The sweat response recordings rise and fall with emotions. Those visibly in rapport appeared to synchronise in movement and speech and their line recordings flowed together on the page. Those not visibly or audibly in rapport showed lines that moved separately “like jittery birds”, which Goleman described as a picture of disconnection. (2006, p. 28). The examples given in this section have

focus on the non-verbal components of a dyad in both clinical and non-clinical settings. This next section looks at the interplay of verbal and non-verbal communication.

Verbal and non-verbal behaviour

Verbal communication is commonly regarded as just the words we speak, whereas non-verbal communication is the tone, timbre and volume of voice and all other body language including the minutiae of facial expressions (Burgoon Guerrero & Floyd, 2010). Communication is said to be mostly non-verbal with figures ranging from 66% to 93% (Burgoon, et al., 2010). This means the verbal component is at most one third of total communication. Verbal content has links with understanding, factual and cognitive messages, while non-verbal content is linked to emotional, attitudinal and relational communication (Burgoon et al., 2010).

It seems people are constantly communicating both consciously or unconsciously. Watzlawski (1967), was the first to emphasise that we cannot not communicate saying, “activity or inactivity, words or silence all have message value” (p. 49). Watzlawski (1967) also attributed the label of digital to all verbal, and analogue to all nonverbal communication. A communication like a phone-call is digital (or verbal) with only the nonverbal cues from voice tone, speed and resonance, it can be limited by the lack of analogue information that would happen with a face to face communication. The words by themselves can give us a condensed message, which is what is seen in a text message or an email. Digital communication is prevalent today, and it is a common experience to have sent or received a text or email that is misinterpreted due to brevity, text language or misspelling. It is more challenging to establish rapport with digital only communication, analogue provides a fuller sensory input (Watzlawski, 1967).

Non-verbal behaviour is a continuous stream of movements and expressions (Tickle-Degnen & Rosenthal, 1990). Out of this stream we try to make sense of and interpret gestures, a raised eyebrow could have a quizzical meaning, or it could mean doubting, without context it is difficult to know for sure. So much of rapport is physiological with matching posture, movement, rhythm, gesture and blink rate or non-verbal with matching voice tone, tempo, volume, speed and intonation (Collingwood & Collingwood, 2001). Rapport may even be established with breath, either breathing in time with the other person or matching breathing with a repetitive gesture like a finger tapping (Collingwood & Collingwood, 2001). The ability to interpret this non-verbal language is learned and there is an expertise gained as these signals have been picked up since birth (Heyse-Moore 2008).

There is the understanding in Neuro lingual programming (NLP) that rapport is maintained superficially on the conscious verbal level while most communication is at the unconscious nonverbal level (Antic, 2006). So, while a synthesis in our communication occurs naturally it works best for rapport when what we say and how we say it are congruent. Carl Rogers (2016) describes congruence as a matching of experience, awareness, and communication and it is when the therapist “is fully and acutely aware of what he is experiencing at this moment in the relationship” (p.282). Congruency is necessary for the person receiving the message

communicated to feel connected. People rely on what they see over what is said if there is an inconsistency between verbal and non-verbal messages (Burgoon et al., 2010).

Some of the non-verbal behaviours the literature suggested as promoting rapport and connection included: Maintaining eye contact, leaning forward, nodding, and absence of fidgeting, (Epstein & Street, 2007). Speech rate and volume, posture, gesture and touch are important for rapport, empathy and support (Duke & Bailey 2008). Eye contact, smile, touch, (Dahlin 2016). Non-verbal communication like sitting with patients was identified as important to establishing a relationship of mutual trust (Seccareccia et al., 2015). In their work, Epstein and Street, (2007) found that warmth, caring and confidence may be communicated more through non-verbal channels like tone of voice. Burgoon (2010) found head nodding, forward lean, direct body orientation, uncrossed legs and arms, arm symmetry was associated with positive health outcomes. There were far fewer examples of verbal content that promote rapport. Wittenberg et al., (2013) refers to verbal clarity and to messages that are person-centred, and Dahlin (2016) suggests conversational proficiency and facilitative language, and Dunne (2005) points out the use of jargon can cause isolation, to consider the words and language used, to be understood. The power of words and language is thought to be “exceptionally cryptic”, (Fuks, 2011). Whereas, Duchan and Kovarsky, (2011) stress the importance of verbal attunement to rapport building.

Of note, the literature was lacking patient and families verbal and non-verbal communication, yet they are communicating constantly in many of the same encounters. This lack of patient-focused research is noted by Epstein and Street (2007), and they talk about the communication encounters with the patient and family members needing to be added to research required in the palliative care area. Non-verbal communication research is prevalent, but there is scope for more, as being aware of how nurses and doctors come across to patients is so revealing and useful to improve practice. Healthcare professionals may think that what they know and what they say is important, but patients give more weight to a doctor’s nonverbal behaviour than to what they say (Burgoon, et al., 2010). Therefore, what is said is important but how it is said is more so.

Silence and holding space

The ultimate in non-verbal communication is silence. According to Max van Manen (2014), there are 3 types of silence used in human science research. Firstly, literal silence as in the absence of speech, epistemological silence as when we face the unspeakable and ontological silence which occurs at those moments of greatest meaning or fulfilment in our lives. Silence is more than just not talking and for busy health practitioners not talking can be hard to do. The study by Beckman and Frankel (1984), showed the mean time of 18 seconds before patients opening statements are interrupted by doctors, followed by incorrectly assuming the first problem stated is the one for which they sought treatment. Hall et al. (2009), showed the interactive patterns indicative of rapport can be present in the first minute of an encounter with medical students and patients. Silence and rapport have a relationship as shown in the

Sharpley, Munro and Elly study (2010). Silence was testing for some counsellors, but the clients were appreciative of the silences. The results found higher amounts of silence during the minutes rated as 'very high' in rapport versus those rated 'low' in rapport. Counsellor-initiated and client terminated silences were more likely to contribute to rapport than silences initiated and terminated by the counsellor. (Sharpley et al., 2010).

Kelemen, Kearney and Groninger, (2017) note the difference between an awkward silence and an empathetic deliberate silence. The first is an indicator of uncertainty, of not knowing what to say and creates discomfort; the second is an intentional safe space for the patient or family member and it comes from the practitioner having attention, empathy and emotional balance. Kelemen et al., (2017) linked this type of silence to the concept in therapy literature of "holding space", the practice of active listening and allowing others to initiate action. Holding space is what the palliative care nurse caring for the mother of Heather Plett (2015) was able to do. Holding space is offering unconditional support and letting go of judgement and control, and is a complex practice that requires care and attention to develop (Plett, 2015). Sometimes the nurse is holding space for family, while the family holds space for their loved one dying (Plett, 2015). Learning to listen to silence and interpret its hermeneutics is suggested by Fuks (2011). By observing and listening to silence it is possible to calibrate to the breathing and movements of the eyes and facial muscles to create rapport (Collingwood & Collingwood, 2001). This calibrating of micromovements is a useful skillset for caring for unconscious patients and for settings like the important first meeting of the patient.

Part Two

The first meeting

"Hello, my name is ... and I am your nurse today." This is how many nurses start building rapport, a seemingly obvious verbal beginning to a relationship with their patient. It is also the name of the movement founded by Dr Kate Granger before she died, #hellomynameis has over 1.8 billion impressions since August 2013 (Granger, n.d.). This social media site was inspired as a result of her experiences as a patient with so many literally nameless health care professionals caring for her. It is where pledges are made to honour the power of the initial introduction, which can make a difference to patient outcomes (Granger, n.d.) The power of a good introduction is more than courtesy, "I believe it is the first rung on the ladder to providing truly compassionate patient centred care. It is also vital in developing the all-important rapport and trust on which to build a therapeutic relationship." (Granger, 2013). Connection in healthcare can bring together people with different agendas for a common good, as Dr Kate Granger posts "Introductions are about making a human connection between one human being who is suffering and vulnerable, and another human being who wishes to help." (Granger, n.d.) The moments of really meeting as people is when rapport begins, and those moments of rapport ideally continue throughout the nurse-patient relationship (Ross, 2013).

As well as this initial verbal communication though, there is a complex non-verbal relationship that has started before this introduction. It is expressed by the nurse with how they walk in,

their facial expression, their gestures are and even what their clothing is saying (Heyse-Moore, 2008). There is much that happens in this first meeting, including the instantaneous assessments being made by each person based on looks and feelings. There is a period of time in the first meeting, where there is an evaluation of each other (Heyse-Moore, 2008; Tickle-Degnen & Rosenthal, 1990), a determining if and how the nurse and patient can work together. It is also thought that the first few minutes of a meeting are crucial for rapport to develop and for trust to emerge (Leach, 2005). What happens in this first meeting can set the tone for the relationship between the nurse and the patient including what Daniel Goleman, (2006, p. 26) calls the 'hidden biological dance' we undertake in our everyday interactions.

During the first meeting there is an adaptive technique called "Reading the room" which can be used to engage palliative care patients and their family. According to Kelemen, et al. (2017), it is not only "reading" the people and their dynamics but also taking in sensory cues, such as lighting, noise level, eye contact and body posture. The responsibility lies with the nurse to make use of this function, the impetus is with the nurse to make a connection even if it is only a tendril because without connection, "tasks will be done but no healing will occur". They also found that the calibre of the nurse's ability to communicate consciously and effectively can be what makes a difference to a patient's stay. (Kelemen, et al., 2017)

Effective Communication

The ability to communicate consciously and effectively would seem to be a normative type of communication to expect from a nurse anywhere, and yet there is suggestion that effective communication is challenging for some practitioners (Hill, Evans & Forbat, 2015). In this section 'effective' is understood in the context of the nurse-patient relationship with interactions that are helpful or of benefit to the patient (Stein-Parbury, 2014).

Effective communication is fundamental to health and health care (Duke & Bailey, 2008). Patients who experience effective communication with healthcare professionals report greater satisfaction with their care, higher levels of understanding about their condition and more likely to adhere to treatments (McCarthy, 2014). Strong interpersonal skills are described by McCormack and McCance (2010) as more than the sum of the parts; it is the ability of the nurse to communicate at various levels, using verbal and non-verbal skills and emotional intelligence for each person-centred interaction. It requires knowing one's self to be able to know others; it is through understanding of self as an emotional being that gives understanding of the emotional being of others (McCormack & McCance, 2010). Rapport is considered by Duchan and Kovarsky (2011), to be key to the meaning-making that occurs in a dyad. "This places rapport in a central role in communication rather than as a mere lubricant" (Duchan & Kovarsky, 2011).

Malloy (2016) begins her chapter citing excellent communication is the most valuable skill a nurse can possess and endorsed as an essential element in palliative nursing by Dahlin (2016). Skilful communication with patients and families is crucial to provide quality end of life care and

has a negative impact when lacking (Seccareccia et al., 2015). There is an art of talking to dying patients (Seccareccia et al., 2015). As found in their study, patients wanted staff to be warm friendly and smiling, and feeling comfortable (Seccareccia et al., 2015). Which is similar to what Carl Rogers (2106) called an unconditional positive regard with a warm caring attitude that says, "I care" (p.283). A skilled communicator in the palliative care setting learns how to engage effectively and is able to adapt communication for particular goals, (Dean & Street, 2016). Such as listening. Seccareccia et al. (2015), found being heard was of central importance to the patient, that when a nurse was listening actively, it meant "hearing what the patient says not just listening to the words". Using active listening can create the rapport for a real partnership with patients to feel heard and affirmed (Bryant, 2009). It is both really simple and really difficult to listen, "it means not talking and this is hard" (Raphael-Grimm, 2015, p.50). Good listening reduces patient anxiety and helps patients see their nurse as empathetic (Seccareccia et al., 2015). Making gestures like touch and gently holding a hand while talking with a patient, can reduce the physical and psychological effects of stress and reinforce a sense of safety (Burgoon et al., 2010) and considerable comfort (Raphael-Grimm, 2015).

As discovered in the verbal/non-verbal section, not only what is said but how it is said is important. More than verbal and non-verbal content though, the whole style of communication nurses engage in affects rapport and connection (Cloyes et al., 2012). A collaborative style is considered important and can empower a patient to participate in their own care, whereas a parental/facilitative style that has a client "follow orders" may become a compromise to rapport, respect and compliance, (Leach, 2005). The study by Cloyes et al., (2012) explored naturally occurring communication between hospice nurses and family caregivers in the home. They found a facilitative style encourages a higher level of family engagement in decisions, a more partnership focused relationship, whereas a directive style is task orientated and informational. The facilitative style is useful to connect with patients and families by using other-orientated language, emotional expressiveness, vivid speech and by making space for caregivers to talk, all suited to palliative care. This style is aligned to "therapeutic use of self, or mindfulness where having a patient centred, relationship centred, goal directed, reflective practice is highly valued" (Cloyes, et al., 2012) and which Stein-Parbury (2014), calls therapeutic agency. It is likely to support communication that is "interactive, co-constructed and emotionally grounded" and allows rapport to play an integral role, (Duchan & Kovarsky, 2011)

Counter to this, Duke and Bailey, (2008) expose poor interpersonal skills resulting in ineffective relationships between patient families and healthcare team, with increased likelihood of complaints, dissatisfaction and negative outcomes. Skilled nursing communication is not always a result of communication skills training or how long one has been nursing. Nor do communication skills necessarily improve over time or with experience as observed by Duke and Bailey (2008), who also make the case for continued education and training, that take beliefs and attitudes, and death and dying into account.

Rapport as antecedent to trust

Communication and connection are essential to establish a trusting relationship and improve the patients experience (Dahlin, 2016; Seccareccia, et al., 2015). Ross (2013), says that establishing rapport is central to any healthcare professional-patient encounter and trust is also considered an integral component of the therapeutic relationship. Leslie and Lonnemann (2016) undertook a nursing literature review of trust; identifying antecedents, attributes, and outcomes with registered nurses and patients in home healthcare. Of the elements identified before trust is established, one is ensuring a positive first visit. Rapport is part of the first visit, when the nurse “acts like a guest” and takes the required time to make a connection with the person by responding to the “gestures, body language and conversation” of the patient. The nurse needs to demonstrate 1). active warm caring communication 2). a sense of connection and 3). reciprocity. These attributes are also needed to create rapport. Trust was noted as not given freely but had to be established on both sides. (Leslie & Lonnemann, 2016).

Epstein and Street report that patients who have “greater trust and rapport with their clinician can lead to an openness and a willingness to discuss personal and sensitive topics” (2007, p.132). Davies and Oberle (1990) also talk about the interrelatedness of connection and trust from the other viewpoint, saying until trust is developed connecting will not occur. An example may be where a surgeon is trusted to do a good job but may not have rapport with their patient, or a practitioner may easily create rapport but there is not enough confidence in their competence to establish trust. It is necessary to have both trust and rapport for the relationship to be a healing one (Kelemen, Kearney, and Groninger, 2017).

A trusting and connected relationship was a key finding for Mok and Chiu (2004), helped by the nurse demonstrating skill and sensitivity to the unique responses of the patient (Canning et al., 2007). A factor that may affect trust emerging was observed by Mok & Chiu (2004), as the nurse-patient relationship is not reciprocal and not equal. The nurse is not dying, the nurse can go home and de-role and let go of the suffering (Mok & Chiu, 2004). Duke and Bailey (2008) cite poor communication is linked with erosion of trust and the patient feeling not seen or understood and therefore less likely to disclose fears and concerns to healthcare personnel. This type of communication is linked to poor job satisfaction and increased job stress and burnout (Duke & Bailey, 2008).

Nurse patient families relating

Palliative care is both patient-centred and family-centred (Epstein & Street 2007; Dahlin, 2016; Wittenberg et al., 2013). The communication needs of the patient and their family are part of the mix when developing relationships for care. Strong patient-family-nurse relationships are hallmarked by trust, rapport, respect, and involvement of all parties (Dahlin, 2016; Epstein & Street, 2007) and considered a “critical foundation” of specialist palliative care nursing (Canning, et al., 2007). Patients and their families want to be involved in care, be informed of options, feel listened to, and feel known as a person, not a disease. Both the patient and the family members appreciate respect and value having clear explanations given by caring nurses

(Dahlin, 2016). Hospice and palliative care can be destabilising for a family as it “suggests an outcome that will ultimately result in a shift in the family system” (Wittenberg et al., 2013 p. 123).

The nurse-patient relationship is the core of nursing according to Halldorsdottir (2008) who uses the metaphors of the bridge and the wall to describe the variation in caring connectedness. The bridge is representing caring connection and communication that patients experience with nurses, while the wall is reflecting the lack of caring, the lack of communication and the lack of connection patients can experience (Halldorsdottir, 2008). This could also apply to family interactions. It is the nurse who is primarily responsible for developing and maintaining client rapport (Leach, 2005). Davies and Oberle, (1990) identified making, sustaining and breaking the connection as a nurse responsibility. The nurse makes and sustains these connections with patients and families “to empower them” (Davies & Oberle, 1990). Patients may also initiate connection (Halldorsdottir, 2008) which requires the nurse to listen and then respond. Building rapport with patients and families was found to be the way to build trust and kinship (Seccareccia, et al., 2015). Their research aimed to identify elements essential to quality of care in palliative care. Communication was identified as the cornerstone for patient and caregiver satisfaction, with the subtheme of “building rapport” as a key approach to supporting family members whose loved ones are dying. Patients stated that good rapport with staff provided a sense of belonging and made them feel the care was genuine. Simple things like learning names of patient and families were reported as helpful and respectful (Seccareccia, et al.,2015).

Whānau is the Māori word for family. This is a term used colloquially in New Zealand. As described by Mason Drurie, (2001), “whānau can be whakapapa whānau when all members descend from the same ancestor and their shared heritage goes back 4-6 generations after which this group blends into the wider hapu. Whānau can also be kaupapa whānau who are not actually related through any ancestral link but who behave towards each other in a family-like manner, usually bound together by a shared commitment”. (p.190-191). In palliative care it is common to see both kind of whānau.

Tess Moeke-Maxwell (2014), is clear that respectful and culturally sensitive nursing care that is whānau-centred (family-centred) is vital for Māori palliative care. Recognising that people actively draw on elements of their culture to manage times of stress, she offers nurses a Māori model of care with the image of a pair of cupped hands, te kapunga (Barton & Wilson, 2008). The left hand is nursing practice and the right hand is Māori practice. The palms are representing sustenance, life and effective nursing care, the fingers are each representing different aspects of tikanga. If all ten figures are put into practice it would exemplify palliative care nursing. The need to provide palliative care that is whānau-centred is “crucial” for the person and their whānau (Moeke-Maxwell, 2014). One of the aspects of whānau-centredness is Manaakitanga, the concept and value of respect, hospitality and generosity. Manaakitanga is reciprocal unqualified caring and is seen “in everything you do to care for the people” (Richie,

1992, p.75). It is viewed as “imperative” that the nurse provides manaakitanga to the Māori person and their whānau as a sign of holistic caring (Barton & Wilson, 2008).

The need to attend to the meaning of death and dying for the patient and their families is recognised as a key part of palliative care communication (Duke & Bailey, 2008). There can be challenges for the nurse to balance the needs of both patients and their families. There can be complex existing family dynamics with the added stress of someone in their family dying. This time of heightened emotions sometimes means the families intentions and actions may cause distress as well as comfort. Both patients and families come to palliative care with their own beliefs, values and emotions and goals which can influence communication and care (Dean & Street 2016; Epstein & Street, 2007). When conflict arises, Dahlin (2016), advises to remember the patient’s needs and wishes and Wittenberg et al., (2013) encourages nurses to become familiar with the family’s unique communication style to mitigate conflict. Sometimes family members are not asked their opinion if they are perceived to be too talkative and lengthen visits or be disruptive (Epstein & Street, (2007). On the other hand, families felt frustrated by sparse information, infrequent communication conflicting communication between providers, and communication from staff only when the situation is serious (Dahlin 2016; Wittenberg et al., 2013). Chochinov, et al., (2015), conducted a study to discern the impact of the patient dignity question (PDQ) on patients and families and its influence on health care personnel in palliative care. Their conclusion was the patient dignity question offers an effective way to elicit personhood for patients and their families and staff (Chochinov, et al., 2015).

It is not known how a high-quality connection is formed, or how it helps a patient adjust to illness (Epstein & Street 2007 p. 131). However, it is known there are nursing attributes that facilitate connection such as kindness, warmth compassion and genuineness (Duke & Bailey 2008; Johnson & Smith 2006; Mok & Chiu 2004) emotional intelligence (Dahlin, 2016) being nice, having human sensitivity, taking time to be present and caring (Taylor et al., 2001) and friendliness (Leach, 2005). Janssen and Macleod (2010), suggested doctors develop a relationship with those they are caring for as individual human beings. A qualitative study (McCarthy, 2014) looked at healthcare professionals (HCP) communication in a chemotherapy unit from the patient participants viewpoint. One of the things patients liked most was as the relationship developed they could talk about everyday things not just illness and treatment. They also valued being treated with respect, sensitivity and compassion and the involvement of family members, while a good sense of humour, listening skills and kindness were important in the nurses. O’Brien (2016) makes the comment that “you won’t find much on kindness in your average nursing dictionary or textbook” He reflects that patients and family accounts of care often use the term kindness but questions whether nurses themselves value kindness. Kindness has a part to play in relation to rapport, trust and empathy (Ballatt & Campling 2011), in the therapeutic relationship.

Rapport and whole person caring

There is a thought-provoking statement from Sally Gadow (1980, p.87) “Regarding the patient as a whole would seem to require nothing less than the nurse acting as a whole person”. To care for the whole person means to care for them in mind body and spirit, and is a tenet of palliative care nursing (Canning, et al., 2007). “Spirit is relational in its expression. That is, it is expressed in relationship, in dialogue, in communion with others and with the Other” (Mount, 1993). This relational spirit and caring communion can be expressed while sitting with a dying person.

“It is our responsibility to listen to people as they struggle with their dying. We need to be willing to listen to their anxieties their fears their unresolved conflicts their hopes and their despairs. We need systems of care where people are able to find their deep sense of meaning and purpose in the midst of their suffering, where they can find peace”
(Puchalski, 2002).

This is similar to the skills Duke and Bailey (2008) suggest when faced with discussions of an existential nature with patients. That is to have the willingness to be present and stay with the person while holding the space for the other’s suffering. Dunne (2005), defines presence as a way of placing ourselves completely in relationship to understand and be there for the other, and goes on to say this presence creates healing and peace that can facilitate grieving for patients and families. From Carl Rogers, “I have found that the more I can be genuine in the relationship, the more helpful it will be”. (2016, p 33). Stein-Parbury (2014) describes “being for” the patient as a moral position, an attitude and a commitment from the nurse to embody caring, whereas “knowing the Patient” requires nurses to know the patient as a person and assists with holistic care planning and clinical decision-making, (Stein-Parbury, 2014). One study of nurse-patient relationships in palliative care says it is up to the nurse to begin the encounters with patients (Mok & Chiu, 2004) and that the nurses who developed trusting connected relationships demonstrated a holistic approach to caring, had awareness and understanding of patients suffering and needs, while being reliable, proficient and dedicated. Nurses reported feelings of personal growth, satisfaction and enrichment from these encounters (Mok & Chiu, 2004).

A good place for nurses to start working holistically with Māori people is to recognise wairua, or spirit and beyond the physical realm (Moeke-Maxwell, 2014). Wairua is a fundamental dimension of Māori health and particularly when caring for the dying. Moeke-Maxwell also stresses the importance of nurses coming to grips with the concept of mauri, the vital essence or life force, as it will increase the nurses’ awareness of the sacredness of each person and their whānau. “Everything the nurse does from the first point of contact until the last contributes to the mauri being strengthened or weakened within each patient/whānau encounter” (Moeke-Maxwell, 2014). Simply be aware that “everything has a spiritual dimension” (Ritchie, 1992).

To be person and family-centred requires the nurse to have strong interpersonal skills linked to emotional intelligence, McCormack and McCance, (2010). The sort of intelligence that Carl

Rogers demonstrates, "I have found it of enormous value when I can permit myself to understand another person" (2016, p.18). This kind of understanding is a choice and it is risky.

"If I let myself really understand another person, I might be changed by that understanding. And we all fear change. So, as I say, it is not an easy thing to permit oneself to understand an individual, to enter thoroughly and completely and empathically into his frame of reference. It is also a rare thing" (Rogers, 2016, p.18).

Giving another person your undivided attention is both powerful and healing, according to Heyse-Moore, (2008) and asks practitioners to consider the opposite. What happens when that attention is withheld? Heyse-Moore (2008), also asks us to check where our attention is and suggests it needs to be both outwards towards the patient and inwards to one's own inner processes. If there is resistance with connection at this point the nurse needs to check if it comes from within, "as the nurse who withholds herself is unlikely to allow the patient to emerge as whole" (Davies & Oberle, 1990). A relationship that allows the emergence of the whole person between nurse and patient is one where they meet and know each other as people as well as nurse and patient (Stein-Parbury, 2014). There is often a transformative effect for both nurse and patient with this level of connection. This is where whole person nursing by whole nurses may be found.

Part Three

The Barriers to creating rapport and connection

Nurses coming into palliative care often have little preparation in the kind of communication skills that palliative care requires. These skills are learnt by trial and error, on the job, rather than taught formally or mentored (Dahlin, 2016). This means there is unlikely to be an overall concept of palliative care communication and all that is involved (Dahlin, 2016), which may be a potential barrier to connection as skills and confidence are gained. Ross (2013), laments that opportunities to hone skills and personally connect with patients are often overridden by the need for information, decisions or tasks. Duke and Bailey (2008), point to the challenges to effective communication by nurses in palliative care raised by the awareness of their patient's death. Nurses hesitating or doubting themselves frequently underestimate the power that their own beings can have in influencing the health outcomes of their patients (Minicucci, 1998). It is noted that the most difficult conversations in palliative care are existential in nature and practitioners are challenged by being in the face of another's suffering and being unable to do anything for the person (Duke & Bailey, 2008; Hill et al., 2015).

Part of the challenge with creating rapport is it is misunderstood and under-appreciated. Duchan and Kovarsky (2011), say, "rapport is often viewed as an exchange of pleasantries" and that communication itself is wrongly metaphorised as a pipeline of messages. With these flawed premises rapport is only noticed when it is not there or problematic (Duchan & Kovarsky, 2011). Recognising the potential difficulty with rapport and nursing Watson (2008), says "Perhaps one of the most common problems arising in nursing is the failure to establish

rapport, being insensitive, unable to connect, or create an alliance with another “(p. 74). Failure to connect was found to lead to misaligned expectations, distress, unmet needs, and perceived low quality of care. (Seccareccia, et al., 2015). This failure to connect can be related to nurses not resolving their own grief and being fearful of triggering emotional responses in others (Dahlin, 2016). In low quality connections (LQC) there may be a weak tie between the people, but the connective tissue is damaged and feels like a “little death in every interaction” (Dutton & Heaphy, 2003). Without a belief in the worth or value of others and in their inherent strengths and capabilities, the nurse will be unsuccessful in providing supportive care. (Davies & Oberle, 1990). Despite the references previously to rapport being mutual and having a reciprocal nature, this is not always the case for nurses and patients. There are times when there is a lack of mutuality and reciprocity, when maybe the nurse or the patient or family member do not want to or cannot connect (Stein-Parbury 2014; Wittenberg, 2013). This may result in a unilateral relating (Morse, 1991).

Not having enough time is cited as a barrier to connection. The tension of completing the expected tasks of a shift and meeting the emotional and psychological needs of the patient and the families is recognised as difficult (Hill, Evans & Forbat, 2015). If pressured by time towards doing tasks then the level of communication can become superficial and ineffective, (Duke & Bailey 2008; Wittenberg et al., 2013) and time constraints can also have a negative impact on patient outcomes (Leach, 2005).

Patients and families may not wish to appear complaining, so may not ask questions or seek clarification to information (Dunne, 2005). Barriers to the trust relationship forming were particularly a lack of respect, where the patient felt unaccepted, and incompetent or unethical care, (Leslie & Lonnemann, 2016). An inability to adopt another’s viewpoint may reveal itself in awkward pauses, and this lack of coordination can be felt as a lack of rapport, according to Tickle-Degnen and Rosenthal (1990). Culture and language can be barriers to connection when customs are unknown of the dying person, or how to express complex ideas with limited shared language, (Dahlin 2016).

Brown (2010), has researched shame and its impact on relationships and connection. Equal to the need to connect, there may be a fear of disconnection which can act as a barrier to meeting the other. As long as a connection is considered valuable there is fear of its loss and disconnection (Brown, 2010). This fear of disconnection is linked with shame and guilt. These are feelings that can be hidden for a lifetime and it may be the dying process makes them more likely to appear. The study by Hill, Evans and Forbat, (2015) looked at the responses of nurses working in hospice to the psychosocial needs (PN) of patients. Results showed there were four main ways of reacting: Dealing with the need as it arose, ducking the need, diverting the need to others and deferring the need to be dealt with later. There was a reluctance to deal with difficult emotions, even from nurses with education in this area. Ducking diving and diverting may have an effect on nurse-patient rapport if the patient feels unsupported with emotional or psychosocial needs. Raines and Ewing (2006), suggest noticing one’s own reactions, if there is

emotional trigger, and check if the responses help or get in the way. Watson (2008) sees a lack of connection as a lack of a reflective mindful awareness on the part of the nurse.

Rapport, Quality Outcomes and Research

Measurement of the quality of rapport on patient outcomes in palliative care is an under-researched area. The closest found is the study by Seccareccia et al. (2015), which focuses on communication and quality of care in palliative care units as assessed by patients, caregivers and nurses. Their findings assured the importance of communication and rapport in palliative care. Duchan and Kovarsky (2011), suggests rapport matters when evaluating outcomes of therapy. Otherwise judgements on how well an encounter with a patient goes, is perceived potentially differently by the participants (Epstein & Street, 2007). In other words, it has been difficult to assess the effect of rapport and connection on outcomes, as each person in the interaction will have a different perception. Leslie and Lonnemann, (2016), found if the nurse and patient have rapport and the beginning of a trust relationship then outcomes for the patient can tend towards 1) improved collaboration and adaptation to illness, 2) a sense of security and 3) creating additional trusting relationships. Good communication skills between patients, nurses and family members is of paramount importance for effective patient outcomes, (Dahlin 2016; McCarthy, 2014). It is hard to find the evidence to support these statements. In the area of organisational research Dutton and Heaphy (2003) make the case that high quality connections are life-giving and low- quality connections are life depleting. The links are there but research is needed to translate this to the health/ palliative care setting to confirm the relationship with high quality connections and effects on health for nurses and patients and families.

Despite the amount of research available on communication and rapport, there are gaps. One of the gaps identified is around experiential palliative care connections with no current literature on patient family and nurse rapport. There has been a call for more research in the area of rapport by Leach (2005) and Ross (2013) as they found only a small number of studies dealing specifically with rapport building skills. Cloyes et al. (2012), cite “substantial gaps in knowledge about how patients, caregivers and providers interact in real life” and that this is particularly true in end of life care. Also noted, there is more research available on the physician-patient dyad than other relationships, with little known about the unique elements of nursing communication (Cloyes et al., 2012; Dahlin, 2016). There is relatively little research focused on how nurses communicate with family and patients in the hospice setting, (Cloyes et al., 2012)

Even though there is more medical research undertaken there are still gaps. With Hall, et al. (2009), saying not much light is shed on the concept of rapport during the medical visit in spite of its acknowledged importance. Epstein and Street (2007) recognised that communication research tends to address one-off clinical encounters whereas the patient will have numerous encounters with health care professionals over a period of time. They also recommend to “assess patient perceptions” of their healthcare professional relationships and goals of care.

Epstein and Street (2007) identified the lack of research into family involvement and the roles the family play in communication in palliative care.

Summary

The aim of this Literature review was to assimilate what is known about rapport and connection generally and in the palliative care setting with nurses, patients and families in particular. Also, to determine a context for this study and the gap it may contribute to. The literature found was divided into three parts.

Part One: The terms rapport and connection were defined, and a link made to their intersection of meaning in the literature and how they are being applied in this study. From there the characteristics of rapport were teased out from the literature with the three key elements of Mutual attentiveness, positivity and coordination cited as essential to rapport (Tickle-Degen & Rosenthal, 1990). A number of benefits for rapport and connection are mentioned, such as improved patient compliance, improved patient satisfaction and less complaints. Rapport is thought to be generally positive and life enhancing although evidence for these claims is difficult to find. Rapport uses both verbal and nonverbal communication and has conscious and unconscious components. There is growing evidence to link neurobiology with rapport and connection with discoveries like two brains can create neural coupling and become in-sync with no words spoken. The use of silence is found to be more than not talking and has significance when listening and holding space for another person. Patients and families like silences and perceive the practitioner to be there for them when this is done comfortably.

Part Two: The power of the introduction as Dr Kate Granger endorsed so clearly, is an opportunity to really meet someone, and to set a respectful tone of human meeting human. As the first meeting can be such a laden encounter of assessments and judgements, the first moments of meeting can really matter. There is emphasis on having effective communication skills clinically and rapport is considered part of these skills. Communicating with dying patients is thought to be an art as well as a skillset that is learned with experience. It takes a confident self-aware practitioner to sit, listen and be present with warm regard and genuine interest for the other. There are links with rapport and trust, and from the literature it is unclear if one is necessary first for the other to be present. What is referred to is that relationships that have both trust and rapport are more likely to be healing in nature. Palliative care is both patient-centred and family-centred, it is constantly recognising the intrinsic value of including the loved ones of a patient in their care and discussions. Having a cultural awareness of the patient and family is crucial to connecting. The dynamics of whānau and family care can be complex, unsettling and mutually rewarding. The nurse makes and sustains connections with patients and families to be able to empower them (Davies & Oberle, 1990). Being collaborative and informative is perceived as useful, patients and families need the nurse to connect and communicate with care and kindness. Whole person care is when the whole person gives care to another person treated as whole. Always considering the physical, emotional, psychological and spiritual domains of care. Rapport is expressed in whole person care as being present,

being in communion and holding space for the other, these are practices to becoming whole practitioners.

Part Three: There are many potential and actual barriers to nurses, patients and families connecting. The literature was weighted to place responsibility with nurses, in terms of lack of confidence, skill and self-reflection. The barriers to connection were cited as nurses ducking diving and diverting patient's psychosocial concerns, uncomfortable to sit with a patient's suffering and not encouraging trust. There is also a tension between time for tasks and workload and time to connect. Feelings of shame and fear of disconnection are possible blocks to connecting and would benefit from more specific research. The effects of no or poor connection are reported to be misaligned expectations, distress, unmet needs, and perceived low quality of care. (Seccareccia, et al., 2015). There seems to be a link with rapport and the quality of care for patients, but the evidence for this is difficult to find at present.

The literature makes claim that rapport is essential to relationships in the palliative nursing context and yet it is not well researched or evidenced. It is often tucked into studies as a sub-theme or into textbooks as a part of communication skills. It is perceived that rapport is difficult to capture in research as results may differ from person to person. There are calls for this research to be done from medical and nursing sources and it seems important to represent patients and families as their research voices are only dimly heard. From this data, it is revealed that although there is much written about rapport, it is not necessarily overt, often mentioned deep in texts, and piecemeal across disciplines such as teaching, counselling, psychology, research, medicine and nursing. It also reveals that rapport is at once a universal concept that is used and talked about and yet has a mysterious ephemeral quality that is poorly understood in the clinical setting. It is surely an alchemy of art and science. It is a phenomenon.

Chapter 3: Phenomenology as Methodology and Method

The Purpose of this chapter is to demonstrate how the methodology, method, and research design align and fits together with the overall research aims of the study to address the research question. The first part of this chapter (Part One) is exploring the philosophy of Phenomenology as methodology and providing rationale to support this research approach for this project, it also includes a brief background to Phenomenology. The second part of the chapter (Part Two) covers the phenomenological method, the research design is detailed with sections on ethics, handling of data and other research considerations included.

Part One: Phenomenology as Methodology

Phenomenology is considered to be a philosophy and a methodology and a valid form of method, (van Manen, 2015). Van Manen (2014), sees Phenomenological human science as being essentially discovery orientated, allowing the finding out of what a certain phenomenon means and how it is experienced. Therefore, this project adopts the concept of holding rapport as a phenomenon to be discovered, that is, to hold a sense of wonder about the meaning of rapport as it occurs every day, and to wonder about what it is at its essence. The taken-for-grantedness of rapport has led it to be 'shrouded in unconsciousness' (van Manen, 2014), and this study provides a way of looking at what is behind the shroud of the everyday task of nurses meeting patients and families. It allows access to a different view of experiencing the words of the participants and to uncover the meaning of rapport and connection while reflecting its value in the clinical setting.

Research methodology is the world view or epistemology that flows through the study from beginning to end. In this case the methodology is Phenomenology, in particular Hermeneutic Phenomenology as influenced by Max van Manen (2014; 2015). The term Hermeneutic is the theory and practice of interpretation, with an etymology coming from the Greek god Hermes as messenger from the gods to mortals (van Manen, 2015). While this connection to celestial communication is an interesting image to hold, for ease of use in this study the term "Phenomenology" will be used throughout and understood to be of a hermeneutic nature.

When considering which research methodology to use for this study, a Phenomenological approach emerged as the most congruent to answer the research question:

What are the lived experiences of rapport for nurses, patients and families in palliative care?

As the primary questions left unanswered from the literature search were "What is the nature of rapport?" and "How is it experienced?" both of which can be addressed in a phenomenological way (Taylor & Francis, 2013). As does "How does the phenomenon show itself?" (Smith, Turkel, & Wolf, 2013). These questions fit well with rapport being considered a phenomenon and considering how it shows itself in the relationships with nurses, patients and families in palliative care. Oiler, (1981) claims the phenomenological approach is appropriate

for nursing research because the nursing profession has a reverence for the client's experiences and for the quality of the nurse patient relationship. Both Benner (2008) and Mak and Elwyn (2003) describe phenomenology as holistic which particularly suits patient- based research. It also seems Phenomenology is used when little is known about a topic, when the research context is poorly understood, the boundaries ill-defined, and the nature of the phenomenon is not clear (Morse 2003, as cited in Klopper 2009). The analysis of the literature reviewed suggests that rapport is partially understood and the essence or meaning as experienced is unclear.

According to van Manen (2015), the methodology one chooses ought to maintain a certain harmony with the deep interest that makes one a (nurse) in the first place. For me that is a commitment to communication and connection with the people in my care, and as such I can personally and professionally align to the existential requirements of the research methodology as described by van Manen (2015). He also says that research and writing are inseparable, so by being a nurse undertaking a phenomenological research project means also undertaking to become a thinker and a writer with thoughtful attentiveness to the phenomenological approach.

As rapport is a key part of communicating effectively with patients (Bryant, 2009) and to developing a trust relationship, rapport is also considered to contribute to excellence in nursing care and to improving patient outcomes (Mok & Chiu, 2004). The intention of this study is gain understanding and inspiration that allows nurses to have a fresh awareness into how they approach rapport with their patients. A phenomenological study has potential to contribute to palliative care nursing by adding rich data about the experiences of nurses and patients and their rapport. This richness of data shines light on this fundamental aspect of relationship and contributes to making the concept more meaningful (Dunne, 2005). Palliative care as a sector is looking towards phenomenology more in the 2000's to explore the many phenomena that are part of caring for the dying, such as nurses understanding of honesty (Erichsen, Danielsson & Friedrichsen, 2010) and understanding the desire for euthanasia (Mak and Elwyn, 2003). Using Phenomenological interviews gives voice to all participants (Janssen & Macleod, 2010) including family members, unfolding a deeper understanding of what the experience of rapport actually is, as experienced by nurses and patients and whānau. Conducting this study is a response to the call for more research on rapport in nursing, medicine and allied health (Epstein & Street, 2007; Leach, 2005) and will add to the existing body of knowledge about the type of nursing communication that best serves patients and their families during the universal human experience of dying.

Background to Phenomenology

As a young man in the nineteen sixties in the Netherlands, van Manen became interested in Phenomenology as it was pervasively influencing art music writing and social thinking (van Manen 1997). He has maintained a fascination which infuses his writing as a phenomenologist and an educationalist with a love of pedagogy over the last few decades. He has focused on

deciphering the practice and meaning for students of education, psychology and health sciences, resulting in this methodology being adopted for many research projects across many subjects including palliative care, (Janssen & Macleod, 2010; Johnstone & Smith, 2006; Mok & Chiu, 2004). Van Manen refers to the contribution of the many before him who influence the place where he sits within this field of phenomenology and considers it important for researchers to know of and to have read the phenomenologists who influence their particular research (van Manen, 2014). The history around Phenomenology has some of the great thinkers of last century sharing and critiquing their philosophies and ideas, dedicating careers to writing about what it is to be in the world, what it is to be a human being experiencing meaning.

The phenomenological movement had early beginnings with Franz Brentano (1838-1917) placed as a forerunner to what is known as the philosophy of phenomenology, (Spiegelberg & Schuhmann, 1982). From this inspiration came Edmund Husserl (1859-1938) who is credited with being the founder and remains a central figure of phenomenology today (Spiegelberg & Schuhmann, 1982, p.70). His philosophy has as a central tenet “the wonders of wonders is pure ego and pure consciousness”. This is where Husserl seems fascinated that there is “such a thing in the world as a being that is aware of its own being and of other beings” (Spiegelberg & Schuhmann, 1982 p. 81). The term transcendental phenomenology began with Husserl. It is commonly regarded that Martin Heidegger (1889-1986) was the legitimate heir to Husserl in the realm of phenomenology and was mentored by him to assume this role, but it appears this was a challenging relationship with the two diverging their thinking in the late 1920s with Heidegger announcing, “That man alone... experiences the wonder of all wonders: *That there is being*” (dass Seiendes ist) (Spiegelberg & Schuhmann, 1982, p. 347). This existential phenomenology of Heidegger was labelled by him as “thought of being”. He remains a major influential figure in Phenomenology.

In France meanwhile, Jean Paul Sartre (1905-1980) an accomplished playwright, novelist, critic, political figure, was also a philosopher. He reluctantly accepted the label of existentialist while also being regarded to be heavily influenced by phenomenology and particularly Husserl and Heidegger. The central themes in his philosophical writings were concerned with the meaning of freedom and the meaning of being with him famously claiming “We are condemned to freedom” (p. 540). As contemporaries, Maurice Merleau-Ponty (1908-1961) and Sartre shared a challenging relationship as philosophers, over the years moving from close friends to eventually becoming ideological rivals (Spiegelberg & Schuhmann, 1982). Merleau-Ponty’s major work was the “Phenomenology of Perception” where he both echoes Sartre and defies him with “We are condemned to meaning” (Merleau-Ponty, 1996 p. xix).

Of the many themes that are woven through these phenomenologists work, it could be said they share interest in Meaning and Essence and Being. These are themes that will be reflected upon in this study in relation to What is the meaning of rapport/connection; and what is the essence of the experience of rapport/connection in the clinical setting and What is rapport like

for the self and the other as beings. According to Benner (2008), Phenomenology is at once philosophical and methodological. We have dipped into the philosophical background and the rationale used to select Phenomenology for this study. It is also necessary to describe the phenomenological approach as method, as it has been applied throughout this project.

Part Two: Phenomenology as Method

Phenomenology is a method for questioning, and for discovering in detail what the “lived experiences” of the participants are in relation to the phenomenon being studied (van Manen, 2015). “Method refers to the way or attitude of approaching a phenomenon”, (van Manen, 2014, p. 26). The key way to approach a phenomenon to access pre-reflective experiences is by using or even living with epoché and reduction which van Manen (2014) credits as the great finds of Husserl’s phenomenology. The terms epoché and reduction are explored in the researcher preparedness section below. What is being asked of the method, is to be a way of breaking-through of the taken-for-grantedness of the experience of rapport and connection, to be a way to gather descriptions of the pre-reflective experiences of the participants and to be a way to explore how their words reflect meaning. The way to do this as method, is not as defined for Phenomenology as for other research approaches (van Manen, 2014). To assist with understanding the method of Phenomenological research, van Manen has written about six methodological themes. He offers these as a framework with the understanding they do not work in isolation but perform best as a “dynamic interplay” of all these research activities (van Manen, 2015, p. 30-34).

1. Turning to a phenomenon which seriously interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualise it
3. Reflecting on the essential themes which characterize the phenomenon
4. Describing the phenomenon through the art of writing and rewriting
5. Maintaining a strong and oriented pedagogical relation to the phenomenon
6. Balancing the research context by considering parts and whole

These six methodological themes have been sitting in the foreground of my thinking when planning and creating the overall research design in its practicality.

Research Design Outlined

The aim of the research question and the phenomenological methodology is to transform the participants lived experience into a text that reflects and has resonance with the discovered essence of rapport and connection. In phenomenological research the access to peoples lived experiences is through the sharing of their experiential accounts (van Manen 2015). As this project seeks to provide in-depth description and understanding of the experiences of rapport from the viewpoint of nurses, patients and families in palliative care, it was decided this would be best achieved by phenomenological interviews. The interviews were phenomenological by nature, semi-structured, conversational, recorded and professionally transcribed. Thematic analysis was undertaken alongside description and interpretation as per van Manen which

culminated in a “textual expression” of the essence or meaning of the experiences of rapport and connection shared in the interviews (2014; 2015).

The key areas of this design will be covered and detailed as to what was planned and implemented. These key areas are: Researcher preparedness, the method of data collection, the selection criteria, recruitment and consent of participants, the interview style and questions, and thematic analysis and phenomenological writing. Also covered are: other research considerations, the sensitive handling of data and research ethics and Maori consultation.

Researcher Preparedness

As Phenomenology can suffer from being used just as a label for qualitative research with neither the language nor the philosophy of phenomenology being integrated into the study (Taylor & Francis, 2013) guidance of researchers familiar with phenomenology have been sought to undertake a study deserving of the name (Armour, Rivaux & Bell, 2009). This included reading phenomenology texts throughout the project, learning particularly about the epoché and reduction. Van Manen sees a human science researcher “as a scholar; a sensitive observer of the subtleties of everyday life and an avid reader of relevant texts in the human science tradition”, (2014, p. 29). I understand this to mean that the philosophy needs to be read understood and essentially become part of the researcher’s worldview at least for the time of the project, it requires immersion.

To take up the phenomenological method requires the researcher to reflect on his or her own assumptions with the aim of making them as clear as possible (Benner, 2008). To assist the researcher to develop a practice of reflecting in a phenomenological way, van Manen writes about the two concepts of epoché and reduction (2014; 2015). Epoché is from the Greek, meaning abstention, to stay away from, adapted by phenomenology to mean the suspension of the attitudes of taken-for-grantedness or pre-suppositions (Moustakas, 1994). Van Manen describes this as an openness of taking a new view that disturbs the taken-for grantedness of the everyday phenomenon. “The epoché is how we open ourselves to the world as we experience it and free ourselves from pre-suppositions “, van Manen, 2014, p. 220. As Moustakas, (1994, p. 80) writes, “The challenge of the epoché is to be transparent to ourselves, to allow whatever it is in consciousness to disclose itself so that we may see with new eyes in a naïve and completely open manner”. The reduction literally means to lead back, from the Latin, re-ducere and the reduction “is an attentive tuning to the world when in an open state of mind (epoché) so in this openness insights may occur” (van Manen, 2014, p. 218). According to van Manen, the reduction is not a procedure, rule, or strategy that can be applied to the phenomenon being studied it is more like “a complex reflective attentiveness that must be practiced for phenomenological understanding to occur” (2014, p 221).

Data collection methods

As evidence from phenomenological research comes from first-person accounts of their life experiences, (Moustakas, 1994), it was decided that the interviews for this project be in-depth

semi-structured and of a conversational nature. (van Manen, 2015). Face to face interviewing was chosen, as engaging directly with the patient is considered the most valid way to collect data regarding quality of life issues for people who are dying (Janssen & Macleod, 2010). The Interview length initially was expected to be from 30 - 60 minutes with special consideration of the wellbeing of the patient participants at the time. As an experienced nursing practitioner, I have assessment skills and empathy to check a participant's level of energy, for example, some interviews may have been rescheduled or cut short due to participant fatigue or unwellness. I was vigilant about being flexible and proactive in accommodating each person's needs. The actual time range for interviews was from fifteen minutes to one hour fifteen minutes. Of note from Seymour and Clark (1998), "the skilled phenomenological investigator gathers data in ways that are minimally intrusive, and which maximize the abilities of the research respondent to contribute". This was particularly relevant for patient interviews and one of the family interviews where in a short time they had said all they had to say. There was no advantage to prolonging the interview. Sites for interviews were in quiet, private rooms onsite of the local hospice with "interview in progress" sign (or similar) on the door. The patients chose their own rooms and for family members an interview room in the hospice was made available. For the nurses the interview venue was offered to be either onsite or away from clinical area as they wished. This resulted in two interviews offsite and three interviews onsite. All the interviews were audiotape recorded and professionally transcribed. Prior to interviews beginning, there was a restating and checking of consent and privacy issues and data handling, with participants given the opportunity to ask any questions. Field notes were taken by the researcher either directly after the time of the interviews or later to assist with analysis and understanding.

Participant sample size and selection

To gain "localised, personal accounts from people who have experienced a particular phenomenon and are willing to speak about it" (Taylor & Francis, 2013, p. 191) it was decided participants be self-selecting for nurses and purposive in the case of patients and family members. Participant numbers sought were 3-5 hospice nurses and a combined number of 5-6 for hospice inpatients and family members. This is considered an appropriate sample size for the in-depth nature of a phenomenological study where the process of gathering quality data has greater focus than high participant numbers. (Taylor & Francis, 2013). Below are the inclusion and exclusion criteria used for selection of participants

Selection Criteria for study			
	Nurse	Patient	Family Member
Inclusion	-experience in hospice/ palliative care (2+ years) -Currently working in palliative care -RN/EN	-a diagnosis of life- threatening illness with life expectancy of >2 years and not < 2 weeks. - a hospice admission in last 3 months	-a relative with life limiting illness/condition - their relative has had a recent hospice admission - interested and willing to undertake interview process

		-Interested and willing to undertake interview process	
Exclusion	nonclinical/management role		

The nurses who participated

The aim was for five nurses to participate in the interviews and this was achieved with five people responding readily to the approved internal email inviting participation in the study. There were three registered and two enrolled nurses who expressed interest. I met with each of them and discussed the project and answered their questions, from there they responded with signed consent forms. They were then acknowledged as accepted and a time was made to interview them individually.

I began each interview with the soft and rapport building question of “How long have you been nursing and in palliative care nursing in particular?”. The answers from each person ranged from 6 to over 40 years with the total number of years nursing at 110 and for palliative care it was a total of 40 years. These are undoubtedly experienced nurses with a particular depth of knowledge of caring for patients both living and dying. It was a privilege to interview them and each gave generously of their time and experiences with rapport. It was proposed that participating nurses be offered 8 hours for professional development credit, in recognition of the time needed to read proposal, sign consent, participate in interviews and subsequent member checking and report reading. Being involved may also provide encouragement for other nurses to undertake or support research.

On receiving their transcripts to check for accuracy, the nurses expressed some sensitivity to seeing their words in print. It was disconcerting for them to see the words and incomplete sentences and fillers like um and yeah, that are often in our spoken language. There was reassurance given that their words would be used respectfully with some small grammar edits to ease the readers way. As is common practice, names and some details of narrative altered to provide a deep level of identity protection without affecting the essence of the telling. Therefore, along with removing first names and assigning nomenclature Nurse A, Nurse B, Nurse C, Nurse D, and Nurse E, some details of stories have changed to offer protection to the nurse and patient and family members identities.

The patients who participated

This was a special group of three people who wanted to be interviewed for this study. To meet the study criteria, they had to have a life limiting illness and be both willing and able to

participate. The method for recruitment of patients was gentle, with an invitation to find out more about participating in a study about rapport and connection in the clinical setting if they were interested. This invitation was by way of a small leaflet (appendix, i), as approved by the Nurse Manager of Hospice for those assessed as potentially qualifying and interested, for the patients to see, and talk to their nurse about. Once a verbal indication of interest was obtained then each person met the researcher. This was to provide the research project information sheet (appendix, ii) verbal and written information outlining the study purpose, procedure, and proposed handling and use of data. Once the consent form (appendix, iii) was signed, a time was made for an interview soon after with the reassurance that there was flexibility to withdraw, decline or reschedule for any reason. All three interviews were undertaken in the patient's own rooms in hospice as was their stated preference. The door was closed and the do not disturb sign put up to provide a secure private environment. Two patients spoke to me individually and the third had her partner with her as support.

On discussion with staff in hospice the interviews were planned to be approximately 15-30minutes long with vigilance paid to the patients for fatigue, pain, nausea and breathlessness. The interviews began with asking how long they had had contact with the health system for their current illness and how many doctors and nurses they had met along the way. "Dozens", "many", "many and more" were the answers which allowed the questions to follow about the types of connections they had encountered along the way. The questions were asked about palliative care generally to include their experiences at home or clinics or hospital as well as hospice, as each of these places can provision palliative care. It also meant those who had only been in hospice a few days could safely bring up previous experiences. Every effort has been made to protect the privacy of these participants and all identifying names places and details have been altered. Once the consent forms were signed the identities of these patients referred to throughout this text became Patient A, Patient B and Patient C.

The family members who participated

There were four family members who met the criteria and participated in the interviews. Three were family members who signed consent forms and were interviewed as individual members of a family with a loved one who had stayed in hospice. Plus, one man who sat in a support role for his partner's interview and with his permission, some of his comments are reflected here also. Apart from him the family members were interviewed separately in a private clinic room in the hospice which had been booked and had an "In Session" sign on the door to avoid interruption. These interviews had less time constraints and varied in time from fifteen minutes to over an hour depending on what the participants indicated was comfortable by checking with them during the interview. The interviews began again by asking how long they had contact with the health system with their family members condition and how many nurses had they met along the way, to give context for their experiences of rapport. For privacy, the identity of this group was altered to Family 1, Family 2, Family 3 and Family 4.

Interviews and Questions

It was important to have an attitude of warmth respect and equity as researcher for each participant. It was also important to provide a relaxed atmosphere for the interviews to be conducted in, privacy was ensured with closed door and sign on the door to alert a session was in progress. There was an acknowledgement of appreciation at beginning and end of each interview, there was a reiteration of care taken with privacy and handling of data and that the interview would be audio recorded. Reassurance was offered that the transcript would be made available for them to check accuracy if desired.

The planned topics included: Connection and rapport between nurses, patients and families, with examples of when this is present and when it is absent. What works and what does not to make a connection with each other. How does the quality of connection affect care delivered and received?

A conversational interview approach was used and to attain the “free flow of consciousness” that will allow for deeper inquiry into the research subject (Taylor & Francis, 2013 p. 207), some questions and prompts were prepared to facilitate this flow. These questions were open-ended and posed informally and balanced with the use of nonverbal encouragers such as nods and silences. Examples of questions which were used. The first three questions are group specific and used as rapport building questions to provide context to the questions on rapport and connection.

- How long have you been nursing, and particularly palliative care nursing?
- How long have had this illness/condition? How many nurses have you met in this time?
- How long has your family member had this illness/condition? How many nurses have you met in this time?
- Can you think of an example of when you felt rapport/connection with a patient/nurse/family member? (Given time to think) What was that like?
- Can you think of an example of when you did not feel rapport/ connection with a patient/nurse/family member? (Given time to think) What was that like?

Examples of additional questions

- What is that like when the rapport between you goes well?
- What is that like when the rapport between you is difficult?

Examples of prompts used:

- Tell me more about that?
- What was that like?
- What else can you tell me about that?

As the researcher, I read a page with these questions prior to each interview with a reminder about the epoché and setting aside pre-judgements, biases and preconceived ideas about who

and what and how things were said in the interview. Moustakas (1994), mentions the epoché process may also be necessary during the interview, this was sage advice as I became aware of my own thoughts at times and my readiness to speak instead of listening and receiving from the participants. It was useful to have the word epoché to remind me to be present and open to what was being said or not said.

Thematic Analysis

The phenomenological understanding of a theme, entails reading the text with a question: What is being revealed about the meaning of the phenomenon being studied? Although a theme is understood to be only capturing one aspect of the lived experience, it is a useful means to getting at the meaning of the experience (van Manen, 2015). Thematic analysis requires attention and openness (epoché) to develop themes that are insightful and reveal essence or meaning of the phenomenon (Van Manen, 2015). Thematic analysis can “capture some of the phenomenological qualities of the experiences” as engagement with data and analysis takes place (van Manen, 2015, p.88) What can be revealed with themes is the expression of meaningful patterns, stances of participants or concerns (Benner, 2008). These revelations and themes come by staying close to the text, (Benner, 2008) which is why extended text inserts and exemplars are used in phenomenological writing.

The basis for the thematic analysis for this project is coming from van Manen’s Human Science Methods chapter, (2014, p. 319-323). In this chapter van Manen refers to Thematic analysis regarding the text in three levels. “In exploring themes and insights, we can treat texts as sources of meaning at the level of the whole story; at the level of the separate paragraph; and at the level of the sentence, phrase expression, or single word” (2014 p. 320).

1. Wholistic reading approach: Each interview was therefore read through looking for the phenomenological, ordinary or fundamental meaning in its wholeness. A phrase to capture this meaning was then formulated in relation to rapport and connection.
2. Selective reading approach: Reading through the text again, letting the eye wander over a paragraph, asking what is being revealed about rapport in this paragraph, highlighting the phrases or passages which were “evocative or possess a sense of punctum” (van Manen, 2014, p. 320) about rapport and connection.
3. Detailed reading: this was a line by line or sentence by sentence reading of the texts again, with the aim to capture what this sentence reveals about rapport and connection.

These three processes produced a document for each interview which held all three approaches: an overall impression of the essence of the experiences described, the selected paragraphs that were looked at for punctum and the detailed analysis of each highlighted sentence. These documents formed the basis for the analysis for each interview from the nurses, patients and family members. This method enabled selecting exemplars from the texts which demonstrate the meaning or understanding of the phenomenon (Mak & Elwyn, 2003; van Manen, 2014).

As the interviews occurred in groups; with the nurses first, then a gap for the patient interviews due to recruitment issues and then the family interviews; this was also how the texts were analysed initially with overall themes looked at later.

Thematic analysis revealed the essence of the whole of the interview content fell into two domains, that of being connected and that of being disconnected, with various sub-themes under each. These are the headings used in Chapter four: Being Connected and Chapter five: Being Disconnected with the in-depth descriptions from the participants to illustrate each theme.

Chapter 4
Theme: Being Connected
Sub-themes:
<ul style="list-style-type: none"> • Being connected to self- a sense of safeness and self-awareness, being real and present • Being connected to other- a sense of safety and confidence, of being conscious and deliberate, genuine personness, acceptance and inclusion, lightness, kindness, and friendliness or being like family • Being connected to place- hospice • Being connected to spirit
Chapter 5
Theme: Being Disconnected
Sub-themes:
<ul style="list-style-type: none"> • Being disconnected from self- related to feeling unsafe and vulnerable, being not present or partially present • Being disconnected from other- related to feelings of separateness, belittlement, a sense of uncertainty or not known-ness and one-sidedness

Phenomenological Writing

As a starting point for writing, van Manen says “Phenomenological writing is not just a process of writing up or writing down the results of a research project” (2014, p.20) He describes writing as a reflective process and a reflective part of the phenomenological method that attempts to recover experiences from life as lived. The aim is not to make the experience into a thing or an object but to contemplate on the meaning of the living moment. Van Manen (2016), talks about the challenge of avoiding objectifying as it is so commonplace for us to do this, compared to the way of thinking that is required to write in an evocative analytical way. An understanding of phenomenological writing has grown while analysing and reflecting on the texts and writing about the findings. The stance from the acquisitive research mode changed to one of living with phenomenological reflection and writing about the lived experiences shared during the interviews. Immersion into the stories was achieved by reading re-reading transcripts and listening to recordings, and, looking at each selected sentence several times to find or come to its inceptual meaning. This process of reflecting on the inceptual meanings from

the lived experiences required patience to create text that expresses the uniqueness of what is uncovered, what was previously unseen, yet resonates as truth as an experience. From a methods viewpoint this involved learning how to reflect and write about phenomena and “bring participants experiences into language” (van Manen 2015, p 35).

Phenomenological text depends on cognitive meaning, argument, logic and conceptual intelligibility but it must also appeal to the non-cognitive mode of knowing an inner meaning, (van Manen, 2015). There is also a call for the writing to resonate and reverberate with reflective being with words like evocative and epiphany (van Manen, 1997) called upon. Working with these ideals the resulting thesis has considered the effect of appealing to the cognitive and non-cognitive responses of its readers and to be accessible thoughtful and evocative.

Other Research Considerations

This section considers the backroom features of the research project that are not content driven but are necessary to create a research text with rigour and integrity.

Rigour- This study includes in its design, techniques as based on Lincoln and Guba (1985) that serve as checks and balances against the imposition of researcher bias to ensure the study can provide trusted information on this important human phenomenon. (Armour, Rivaux & Bell, 2009). Moustakas (1994, p. 84) adds this, “In accordance with phenomenological principles, scientific investigation is valid when the knowledge sought is arrived at through description that makes possible an understanding of the meanings and essences of experience”. Every attempt therefore has been made to keep the text accessible to understanding. Benner (2008), also says that rigour involves staying true to the text, with Seymour and Clark (1998) adding, to generate a credible and insightful account.

Prolonged engagement - judicious length of time required to have rapport with each person participating, to enable a depth of interview based on trust. This was different for each group. The nurses were all known as colleagues and prolonged engagement and rapport were achieved. For patients the window of opportunity for rapport and interviewing was brief for health and energy reasons but was achieved each time. For family members the focus for them was their loved ones so again the window of opportunity to meet with them was limited by their visiting schedules. For each interview rapport was created and this is borne out in the depth of sharing in the interviews.

Persistent observation- while interviewing to have specific topics to cover and explore them in-depth with full sensory awareness. Understood as part of epoché to be in a state of openness and awareness.

Triangulation- to use multiple data sources to gain different perspectives on a given topic: field notes, interview tapes, transcriptions, researcher reflexive diary, checking literature once a theme identified.

Debriefing and feedback- Regular scheduled meetings throughout project with Supervisor and/or experienced researcher in phenomenology.

Member checking- Checked transcriptions were offered to participants to review their own transcript if they wished. This was offered to all participants, but nurses were the only ones who wanted to do this.

Thick Description – this small sample size will give in-depth information and enables rich descriptive data to be reflected in analysis and findings.

Audit trail- reflexive diary to record thought feeling and decision rationales. Keeping true to proposal outline and timeline with careful documentation of changes and rationales for decisions made. Phenomenologists demonstrate the accuracy of their data by including detailed case studies, extended extracts of interviews and from field notes. (Seymour& Clark, 1998).

Researcher reflexivity- While analysing interpreting and writing and aiming to keep a phenomenological sensitivity to the project, it was useful to hold the questions: Does this account attempt to explicate being, of the thing itself? (Taylor & Francis, 2013). Is this what the experience is like? What is my thinking about this? Recognising a story within a story; as a researcher needing to have rapport while researching rapport, I was cognizant of my own rapport with participants, as highlighted by Green and Thorogood, (2009) and McGarry, (2007). A reflexive diary was kept by researcher to distinguish pre-knowledge of being a nurse working in palliative care and having previous communication training. Exploring ongoing experiences with rapport and connection as researcher and nurse, to record thoughts, feelings, inspirations, discouragements, creativity and decisions, separate from the research text to be included if relevant. Sensitivity was applied to researcher/ participant relationship and potential power imbalances, particularly due to potential vulnerability of this patient group (McGarry, 2007; Taylor & Francis, 2013). Although regarded as a vulnerable group, there is research to suggest people with life limiting illness will perceive benefits from participating in research and that patients often wish to be involved for altruistic reasons as observed by Fairhall, et al., (2012).

Ethical Considerations:

Ethics approval was gained from University of Canterbury (UC) (appendix, iv) and site approval was gained from the Hospice ethical advisory group. Issues considered for these approvals included: the nature of the topic, interviewing dying persons while protecting their wellbeing, privacy and confidentiality and ensuring withdrawal from the study was possible with no questions asked and no coercion. The research project Information Sheet covered issues regarding data recording and handling. Participants were made aware what happens to their data if they withdraw from study, that after a certain date (July 3rd, 2017) that data from their interview, may still be included in the final report. Up until then their data could be withdrawn. Confidentiality is covered in the consent agreement and demonstrated by a code being allocated to each consent form which is used throughout the study. Removing all identifiers

from transcripts such as names and locations before transcripts are used (Green & Thorogood 2009) and given to participants to review. Stringent security of data handling including password protected electronic files and using a locked file for hard copies of documents and back-ups has been adhered to. No deception has been involved at any stage of this study.

Other researcher responsibilities include ensuring the care and wellbeing of each participant during the interview process and any follow up. Each interview began by offering a warm welcome, reiterating confidentiality, having awareness of cultural needs and potential sensitive issues, while demonstrating respectful time management and ending with genuine thanks (Taylor & Francis 2013). Ensuring rest periods for patients prior to an interview and being sensitive that interview times may be cut short if patients became unwell or fatigued. In that case a later interview could be planned if consented.

The researcher aimed to demonstrate a general awareness and ability to manage potential participant issues of tiredness, emotional expressions and catharsis (Taylor & Francis, 2013). The intention of the questioning was to discover experiences of rapport and connection; it was intended that this would be a benign process. However, in the unlikely event of emotions being triggered, time would be given for the feeling to pass. As an experienced practitioner I have assessment skills which enable me to recognise the difference between a healing expression of feeling and a distressed one. If the participant was feeling distressed the interview would cease and support offered. If the offer of support was accepted a referral would be made for either Kaia whina or Family Support to see them, at no cost to the person.

This study is thoughtfully planned and intends no harm, offence or deception. The researcher is aware of moral, and cultural sensitivities as an experienced practitioner working in this area and has used careful thoughtful language and non-verbal communication at all times. In the unlikely event of offence being taken, there was a plan to offer immediate support for the person affected, from either a Kaia whina or a member of the Family Support team. An apology would also be offered by the researcher.

Māori Consultation

Māori consultation was sought as selection criteria for this study was open ethnically and as early engagement in consultation is recommended, an application was made in August 2016 (via UC Māori consultation webpage). A letter of support from Ngai Tahu Consultation and Engagement group was received (appendix, v). This study seeks to have awareness of specific cultural needs of Māori in palliative care particularly during the research process and invites consultation to improve this awareness. The methodology of Phenomenology has synergy with Treaty of Waitangi principles as it invites participation and partnership whereas protection is more specifically covered with both the consent form and confidentiality clause and researcher responsibilities as outlined in the Ethical Consideration paragraph above. Interviews was centred on patients, with their whānau present if desired, and recognise the physical, social, emotional and spiritual elements of wellbeing - tinana, whānau, hinegaro and wairua

(Muircroft, McKimm, William & Macleod, 2010). Respect was shown to each person involved and their contributions honoured and received as the taonga (treasure) they are.

Conclusion:

This chapter has focused on the methodology, method and research design chosen for this project and ensuring there is alignment with these to gain a deeper understanding of the research question and achieve the study aims. Phenomenology has provided the philosophy for both the methodology and the method, with a research design that is congruent with this philosophy. This continuity of approach has allowed immersion into the phenomenological research paradigm.

Part One: Phenomenology as methodology. This part of the chapter covered the broad notion of Phenomenology as a philosophy and a methodology for research. There is a brief look at a few of the key phenomenologists and particularly Max van Manen as the guiding light for this study.

A rationale has been offered as to what makes Phenomenology a sound choice for this study, including the gap in literature which produces questions about what rapport is like and what is experienced in terms of their rapport and connection when a person is dying, which helped to shape the research question in a phenomenological way. There is precedence with nursing adopting phenomenology as a research approach as its philosophy fits with the nurse's reverence for the patient's experience and the quality of the nurse-patient relationship (Oiler, 1981). With Palliative care nursing looking to phenomenology to explore some of the sensitive issues arising from caring for the dying (Mak and Elwyn, 2003). This study hopes therefore to add to the body of knowledge of palliative care nurse-patient- family relationships.

Part Two: Phenomenology as method. This section covered the method as a description of how this research attitude is taken, and how lived experiences are captured and how the meaning of the phenomenon is understood and expressed. The six research activities are listed with the understanding they are dynamic and evolving with each project. The research design is detailed and includes researcher preparedness, data collection methods, participant sampling and selection, the participants themselves, interviewing and questions, thematic analysis and phenomenological writing. The backroom design is also detailed under the headings: other research considerations, handling of data, privacy ethics and Māori consultation.

Therefore, with an ever-unfolding awareness of Phenomenology as methodology and method in place, it is time to turn again to the research question: "What are the lived experiences of rapport and connection for nurses, patients and families in palliative care? and to consider what was offered in the interviews that helps to answer that question. To manage the amount of data and to create an ease for reading, the findings have been divided into two chapters. As the essence of the whole content of the interviews falls into either experiencing "being connected" or "being disconnected", Chapter 4 therefore is entitled "Being Connected" and Chapter 5 is entitled "Being Disconnected."

Chapter 4: Phenomenological meanings of Rapport

Being Connected

Max van Manen mentions there is a moment in all research projects when the researcher has to “communicate in writing what they have been up to” with a report (2014, p.363), and the results chapter in particular. This means taking the mind puzzle of insights from the interviews to a kind of written form that is, in essence, true to the participants lived experiences, and true to the methodology. The accumulated pages of detailed meanings that emerged from the transcripts were packed full of interesting, concerning and illuminating truths, hundreds of items, each with their own value to the concept of rapport. The task of this chapter and the next is to bring these lived experiences and reflections of essential meanings together to create a compelling written record of what has been explored, while evoking the gentle nod of knowingness from the reader.

When looking at the whole body of the interviews and the interplay between the participant groups, the essence of the meanings that emerged was twofold, that of: being connected and being disconnected. This chapter, Chapter 4, will lead the reader through the findings from the interviews of nurses, patients and families and share the understandings and different perspectives gained about “being connected”. Thereafter Chapter 5 will look at the theme of being disconnected. The content of this chapter follows the headings below.

Theme: Being Connected
SUB-THEME: BEING CONNECTED TO SELF
Related to- <ul style="list-style-type: none">• a sense of safeness and self-awareness• being real and present
SUB-THEME: BEING CONNECTED TO OTHER
Related to- <ul style="list-style-type: none">• a sense of safety and confidence• being conscious and deliberate• genuine personness, acceptance and inclusion• lightness• kindness• friendliness or being like family
SUB-THEME: BEING CONNECTED TO PLACE- HOSPICE
SUB-THEME: BEING CONNECTED TO SPIRIT

Being connected had two key aspects, that of being connected to self and being connected to other. Each of these had subthemes. Being connected to self, seemed to require: a sense of safeness and self-awareness, and being real and present. Being connected to other seemed to require a sense of safety and confidence, of being conscious and deliberate, genuine personness, acceptance and inclusion, lightness, kindness and friendliness or being like family. Due to the context of Hospice there were also connection to place, and connection to spirit as subthemes. Associated with all of these sub-themes were feelings of peace, ease, love, comfort and satisfaction, with a sense that connection makes things easier and rapport was experienced.

Exploring being connected

According to Matthieu Ricard (2015), "Human beings have a profound need to feel connected, to trust others and be trusted by them, to love and be loved in return", (p. 281). Martin Buber (1959), wrote this about connection, "It is a grace, for which one must always be ready, and which one never gains as an assured possession" (p. 131). Being clear about what rapport is requires some sort of connection first to oneself, and then to the other, the I-Thou of Buber (1959). Connection is considered here in relation to nurses, patients and family members in palliative care and their experiences of rapport. The following are excerpts and insights from the interviews that illuminate this theme of connection to self and connection to other as the participants lived their embodied experiences (Benner, 2000).

Connection to Self

There are considerations here for how one perceives and connects to self, that are useful when thinking about the dying person. The connection to their body is likely to have altered significantly from pre-illness (Lawton, 2000). It is likely they have a greater sense of conscious awareness of themselves as a being with a visible or invisible tumour, an unrelieved pain or a sense of feeling sick most of the day. This is something of what Sartre writes about as positional consciousness, whereas the nurse and the family are more likely to be in the pre-reflective mode of non-positional consciousness, (as cited in van Manen, 2014, p. 327) These are different stances on the "me-as-object" of Sartre, (1956, p. 285). Also, helpful to consider in relation to connection to self, is the work of Zalenski and Raspa, (2006) who have adapted Maslow's Hierarchy of needs to be applied to palliative care. Safety is ranked before social needs in the hierarchy because if the self does not feel safe, it is difficult to be present and connect to the other. The sub-themes identified are safety and self-awareness, and being real and present.

Safety and self-awareness

The need for safety relates to connecting to self and is personal, it is feeling safe and at ease with one's mind body and spirit (Zalenski & Raspa, 2006). The sense of connecting to self also includes having an awareness of self that came from the nurses reflecting on their practice. According to Maslow's Hierarchy of needs, safety is a priority need for all human beings after food and water and shelter. It is a basic physical and psychological need important for health and connection (Zalenski and Raspa, 2006). Without safety the person can be afraid; perhaps

afraid of people, place and reality of dying. Therefore, for the dying patient, the state of feeling safe is vital to their quality of life experience. Safety is also linked to trust. If a patient or family is feeling safe with the nurse, the likelihood is they will be prepared to take a risk and test the potential trust of their relationship. In her PhD thesis Eikeland (2015) says, "The trusting act, taking the risk that may hurt us, is really the decisive point, where trust either emerges or not. Without the risk-taking act, there is not and cannot be trust". This patient took a risk ringing the bell in hospice to have her needs met. She knowingly made herself vulnerable and it paid off.

And I just have to ring the bell, and they're here within seconds really; not sort of waiting around for ages for them to come. Ring the bell and feel safe. I have that feeling I can ring for anything too. But last night I rung the bell for the night nurse, which I felt a bit stupid doing, I felt mean doing; but my pillow was all sopping wet from just sweating, 'cause it's all clingy on the back. Yeah. So, I rung her; I asked her, would she mind turning the pillow. She said, "No not at all." So, she turned the pillow and changed my top for me. You know things like that makes a big difference to me. She was willing to do it, yeah. Didn't ask any questions, just done it. Yeah, just do it and make it comfortable and then you go back to sleep. Patient C.

Despite feeling "mean" and "stupid" for ringing the bell, Patient C, recognised she needed help. That the nurse came quickly and was willing and helpful was really important to Patient C, not only for meeting her physical needs but also her need for care and safety. She was able to "Ring the bell and feel safe" implying this is a risky activity at other times and places. She had to get past her own doubt and fear to ring the bell. Another example of feeling safe from Patient C's perspective was when nurses get her name right.

They're like, you know, they call you by your name. The first thing they ask me is if I want CC or C. I said, "C"; so that was written on the door. It is important to me because I don't very often answer to CC - I will - but I don't like CC anyway. You know, just little things like that. Makes me feel, well they are caring and want to call me by my right name.

Getting her name right, taking the time to check with her and write it on the door, she felt seen and heard and cared for and safe. Such a simple thing and it would seem so fundamental to creating a connection to make sure a person's name is said and spelt correctly. From her experience this is not always done. The other name, "CC" is not her and by using it connection is inhibited, it feels less safe for her when this happens. Patient B highlights the effect of fatigue on connecting safely to new people. She has limited energy and will reserve it consciously if feeling unsafe. She will wait for a sense of ease with the person coming into the room, "to feel as though you're pushing yourself out to get that connection". The patients sense of self-safety is tested when in the presence of the other, in this case by the nurses. The patients seem to need the presence of the other to become aware of their own boundaries and vulnerabilities and decide with each encounter if it is safe for them to connect. For these patients to connect to self, required checking out the other first.

The nurses gave descriptions of self-awareness and connecting to the nursing self. Nurse B looks at how her practice has changed from her lived experience at the beginning of her hospice career when there was some risk to talk at a deep level with patients.

Now I'm not so – scared is not the word but it's the only word I can think of - I'm not scared to talk to someone to dig deep, work harder. Because this is such an intense job sometimes you have to make a connection very quickly because so much is going on in their lives and there's someone dying and there's family and it gets really intense. I've learnt to get in there quickly, because a patient in my early days of palliative nursing wasn't forthcoming. Because probably she was very shy and very quiet, she was reticent, and I was only new at this job. That sort of encounter with her made me think about things. Of all those people that I've looked after I've never forgotten her. Probably what I've learnt, is I am more aware of the subtleties. I'm more self-aware, of seeing things that I wouldn't have seen as an inexperienced palliative care nurse. Nurse B

The experience Nurse B is referring to has affected her practice over time, where she now has developed skills to connect with patients and family “very quickly”. She clearly sees it as her responsibility to connect with the patient. Any reticence from the patient is something to respect but where possible she will work to “dig deeper” to uncover or remove barriers to connection. Over time Nurse B has learnt to overcome her own fear to do so. One of her colleagues Nurse C, says there are times before connection is made when she needs to remind herself to breath deep and have courage.

...even though you feel really awkward, uncomfortable, and you want to run away. You know, this is my role; you know to put myself into that position and just kinda get over it and do what you need to do. Rather than expecting all that courage to come from somebody else; you've just got to step up and just do it. Nurse C.

Here Nurse C is revealing the courage it takes sometimes to enter a room and connect to her nursing self, even when she is feeling uncomfortable, awkward and wants “to run away”. She sees it as a nursing role to have the courage to put herself in the room and join the patient and families lived world in hospice. Sometimes it is having courage to speak into a silent or a potentially hostile space and wait for any reaction to begin the first vestiges of rapport. Ideally the nurse connects to self first and then the people in the room, or at least one of them, to facilitate care of the dying person and support their family.

Being real and present

Nurse C also has a practice to connect with herself to become present, which she uses in each new meeting, with the aim to improve the potential for connection with her patient. She said this was a hard-won practice over time and thinks that is probably as a result of being unsure of rapport when she first started nursing.

I think what I try to do every time is to make it a good experience for myself and for the patient and people that I'm looking after. I've already thought about it before I've even

gone into the room. I obviously try to make it natural. I just like to be in a position where I've put everything else away, and I'm here now, and this is what I'm focusing on is this patient here, right now. I'm really here; as much as I can be, right here, right now. Yeah, exactly. And that's the message, and I think at the very least, the basics of nursing. You know, that's the key to unlocking it all. Isn't it?". Nurse C.

For Nurse C, it is paramount to be present. She is saying that to be “right here, right now” with a person is the essence of nursing communication, the essence of connection. Using the phrase “the key to unlocking it all” implies there is something to unlock with each person to be able to connect. She thinks that to be real and present is what makes good nurses able to help others in a meaningful way. Nurse C explored this further with the idea that not only is being present important but also being genuine in your presence.

And of course, it's a balance; for me it's a balance of being a nice person, a good person to talk to, an open, genuine, natural, normal person, whatever normal is, whoever that is; and also having the confidence of what I'm dealing with clinically, and all the medical stuff, and all the nursing stuff. I feel like there's got to be a really nice combination of everything. You know. The combo. Nurse C.

Nurse C offers a list of personal attributes she brings to her patients as well as her competence as a nurse which together create “a really nice combination”. She uses the idiom “the combo” to give a contemporary feeling to being a well-balanced person and practitioner. Nurse B reveals her intention to meet people in a real way and be the best nurse she can be in the moment:

I don't look at people like, right, I'm going to be the best nurse for you and you're going to remember me forever. I don't think like that at all. Nurse B.

This is Nurse B's way of saying she is being real and caring in her connection with patients and families and that she is not playing a role or manipulating a façade to be liked and remembered.

Being present for Nurse A allows an in-depth connection to develop.

There were some lovely moments as well. I was very comfortable raising issues around their sexual intimacy and what they were able to do and what he wasn't able to do as well. But I think at times that's nice. He used to talk through what would happen in the future about managing his bladder control and bowel control. So, yeah, a very special connection. Nurse A.

This connection was one of depth and frankness, with Nurse A being both present and real for her patient. This enabled them to have talks on a broad and intimate range of topics over many months.

Connection to Other

When meeting the other, Van Manen says, “it can happen that I have a fundamental sense that I do not know who this other is, but I experience him or her as an ethical call”, (2014, p. 338). He is describing what happens once the nurse looks into the face of the patient and the ethical call is made, there is recognition of the responsibility for the other. This first look changes us “And now we are no longer the same as the moment before” (p. 339). He is drawing from Levinas’ philosophy which centres around the ethical encounter that occurs in the face-to-face meeting of the self and other where transcendence and responsibility are inseparable (Levinas, 2003, xxvii). The first meeting, the first time when the face of the nurse meets the face of the patient and the family, is the moment when “this vulnerable other bursts upon my world” (van Manen, 2014, p. 338) and creates a call to responsibility and care. The nurse has a responsibility to create rapport and connection with the other, to care for them (Leach, 2005; Davies & Oberle, 1990). A lot depends on this first meeting and the power of the introduction (Kate Granger, 2013). All are deciding if this is someone who will fit, who can be worked with, who is likeable, competent, compliant or whatever the criteria might be (Stein-Parbury, 2014; Heyse-Moore, 2008). It is when first impressions are made and the embryo of creating rapport and connection begins. One of the nurses starts with Hello.

I just want to say hello; I just want to say I’m your nurse; I just want to say, “Are you okay? Is there anything I can do for you at the moment? Give me a ring on the bell if there’s anything else I can do”. I’m here, this is me; it’s okay, and hopefully things flow nicely from there. You know? And just gain that trust; and it’s a step-by-step process, isn’t it? It’s not something that people just give to you straight away. Nurse C.

The actual words are similar to the ones most nurses might use to introduce themselves and invite the patient to work with them to meet any needs they may have. What Nurse C is consciously offering beneath these words is rapport and the beginnings of a trust relationship, based on acceptance, respect and integrity, she is aware that rapport and trust is “not something that people just give to you”, so she wants to present herself as trustworthy in this initial meeting. She is hoping for a natural feel and flow to the connection.

So, it’s a bit of humanity; when you go in and introduce yourself that’s kind of what you’re giving them. That’s what I want the first impression to be; like that’s what I try to put out there. Nurse C.

The essence of Nurse C’s intention when she meets a patient for the first time is to offer “a bit of humanity” with who she is and the care she wants to offer them. Along with humanity Nurse A referred to the importance of time allocation at the first interview in regard to establishing connection.

I think the fact that first time we didn’t rush them, and I also think at the first interview that I was prepared to be very honest about what the risks were of his disease, what was going

to happen, how we could deal with some of those risks, what his choices were. I felt like we connected. Nurse A.

Nurse A felt the time taken to create rapport helped her to broach the difficult subjects of potential disease trajectory, procedures, complications and choices even within that first meeting.

The sub-themes identified related to connection to other are: safety and confidence, being conscious and deliberate, genuine personness, acceptance and inclusion, keeping it light, a matrix of kindness, friendliness or being like family.

Safety and confidence

The first aspect to safety and connection is personal and the second is social (Zalenski & Raspa, 2006), where the self meets the other. This is when the person feels safe enough in themselves and with the people around them to connect. For the nurses this meant feeling confident to connect with patients and families. The patients and families also want to know that the nurse is safe to connect with.

I feel safe here; very safe here. I can watch him go out the door, I'm quite happy 'cause I know he's gonna go home and do what he's gotta do, like feed the cat and bring the washing in or whatever. Patient C.

Feeling safe, "very safe", in a place where one knows one is dying, is an interesting thing. Patient C uses the word safe in this context obviously not in terms of life and death but in terms of care and kindness. She can trust the staff to respond to her needs and take care of her when needed. Her partner can go home. Whereas she said if she was in hospital:

I'd probably not be quite as content in myself, I don't think. I'd be a bit worried about whether... no I wouldn't be quite content, I don't think. Patient C.

She is implying that she has been less settled or not "quite content" in fact even a little worried elsewhere. Being safe allows her to relax enough to be happy with the staff and hospice, to watch her partner leave with no anxiety for herself. This sense of safeness is helped by basic courtesy from staff.

They are all nice. I have had some really nice staff. Yeah, they're always good; they always introduce themselves. They knock on the door. You can tell them to come in and they'll introduce themselves. Then if I say, "Well I'm just going to have a wee rest." They're quite happy just to leave me alone and let me have a rest. Yeah, they're really good. Patient C.

That the nurses were polite and respectful, allowing her rest time and a sense of her own space being safe, made an impact on Patient C. By saying the staff are "really good" means more than having skills or efficiency. There is confidence expressed in the type of nursing experienced in hospice. She can relax because she feels safe with the people around her.

Oh, course you can have efficient nurses; but I think this breed of nurses here have been well selected for their job. I think that they've got their own speciality I think for these sorts of like patients like me, or a lot worse than me. Yeah, I think so. They're just good, brilliant. Specialist crew I think here really. Patient C.

Patient C acknowledges efficient nurses. The word “but” suggests her perception is that hospice nurses know what they are doing and care for their patients in a particular way that is special. Sometimes the mundane activities of daily living present an opportunity to deepen rapport and connection as with a shower for Patient B.

My nurse today, she's very, um... strong-willed, gets her point across and very loving with it. But the way she came across it just sort of got under the skin and that's the right way to go. (indicating with her hands getting “under the skin”) She's very, very good. She got to me! (sounding pleased) Patient B. (brackets mine).

It was lovely to hear Patient B's obvious delight when telling me about her shower. The message revealed in the telling was “Work with me, get under my skin, get under my protection. Gain my trust and confidence. It's almost a relief or pleasure to let someone in”. She felt safe enough to shower, when she had not before due to the nursing connection made.

Despite his illness and symptoms and his previous experiences. Patient A wanted connection. He had the need to talk with others but also to feel safe with his nurses before expending energy to talk.

I don't think that somebody has to be genuinely interested in me to chat to them. I like people and I like to chat. It's harder to talk, probably now; but I just enjoy people. Patient A.

Although Family Four had confidence to express himself freely "I could definitely bring up anything with the nurses" it can be a more challenging for patients to have that confidence. For Nurse C a benchmark that rapport is being created is when the person feels confident they can ring the bell to call her to meet their needs.

So, to me it means; well, something you can develop over time. We know first impressions are pretty important, so that rapport, that connection to me with a nurse/patient relationship, is when I can establish that my patient feels confident to ring the bell to call me, to tell me things. To know when I say, “Please, I'm here; you're not a burden; you're not keeping me from anything else. I want you to feel comfortable to talk to me and tell me things and tell me that actually things aren't okay at the moment.” That's what it is, that's what it is to me. Nurse C.

“You are not a burden” not the words she actually says to a patient, but this is the meaning she wants to convey to each person she cares for. She has experienced that some patients are reluctant to ask for help as they “know you are busy” or “don't want to make a fuss”. She is creating space for the patient, reassuring them they are not keeping her from anything else, she is saying she has time for them.

And working in hospice, I've learnt people have been through the wringer already with hospital appointments, and multiple admissions in hospital, and coming across all sorts of things, and doctors and nurses and different opinions. So, who am I now? I'm just another person at this point and another nurse. Nurse C.

Here Nurse C is talking about the awareness she has that some patients are traumatised, exhausted and been “through the wringer”. The wringer of their illness, treatments, complications and the number of people involved in their care so far, and here is yet another admission with yet another assessment. She is aware of their need for safety. She asks herself, “Who am I now?” considering if she comes across to the patient as just another nurse or a person who cares. Nurse D had an experience with connection and safety. This was with a couple who were not coping at home.

She ran out to the car to meet me, she was just crying and couldn't cope anymore. She said, “I cannot shower him. I cannot get him in.” And he was barely able to walk. He wanted a shower and was demanding that she shower him, but she's saying she couldn't. So, I asked if I could shower him. And with great persuasion, and gentle persuasion; he did allow me to shower him, and he nearly collapsed in there. Nurse D.

Nurse D was greeted in this dramatic way and knew this required care for both the patient and his wife. She knew that some people need to experience they can no longer do something before accepting the loss of not being able to do it. By using all her skills of connection and persuasion he agreed to a shower assisted by her, not his wife. The shower became the scene of a breakthrough with the realisation that showering could no longer safely happen at home. He had to face his own deterioration which was made obvious with the help of Nurse D.

Showering is a wonderful time for a personal connection. It's so often a personal connection time and here I was just able to say, “Oh gee, this is very difficult. Yes. I said, “I'm struggling to do this for you.” I was honest, and I was on my own. “You just need people to help you at the moment.” He agreed to come to the hospice for a few days. His wife put her hands together to pray and just kept praying and nodding and smiling, “thank you, thank you, thank you”.

Nurse D knows the intimacy and vulnerability of showering someone and the confessional aspect that it can have. Nurse D's way was to work with him, to gently point out the challenges and that he may need help and that help was available. She gained his trust. This episode enabled him to connect to his dying self and to consent to “a few days in hospice” which happened to be his last few days. His wife's gratitude was immediate and obvious with gestures of prayer and words of thanks.

For Family Four safety was experienced in the nightly routine of a wash, turn and settling for the night which is so reassuring for him as well as his wife, it created a sense of security and routine.

Just at night, when I'm there with just her and I, and the nurse will come in and settle her. But it's not just the procedure of it all, it's the way it's undertaken... yeah. Just the way my wife is treated here; just the way she's treated. Thoughtful, very thoughtful, very caring; compassionate. Yes, definitely. It settles her, it does settle her down. Just gives her peace of mind I suppose; and me too when I come to go home, I know she's in very good hands and I'll see her in the morning. Family Four.

He likes the thoughtful caring and compassionate way his wife is spoken to and moved. It settles her, and it settles him for the night, it allows him to leave knowing she is in good hands. He uses the phrase "very good hands" meaning being cared for with great attention skill and care. These are the hands of the nurses, this is an expression of rapport and connection where the care of the patient is entrusted to these hands overnight. This was mirrored for Family Three. For him to feel safe going home and leaving his partner each night, he needed to trust the care and the carers. He felt a sense of relief for her to be in good hands.

Hmm, and I feel good because she's being treated well. So, that's good. Yeah, good. I can go home and relax and know that she's in good hands". Family Three

Family three and Four are both long term couples who have rarely spent nights apart and having their loved ones in good hands is very important for them. It allows them to feel safe enough to leave and for their loved one to let them leave. It gives peace of mind for both couples. Interestingly both Family Three and Family Four are "hands on" carers as well. They know the value of safe and good hands only too well.

Conscious and deliberate

Connection to the other is helped by conscious communication and particularly listening. "Deep listening leads to understanding. Understanding leads to greater connection" (Thich Nhat Hanh, 2013, p.168). Nurse A talks about the value of deep listening. Sometimes nursing means becoming a trusted confidante, offering the patient a dedicated time to talk and be listened to. Nurse A reflects that sometimes the best you can offer to patients is to listen empathetically.

One of the things that happens is they let you into that side of their life and maybe you just listen because we don't have the answers always do we? But just being able to hear what they're saying and appreciate how it is for them and acknowledge how it is for them. If we can help with some suggestions, great. Nurse A.

Listening is like the radiance of the sun, it encourages a moving towards gesture, it is warmth and attention. It is what patients want from their nurses and they perceive it a basic need, like sunshine, and yet it is also wondered at as a precious gift when experienced by the patients.

Patient A says,

The big thing is certain people listen to you. So, it's listening; not over-talking 'cause I can't talk sometimes too much – it hurts. Patient A.

If he is being really listened to, that means he doesn't need to talk as much and it won't hurt him so much physically. Being listened to authentically, for him is linked to care and genuine helping. Patient A's take on communication in hospice.

Most of it's good. I think communication is a big thing here. Most of the people here have really good attitudes; they're all experienced and they're great. They have some really great people here. It's communication, right? Patient A.

What is implied here is that communication is consciously valued in Hospice; whereas in his experience communication is not always valued in other health/palliative care areas. Patient A is also saying how much he values a high level of communication personally, and is asking for this to be validated, (right?).

Nurse E said she sometimes consciously goes into a patient room to check in and to see if she can develop rapport and connection as opposed to going in to do a task. This particular experience is with an upset partner.

Sometimes it's just to really check up on them and see if I can connect. So just introducing myself as usual; I tell them I'm the nurse and I'm so-and-so's nurse for this shift and explain to them what I'm there for and that I'll be coming back to do such and such. I was going back in to check the pump or something and the patient was really settled. The husband was busy on a device; so, I think it took a few more goes, a few more visits. Just "How are you feeling today?" and just seeing how he is – sort of a general question really. I can't remember exactly what my question was; I think it might have been about afternoon tea, because it was an afternoon shift – basic human need. He said "Yes, yes, no I'm alright." I just say, "Been a tough day hasn't it," and then we start just very mildly and not going into specific details but really acknowledging how he might have felt about the tough discussions that were held earlier. Nurse E.

Nurses are aware that "tough discussions" are invariably derailing and grief inducing transition points in someone's dying. Nurse E heard in handover of this partner's unsettled and angry behaviour, so she decided on a slow and deliberate approach to gain connection. She created this connection with this partner as a conscious process where she matched his pace of connection and made repeated visits to the room looking for opportunities to connect. In another way Nurse D fosters moments of connection in the middle of the night between patients and their families.

Because at night I feel that I'm getting a privileged time that belongs to family, I always say that if a person's hovering about whether to stay with their relative overnight or not, it is a good time to tell them about the special moments that happen at night. They'd rather have those moments than the nurse. Nurse D.

There is the potential for special moments in the middle of the night where the patient may wake and speak for a few moments. Nurse D described a recent example where the patient

woke, and she was able to wake his wife to have half an hour talk about an old friend. This was his last conversation and he had it with his wife, not the nurse working nights at the hospice. In hospice each conversation in the last days could be the last one, no one knows for sure.

One of the special times in palliative care that provides a paradoxical opportunity for nurses to practice conscious connection is when caring for the unconscious patient. Sometimes people come into hospice on the point of unconsciousness and there is no dialogue directly with them at all; and often a person may slip into unconsciousness and stay there for some days or weeks before they die. So, for the palliative nurse this can mean finding ways to connect with the unconscious patient as well as relating with the close family and friends who are present with the dying person. The cues from unconscious patients can be micro movements, a slight rise of the eyebrow, a furrow of the brow which was smooth before, a tightening of a lip, all these movements and other cues like sounds and utterances are communication and require the nurse to calibrate to each person to this level of connection where the message can be discerned as pain, discomfort, a full bladder, or perhaps a dream. Other cues come from family.

You get to know the dying patient from the stories that the family talk about and the love that they talk about. That's how you get to know the person. Nurse B.

Nurse B feels that you can get to “know” the dying person through what other people say and their photos and stories. She is referring to when the person is semi or fully unconscious when speech is no longer possible. While Nurse E consciously uses touch and her tone of voice and simple words when caring for unconscious patients.

Touch. And when doing cares, a gentle voice. Tone of voice and just using simple words when you're doing cares or when you're coming in to check on the pump. I still do talk; it's weird. Some families they just made a comment about, "Oh it's okay he doesn't know you're here." I'm like, "We never know, they might have their eyes closed and they might be listening." I presume it, because it is part of maintaining their dignity as well, because they're human beings all the way. I'm feeling like I'm respecting the person. That I don't need a response. I just know that I'm doing what I can most appropriately to connect. But not expecting anything in return. They're not going to talk to me. Nurse E.

Nurse E talks as if her unconscious patient is listening and does not need a response, intuiting what is most appropriate to connect with the person she is caring for. This is respect-in-action. Nurse E follows on to give this account of caring for an unconscious young woman and her husband.

Even though I've not really felt like that I've established that connection or rapport with her, or the family, I decided to offer for him to do the cares (a wash) with his wife. I'm really glad I did because she passed away afterwards. It still gives me goose bumps because it was so surreal.

So, he did. He did her face and he was talking to her. Even when I recall it, it just pulls on your heart. I just remained quiet and just passed the flannel. He was recalling what she used to like and that she always liked to look after her skin. There was just no sign of her going. I can still remember I just cleaned around her nose because I knew she would not like anybody seeing her like that. Afterwards she looked like she was going to sneeze; and then her colour and her breathing just... and so I quickly... got the husband and the two children who were there; and they were there, yeah. And she died. I thought that was pretty special. Nurse E.

Nurse E sets the scene with a husband and wife with whom she has had little engagement previously nor feeling like she had made a connection with them. Something about this scene was different for Nurse E she still gets goose bumps recalling it, she had shining eyes telling me the story, something about the serendipity of helping him care for his wife in this way to meet his need for connection with her and it happened to be just before she died. Without much in the way of dialogue Nurse E and the husband connected in care-giving. The connection was profound through this simple act of care and the thought behind it, Nurse E goes on to explore this idea further:

That's the thing that they said at handover; that he had expressed that he's not had really a quiet time with her that's not interrupted. And I thought well she looks pretty unwell and how much more intimate can a husband and wife be. I thought well he may never get another chance. It's a gut feeling sometimes. Nurse E.

When I ask what the connection with this patient and her husband was like for her, she replied:

Really good. It makes me feel confident about how I feel, because sometimes you do just... I mean they can say assessments and that but there's that indescribable feeling that you just know. It's a gut feeling sometimes. I know in the past I have not been very confident, because I don't want to be in their face, I don't want to be pushy, is this the right thing to do, is this the wrong thing to do. Every time with experience it builds up your confidence along with empathy; because you can be empathetic and understanding, but if you're not confident – for me anyway – to actually do something about it - because you're questioning yourself whether it's appropriate or not - then you just don't do it. Nurse E.

Nurse E feels “really good” about the lived experience of caring for an unconscious patient and her husband. She has gained confidence about trusting her own "gut feelings" and her understanding and empathy stores have been bolstered by the experience. She links empathy to confidence saying that empathy alone is one thing, but it is more important for her to have empathy *and* the confidence to act and that this is more rewarding for her and her patients. She refers to her tendency towards self-doubt and second guessing her actions and other people's reactions to her. This connection has given her clarity and awareness to trust her feelings and her decisions along with solid nursing assessment.

Genuine personness

Being genuine is linked to being congruent. To be congruent is to mean what is said and that feelings match what is being said (Rogers, 2016). For a nurse to be genuine is to be “internally consistent” and this internal honesty tends to facilitate comfort and security (Rogers, 2016). The nurse who brings genuine personness to meet patients and families is more likely to create rapport. The nurse who is aware and respectful of the patient’s personness can facilitate a sense of meaning and dignity for them (Benner, 2001). When Family Four was asked about a time that connection with nurses really stood out,

They’re all very, very good; they are excellent. But there’s one that has a lovely smile, and just appeals to us basically. I keep going back to compassion; her willingness, just her willingness to do everything and anything for my wife and being a gentle person. Family Four.

Family Four recalled the nurse's lovely smile that appealed to him, his wife, their family. When I asked him what he meant by the term “appealed to us” he said it was her compassion, willingness to help and gentleness were values that fit with theirs. She was being genuine in her care and congruent as a person.

They come across as genuine in their caring. They’re normally quite cheerful. If they have problems at home they’re certainly not bringing it into work. They come across as though you’re someone they care about and they’re happy to get to know you and to spend time with you, kind of thing. For both; myself and my relative. These particular doctors and nurses have all done that. Family Two.

Even when time is short, a smile, a pause, a question, can give the family a sense that people rather than tasks are the nursing priority.

They may not have a lot of time but the small amount of time that they have in the room they always have a smile on their face and chat. They’ll interact and not just say, “Hi I’m here to do this,” and then go again. They’ll actually stop and ask my relative how they’re feeling, is there anything they needed; do their job and so forth. Family Two.

Being perceived as genuine by the other person is one thing, but it also requires checking one’s own genuine-ness as a person.

You know people pick up when you’re not genuine. People pick up when you’re putting on a nursing hat, and that’s all you’re doing. I think people appreciate when they know that there’s an actual person in there; there is a mother in there; there is a friend and a daughter, an actual human being that lives in there. I suppose it builds that trust, and that connection is just more genuine really. Nurse C.

Nurse C is revealing her belief that both her own ‘personness’ and ‘nurseness’ are essential to connect with her patients and families; she is clear in the need to be to be congruent as a person and as a nurse to facilitate genuine connections. This is not just wearing “a nursing hat”.

I think you just can't wing it; you know, you absolutely can't. I don't care how much experience you think you've got in nursing, where you've worked, what you've done; you can't wing a connection, a relationship; you can't pretend, you know? It's truly there, or it's truly not and you've missed it. Nurse C.

“You can't wing a connection”, a patient relationship requires conscious connection and genuine presence, from Nurse C's lived experience this means she now has a more humble approach than when she began nursing. It seems the meaning of her message to patients is: “I am right here with you. Tell me what I need to know, as I have no idea how it is for you”. For Nurse C being genuine is important, she used the word “genuine” repeatedly throughout her interview. Creating genuine connections are important and help Nurse E as a nurse and person.

I think it's more to get to know them than to get to know me, but when you do find an opportunity to connect with somebody it also gives them an opportunity to know me as a person outside the scrub suit. Say for example if they ask, “Do you have children?”. Like we've had patients who are mothers and they're like, “Oh yes that age.” And it gives you something to talk about and then it allows them to express and reminisce their years and good memories and sometimes even bad. It actually helps me too. Nurse E.

Nurse E uses generic connective subjects like children to get to know her patients more while sharing a little of herself. She feels she can get to know more of who they are as people, than what their medical history shows for example. The patient in turn, can get to know more about the nurse behind the uniform. There was another example from Nurse E who had empathetic understanding about the loss of playing music in one of her patient's life. She had shared her own love and loss about music as well. “That's right, I met her there as a person and not just a patient”. Nurse E is aware that the nurse needs to be genuine to meet the real person she is caring for. The real person is only revealed to the nurse in limited viewshafts from various sources; an example from Family One about her dying mother.

She had very big problems; she was dying, and she knew that. But she wanted to laugh; she wanted to have a smile; she wanted to have a connection with everybody. Family One.

The message is that the patient's willingness and personness are important considerations in how rapport is established. This woman genuinely wanted to laugh, connect and smile with everybody. It was how she lived and was how she wanted to be while dying, taking delight in the connections being made each day. The nurse is given the clues to pick up and respond genuinely to.

Acceptance and inclusion

For Family Two, rapport is “Treating somebody as an individual and speaking to them as an equal... not treating them like an idiot” One of the themes from her interview was interpreted as, “See me, talk to me, I am family”. How nurses talk to family matters. For Family Two, being respected as an intelligent person was crucial to connecting with her. She gave this example of feeling accepted and equal. The doctor in hospital sat with them and was...

...talking, passing on the information at a level that she knew would be understood; not using big medical words that may not be understood and not talking below treating you like an imbecile. So, talking to you, not above or below your intelligence. The only time she had to duck off was when she was paged; she always spent the time to answer any questions no matter how silly they have seemed to ask. Very friendly and the information that she provided was easily understood. Family Two.

The family member is grateful that the doctor is pitching language and information to be understood and in a respectful way. She is also answering questions in a friendly non-judgmental way. Family Two values this interaction because she has unfavourable comparisons which are hinted at with the use of the word imbecile. Also hinted at is a sense that she knows what belittlement feels like, as in the use of “silly” when asking questions. Nurse A values acceptance of the other and respecting the privilege of caring for those dying, as she describes experiencing both sides of visiting patients in their homes.

Very special, very privileged time. It's incredibly privileged to be able to walk alongside people when they're going through such a personal intimate experience really. Especially with community nursing you see people in their home. It's not easy to invite someone into your home. I remember having a prem baby and I couldn't cope with the Plunket nurse sending someone in to do the cleaning. Found it really difficult even though I was a nurse and knew that I sent people in. But to do it for me, I scrubbed the floor before she came. So, I sort of got a perspective. I've always remembered that experience of how difficult it is for people to let you into their home. We see it warts and all don't we? I think that's an incredible privilege. Nurse A.

This passage reveals Nurse A's sense of privilege to be able to go into people's homes to visit them while they are grappling with their own dying or that of a loved one. “We see it warts and all” is referring to releasing judgement on how people live and die, to describe what is seen for assessment and planning care, but not judge what is seen. Yet she gives an example when she was vulnerable to the judgement of help coming to her in her own home as a young mother “I scrubbed the floors before she came” This experience gave her the empathy around the fear of judgement patients may have, that she brings into her nursing care today.

Just their attitude, friendliness. They make you feel as though you're part of everything here. Better than public, here. Patient C.

It was important for Patient C to feel included, “You are part of everything here” this inclusion was about being informed and given choice. In her view there was little comparison between public and hospice in regard to service, friendliness and staff attitudes to patients. It also perhaps calls into question her ability to feel safe and free from judgement in hospice vs hospital. Being accepted by the nurses as people and family was appreciated by Family Three and Patient C.

They take a sort of caring attitude I thought. Yeah, oh hell yeah. I find they're quite good to us. Family Three, with Patient C adding, "They always ask how he's getting on, or how's he's coping and all that".

Family Three felt cared for by staff. Patient C felt it was important that her partner be included and acknowledged by the nursing staff.

Keeping it light

When talking with patients and families the nurses all used "connective" subjects which are light and connecting. Time is spent finding subjects from their own lives or experiences to connect with the other person. Connective subjects are like a metaphoric connective tissue and it is a matter of finding the places in each other's lives that might conduct connection. Weaving subjects that connect into the care given, getting the balance right, just enough and just the right level of lightness. Nurse D on connective subjects:

You see blueberries in a bowl and say, "Do you grow blueberries? You know to put your coffee grinds on blueberries?" And once you start it it's just a light connection, just a moment. They've got a moment away from their grieving and the patient and their focus, and, oh, there's another world still going on out there. Because sometimes the room becomes their whole life and they quite like you to bring in a little bit of what's out there.
Nurse D

The making of a light connection can provide a moment away from the hospice and a moment to connect to the world, as she says via blueberries. It's a little tendril to something else outside of their own suffering and the nurse can bring potential reprieve. Nurse D is talking about meeting her patient as a person opening up subjects that reveal a little about herself, just enough to elicit a response from the other person to connect with. It is like trading gems, as patients also give a little of themselves to connect with and the response is an offering of something light and lovely from the nurse's world. Humour is another way to keep it light. Nurse B has an easy humour which she used to make connections.

Yes. I'll often say, "I can't carry cups on a tray because I spill them all the time," and I'll often say, "This is why I'm a nurse and not a waitress" and that sort of thing. I don't say that all the time or anything like that but just an icebreaker I suppose. Humour. I use humour as an icebreaker. It might be a family that are tense and tight, so you are more serious with them and mindful of how tense they are and anxious. I use humour, as you know, but I pick my humour and how much. Nurse B.

Nurse B skilfully uses self-deprecating humour in this example, confirming her use of humour as an ice breaker, a way for initiating rapport. It also shows both her vulnerability and willingness to connect with the message of the humour being "I am just like you, a person making my way in the world, with limited juggling skills". Nurse B has also developed a strategic sense of when to use humour or not and is able to match her behaviour and tone to that of the family to facilitate connection.

A matrix of kindness

These interviews revealed that kindness has a particular relevance to palliative care nursing. The definition of kindness for this study is that “kindness is a binding, creative and problem-solving force that inspires and focuses the imagination and goodwill, towards building relationships with patients, meeting their needs and treating them well” (Ballatt & Campling, 2016, p. 16). Being kind as a nurse was explored during the interviews by three nurses in particular. They expressed kindness in three ways: kindness to patients, kindness between nurse and nurse, and kindness to new nurses transitioning into palliative care. Family wanted to see their loved one receive care with kindness and from the patient’s point of view, they want to be seen and known as the people they are, “not just a list of problems” and treated kindly. (Ballatt & Campling, 2016 p. 36).

Oh, definitely. All the staff I’ve had, the kindness does stand out. It means a lot to me because sometimes you think you’re being silly by just asking a simple question; I don’t know, I can’t give an instance. But no, they don’t rubbish you; they just stand there and explain things to you. No, they don’t make fun of you for asking perhaps a silly question. Patient C.

Patient C perceived the staff as having kindness. The example of kindness given was of not being ridiculed for asking a silly question. Patient C also mentions the same thing with the doctors in hospice.

Good, and the doctors I have seen here, they’re lovely; they’ve just sat and talked just to me like I’m an ordinary person, no big words or anything; explaining things to me. So, I’ve been really happy about that. Oh, yeah; I can ask a question even if it sounds silly to me, they get what I’m trying to ask. Yes, that is really important. Patient C.

There is amazement in her voice as she relayed that the doctors sat and talked with her like she was "an ordinary person" and the talk was in everyday language "no big words or anything" explaining things and addressing questions she had in a way that she felt respected. She appreciated the doctors "get" what she was trying to ask, she felt heard and understood. She is also saying that her questions may sound silly even to her, as if her confidence to ask questions has been bruised. The implication is that she has had an experience of being and feeling belittled when she speaks up or asks questions. That the hospice doctors are patient is echoed by both Patient C and her husband. They value staff taking time to sit and talk and listen and Patient C has been really happy about the way she is communicated with in hospice. "I’ve got no complaints about any of the staff here. They’re really great”.

But sometimes it is not great. An incidental question at the end of the interview with Patient B, opened to what seemed to be the main story for her. She must have decided somewhere along the way to tell me this story as there was no hesitation, when I asked her if there was anything else she would like to say. She began by telling me that "probably, it is way too late". Then revealed her long-held story about unkindness which are retold from my field notes.

There was one young nurse, looking after Patient B's mother, this nurse did not believe her mother was even sick, when she was in fact dying. The nurse had thought her mother was putting on an act, "Come on love, it's all in your mind". This attitude "really bugged" Patient B and still does to this day, that her mother was subjected to unkind treatment and not taken at her word when she was sick, in pain and exhausted. Patient B perceived this nurse as being unkind to her mother in her words and deeds. The family always believed the mother was very ill and this was proved on her death when they requested an autopsy. The autopsy report determined that she had died from the effects of pancreatic cancer. This all happened 35 years ago, and Patient B is still "disgusted" by how her mother was treated. Patient B was worried for her mother but was very busy with a sick child, so not able to help her mother as well. She was therefore dependent on nursing staff to do, so she felt let down and she felt her mother was let down. Patient B has carried the impact of this nurse's unkindness with her "passed down the line". As she now approaches her own death, there is a spectre of fear and anger and unresolved feeling. We talked about forgiveness for the nurse's unkindness so long ago, a nurse whose name and appearance were not remembered, just her words and behaviour to her mother. Even after all those years, the tears came freely, her feelings were right there in the telling of this story to me.

We talked about kindness as a benchmark of care, a level of care that is universal, and Patient B thought that nurses should not be operating below this level. She agreed that this experience could be shared with fellow nurses to highlight the generational effect of unkindness, to be aware of the effect of our words and actions on patients and their families, especially when someone is dying. This seemed to lighten her pain a little to know this experience may be used to "help future generations" to value being kind. She ended the interview with "Kindness goes a long way".

Nurse C is clear about the importance of kindness demonstrated by those caring for patients,

A hundred percent, if my family are having health issues and dealing with hospitals, and doctors and nurses; kindness is right at the top of the list; to show some kindness. That's right at the top; and that will change everything. You feel at ease, you feel like, I can tell this person I'm not nagging them, and they're not rolling their eyes at me, and they're not getting annoyed; or they're not looking like that want to be somewhere else, you know. Yeah, yeah, yeah. They're looking like they really care, and if I know that that person cares, they're going to do a good job; they're going to do the best that they can with my health. And that's the way I look at it. If my patients know that I care, I'm going to do my very best. And you know, that's what you want. Nurse C.

Kindness is at the top of her list of attributes in staff caring for her family. Having the lived experience of receiving care with kindness for herself and her family has given Nurse C both empathy as a family member and a nurse. It has given her a deep appreciation for kindness. She describes kindness as a transformational state, "it changes everything", it creates ease and a feeling of trusting the intentions and the ability of the staff. It gives her the confidence to speak

up and ask questions without risk of belittlement or annoyance. She links kindness with caring and links caring with doing a good job. She then applies this to her own practice. However also in this paragraph is the inference to other times when kindness is lacking and perhaps there has been “eye-rolling”, getting annoyed” or wanting “to be somewhere else” on the part of healthcare personnel she has met. These body language messages are of disdain, intolerance and not being present for the other. Nurse C is aware these behaviours do nothing for rapport and connection, as it appears difficult or impossible to connect when these attitudes are present. When she regards nurse to nurse kindness, Nurse C has this to say,

Kindness is the underpinning, actually, for everything. I mean you'll obviously still get on with your job and do the very best that you can. But when you know you're working with people that are nice, that they care about you, that are interested in how your shift is getting on and willing to give you advice and help, it changes everything. It just makes dealing with really hard situations where people are dying, or people are really ill; people are falling, people are ringing the bell every minute; to deal with those things so much easier. Nurse C.

Nurse C enthusiastically endorses kindness between nurses as the “underpinning” for everything in terms of relationships. Nurse C again refers to kindness as a transformational force that changes everything; from just doing the job, to feeling cared for and supported by colleagues while caring for others. It makes coping with a challenging shift “so much easier”. By implication, when that connection with colleagues is awkward or not available, the work itself can become harder and more draining. Nurse C continues with this observation,

And that helps you connect better with you patients, I think, because it just lowers that tension, and that feeling that you are kind of on your own. You know? It's not a nice feeling when you feel like you're not able to connect with the people that you work with, you know, all day or all afternoon. Yeah, that's really important. And I know everyone is different. Some people love to talk, some people don't. You know, but just whatever. And it's that same situation: I'm here for you too. You know, call me if you need help and I hope you're there for me too, yeah. Nurse C.

This paragraph reveals that nurses having connection reduces the tension and feeling of aloneness the job can bring. She clearly implies there are times when the going is hard and suggests there is little support from colleagues. The link is made that it helps with connecting to patients if the nurse feels supported herself. Nurse C returns to the same premise she offers to her patients, the difference here is the desire for this connection to be reciprocal: I am here for you and I hope you are here for me too. Nurse C then mentions kindness towards new staff.

New staff - so important. You're on the lookout for someone you can cling to; not cling to, connect with. And someone that you can trust; and someone that you can talk about your shift, talk about certain patients, talk about your family life. Just someone you can build a friendship with, and someone you can connect with. But it's so important; oh, gosh I can't

stress it enough. You can get burnt out pretty quick on the floor doing that stuff; but you will come tumbling down if there's no one you can lean on. So critical. Nurse C.

Having nursing connection is “so important” and “critical” to have the care and support of at least one nurse on each shift, to know them well enough to really talk to. Nurse C is clear this is an important way to maintain health and wellbeing in hospice as a nurse and so important for new nurses to the area. Nurse D described kindness when helping someone out of bed to the toilet. She is using the pronoun “you” which puts her in the position of the patient.

You get up and then struggle away to the toilet with someone supporting you there and a bit of touch and kindness. And then you go back to bed and probably mostly would settle a bit better because you've changed position, you've moved, and you go back. Nurse D.

By describing this simple event from the patient’s viewpoint allows Nurse D to have empathy for the patient and she realises “it’s a marathon they’ve run just getting to the toilet and back”. Kindness is felt through the nurse’s presence, supporting them and through the “bit of touch”, there is a sense of quiet encouragement for the patient to complete the marathon while they still can. Nurse D also stated “Hospice nurse are so kind” but she added there is a danger of doing everything for the patient and robbing them of their last vestiges of independence. She felt kindness needs to be conscious and thoughtful considering the patient as a whole being. Nurse D, and in fact all the nurses showed kindness through their thoughtfulness and care in the experiences they related in these interviews.

Nurse B thinks it would be high praise “being remembered as the nurse who was kind”, being remembered for being kind to patients and family. By being the nurse that she would like to have caring for her, helps Nurse B connect to her own kindness. Nurse B thinks kindness and connection come together in moments and that are likely to be remembered. “It’s more like moments when those things connect”, and it can be as simple as “a cup of tea and those moments of kindness” Several of Nurse B’s stories in the interview were from when she started palliative care nursing, so I asked her what she thought was needed for new staff to the area in terms of rapport and connection, her reply:

Be kind. Be kind. Be kind. To the new staff. Us (experienced nurses) need to be kind to them. Makes me feel like crying. New staff come here, and the expectations seem to be so high on them and not everybody starts up there. I started not being able to pronounce the words and I was really lucky to be taken in at that level of lack of knowledge, formal knowledge. I think a lot of these girls who are coming, unless they've got a high standard of knowledge, they're just... I don't know. But you can learn. Nurse B.

Nurse B’s reply was immediate and provoked in her an emotional response, “Makes me feel like crying”. She is talking here about the need for kindness patience and support from existing staff for new nurses to transition from a previous workplace to hospice. It takes time to learn, gather experience and to *become* a palliative care nurse. Nurse B knows from experience that kindness helps this process.

Friendliness or being like family

A desired quality for connection from the family in particular, was for the nurse to be like a family friend, popping over for a visit, and that their presence in the room creates an ease, like being a part of the family. Kudos for a nurse's rapport and connection was to have statements made from family members like "I could take her home" "She fit with us" or "like a sister". It gives nurses a place on the inner circle around the patient and family, not to take over but to support guide and sit beside them.

What we want is for you to connect with us like a family friend. Family Two.

This extended to ancillary staff as well,

I think she's cleaning staff because she's made the beds and cleaned the bathroom before, she's brilliant; it's almost like having a family member has just popped in and done her job and is gone again. Family Two.

Nurse B recalls a connection where she was embraced like a family member while caring for a patient who was dying.

There was one lady. Actually, there was a letter from her daughter the other day just up on the office wall and that was one family that I connected really well with and they wanted to take me back home with them. They wanted me to go back with them. And I don't know why. It's just they were three women, probably aged maybe 35 to 40. They were in that age group and we just connected. All three of them and we all connected. It was lovely. It was special. They helped care for her. They talked. They did a lot of talking, a lot of talking about their mum, about their lives, their lives now as women with children or not. It was interesting seeing that letter actually, because you don't forget some people. Nurse B.

Nurse B reveals she and the daughters worked as a team to care for the patient and they included her as a nurse and family member in their talks and connections. She said "you don't forget some people" they stay as your teachers they stay to remind you, it also reveals that the family does not forget either and wanted to acknowledge the connections made at the time of their mother's dying. However, the family also knew that this was a relationship of time and place, acknowledging this with their letter of thanks a year later. Nurse B enjoyed looking after them and was smiling warmly while speaking. She felt she had made a significant connection and that this was a family she will not forget. When asked about a good connection with a patient Nurse E recalled immediately:

Right, I've had a few, but I suppose one of the patients I really had almost instant connection with, because we were both of the same culture; so, there's that...understanding from my side and from her side. We both had young kids and both far away from family. When we had a chance to just talk the two of us, she was able to express the difficulty; the challenge of letting go and letting it be for the sake of the children. So, I talked to her; just kind of talking about how she felt, about if she did pass away how it would impact his grief

and his coping with losing her and looking after the children. With her, I knew exactly what she meant. I think that made a huge difference. So, I was able to connect because we spoke the same language. Nurse E.

This reveals the “almost instant” connection for Nurse E and her patient, their shared backgrounds helped them to connect quickly. Building on this she was able to give her patient the quiet time and place to share her feelings in her own language, away from the brave face she put on for her family. The patient was connected to herself, with insight about her own dying and had a sense of safety with Nurse E. This enabled them to explore the feelings and the practical matters and the what-ifs of dying. Nurse E thinks that knowing what her patient meant made a huge difference with the depth of their connection. Nurse E and her patient were speaking the same language on more than one level. There was a deep sense of satisfaction and affection from this connection for them both. In a similar way Nurse C shared this following experience of rapport and friendship with a patient. They came to a moment when the gritty realness of dying appeared, which required some skill to overcome.

I felt like we had this little, fine friendship. Just that woman to woman, young woman to young woman, where there was that little fine friendship where we laughed about some of the same stupid things; about funny things that husbands do, and things like that...Sometimes actually, those situations are really tricky for me; I find it really hard. Because we talk about their children, and then they say, “Oh, do you have children?” And, yes, I have children. Well, I’m still living and I’m probably going to be around; and we have discussions where, what schools do they go to, and what schools are your... You know, things like that. And it becomes, all of a sudden, we are having a nice talk about things that mums talk about; and then, all of a sudden, we realise we’re actually in two completely opposite positions, and my patient’s journey is going to be completely different from mine. You know? And it’s just laid out; didn’t intentionally mean to bring it out like that, but there we are. It’s nice to talk about other things we have in common; but in that situation, I felt like we were able to get over that hump somehow, that really awkward, uncomfortable place; and just see. Nurse C

For Nurse C, there was a moment when they both realised the chasm between them, that knowing that one of you is dying brings. Having made the realisation that she represents life and survival that can potentially upset the patient, Nurse C made a concerted effort to keep the connection going in a way that served her patient. Giving the power to the patient so that she could pursue talking about their mothering connection or not. It was now her patient’s choice. Nurse C was determined to make herself a source of help and support and not gloss over this awkward place. She was prepared to wait and see how the situation resolved, hoping the quality of their connection enabled them to navigate through, which it did. Another take on how nurses relate like family comes from Nurse D:

And then you’ll hear about grandchildren. It’s a nice connection for the patient especially if it’s a patient you’re talking to or their family. It’s another subject to help with the care of

them. I think it's quite important. It makes them feel like you are part of their team. They're a team looking after their family and that you understand their team a little bit because you've got some similarity. Nurse D.

By considering and understanding the patient and their family as a team Nurse D knowingly makes a connection wanting them to feel she is part of their team. This team idea is akin to the nurse being considered part of the family.

When asked if there had been a nurse with which she had a good connection with this admission, Patient B replied.

Yeah. I was thinking yesterday or the day before, "Oh yes, I'd like her to come home with me. Yeah, there was just a connection which was nice, and that kind of connection does not happen every day. We just sort of agree on a lot of things. We've almost got the same sort of humour at times, which helps as well. It's as though that connection is just there anyway. Patient B.

The ideal for Patient B is for connection to be easy, effortless, like it is just there and feels naturally there. This easy connection with a nurse stands out as not an everyday thing. The phrase "like her to come home with me" implies this nurse would fit with Patient B at home and fit with her family, it is a compliment of significance.

The nurse was very relaxed. She came across as a family friend. She would ask about the animals. She would ask questions and not just get on with the job; she would actually stop and ask questions and spend time interacting and not just do the job and then leave. Not blinker focused. She has a wide, let's called it panoramic view of her environment. Family Two.

According to Family Two, the nurse needs to give the impression of genuine caring and wanting to get to know the person/people being cared for, in a cheerful relaxed unhurried way. This sense of the nurse being unhurried, not thinking about the next task or person to see, set the tone for Family Two to allow her to relax as well. She wanted the nurse to feel like a family friend, with a "wide panoramic view of her environment" and not just there to do a job. The message is to take a moment and consider the big picture when walking into someone's home or a patient's room, as these are clues to giving an understanding and connection for the persons living there. Balancing the comments about the kind of person this particular nurse was with her nursing abilities, Family Two said she was:

very competent, very confident and very forthcoming and very helpful. She was a very lovely girl to deal with. She comes when she's scheduled on of course, but every time it's always the same, she's consistent. Family Two.

Such praise for this district nurse, Family Two clearly liked and respected her, enjoyed her visits and yet knew she was a health professional visiting her mother at home.

For Family One in hospice, the sense of family was experienced as love. She describes one particular nurse:

When I first arrived at the hospice and she was sweet, with respect and love and she was smiling. Her smile is what really got me. Always a smile; always some kind of compassion. I always said you know the best ten days that my mum had, were there (in hospice). I mean she wasn't well, but she had the people I would have loved her to have up until the end.

Family One

There were individual nurses who stood out in hospice. One nurse was sweet, respectful, loving and smiling. "it was her smile that really got me" revealing something in this smiling communication that connected with Family One. The relationships with nurses nurtured Family One as a person, as well as caring for her mother, she felt supported. If she could choose who cared for her mother as she died, it would be these people in hospice.

More than friendliness, from the viewpoint of Family One, one of the key connecting abilities to have as a palliative care nurse is to love your patient and to love your job, and for this love to be obvious to patients and their families, so they are put at ease. Two of the family members were clear about the love that is required to surround their loved one dying. "Dying people need a smile and love" and they need a "loving environment". Demonstrations of love described by the family members were smiling, loving, laughing that "connects to your heart" and holding hands. The family have need of hand-holding at times too, for their hands to be held by a nurse who loves them as well, to be with them and offer support.

Compassion is measured by the love of your job and the love of people; you can't be a nurse without loving people. To me that's paramount. You don't want to be sick and having somebody with a scowl or whatever. Yes, we can't get too connected because otherwise it would be too much burden on them at the end of the day; but there must be a link, there must be something. And it is love; love is the number one – especially on your last step of life. Family One.

"You can't be a nurse without loving people". This reveals her belief that if you are not loving people perhaps you are not nursing. She is saying, nurses need to consider what it looks and feels like for the patient and their family when they watch the nurse interacting, it is better to see a smile in preference to a scowl. She recognises that there must be a link for patients and nurses, that connects them but is not too onerous for either party. She calls it love.

Yes love; it's one hug or one holding hand; something Yeah, holding a hand is important. Yes. Sitting and smiling. They're scared of so many things; they're scared. So, they need compassion and they need love; they need to walk the last part of their life knowing that somebody will hold their hand and just go through with them. You don't know what happens when you die. Family One.

Family One reveals here the vulnerability of the person dying and the vulnerability of her own role as daughter. The dying person may be scared, and so may be the family. The need for a loving presence to walk with them and be there and “hold their hand” to help cope with the fear and unknown-ness of dying. Love is seen in how a nurse acts with the patient as well as what is said, both of which Family One thinks are important ways of connecting. She also offered a description of her own and her mother's experience of rapport and connection in hospice, “It was positive 100 percent; everybody was giving you love”.

Connection to place

Place is a kind of lived space (Paterson & Zderad, 2008). For a nurse to be really with a patient and family in their lived space means to be aware of where and how that space is experienced for them. There is a threshold to cross to come into hospice. At its simplest hospice is a welcoming place where ideally a person who happens to be dying can feel safe and accepted with love and kindness shown in every care. It can be a good place to come to terms with dying and it can be a good place to die.

Oh, it's been good coming into Hospice. Yeah, the surroundings are good. The staff are good. If this is the surroundings I've got for the last few days, I'm very happy. A lot to do with staff I think. I guess it's a lot to do with their attitude, how they present themselves. Yeah and how they interact. Patient B.

Anticipating where she might die, with hospice measuring up physically and staff wise, Patient B is thinking she would be happy to die there. Patient C also contemplated coming back to hospice in the future.

Well, it has surprised me how lovely it is. I didn't really know; I didn't know what it was like, what to expect. It's just like staying in a hotel really; it's lovely. Yeah, lovely, maybe it's the nice staff. And if I had to come back again I wouldn't hesitate. I know what I'm coming into now. Patient C.

After a few days stay, the fear of the unknown is lessened, and Patient C would not be afraid to come back to hospice, to have symptoms managed or to die. Family One stresses the importance of a nice environment as well as people who love you, when someone is dying. The “people who love you” are nurses in this instance.

Just a nice environment, and people who love you. It's so important; so, important. I think the nurses are amazing people. Family One.

For a family member the sense of place was stated as: “Dying in a loving place is important” for both the family and the patient.

Yes, Hospice is a great place to be when you're as ill as my wife is. The hospice is just fantastic; it really is. The nursing staff couldn't be better, and the volunteers. Family Four

He offers praise for hospice, as a whole, and its nursing and volunteer staff. Family Four gave the impression of relief being in hospice with his wife and there was the sense of being in the right place at the right time for them.

I never realised really what hospice did until my relative came in here. It's just really, really supportive and compassionate, and just a loving environment. It really has been. Family Four

Hospice is better than he thought, as people so often say, until they come here they have no real idea of what it is about. He now considers Hospice to be a supportive compassionate, loving environment as experienced by him and his family.

Hospice was like paradise. The problem is it was only allowed a short period, which I think is crazy. Because we had to transfer to a different place. Then in that place I had many problems, because people wouldn't connect. Too many people wanted to go fast. It's like a factory to die. Oh my god! That was a factory... full stop. Family One.

Hospice was "like paradise". What is revealed next is the pain of having to leave hospice to transfer her mother to an aged residential care facility for end-of-life care. This transfer was not easy for them as connections were strong in hospice, and the connections were not replicated in the new place, despite efforts from the patient and Family One to do so. "Many problems", "people wouldn't connect" and "It's like a factory to die" are mainly referring to the lack of connection with staff, which led to them feeling processed and scared. This experience of transferring out of hospice had a negative effect on Family One's grieving, she perceives her grief could be halved by staying with people who loved them and whom they cared about while her mum was dying. If the relationships at the aged care facility were more connected and there was trust established, it may have been different, but what they had there was perceived to be far less in terms of care and connection than in hospice.

The above experiences are also describing Hospitality or Manaakitanga and are the ways family and whānau are embraced and included into hospice. offers warmth and welcome. One of these ways is food for families.

I've always been here over the lunch time with my relative and yet I have only been asked once if there was anything I would like, only once. I feel a little like I'm surplus to requirements. Yet when I was offered food that one time, it gave me the warm fuzzies. Yes. Gosh it gave me the feeling that I was included or that I wasn't expected to leave just because lunch was coming. I guess it would also be different if there was whole family group there, but I'm just there by myself with my relative. Being offered just a biscuit or something would be different. Family Two.

The time Family Two was offered food she was happy to be included and felt "warm fuzzies". It was a simple gesture of hospitality that was appreciated. She said it is the offering that is

important even just a biscuit would help her to feel included. Whereas Family Four has a very different experience of hospitality and inclusion,

Coming in here they ask my wife what she wants to eat and then they turn to me and, "Would I like something to eat?" Quite often I don't want anything to eat but you are included, and you're told what is happening.

Family Four is appreciative and touched by being included with the offering of meals and being kept informed. Being offered food as a family member helps create connection. The family member feels seen and considered. This is an easy way of including family, with the offering of a spare dinner, or a biscuit.

Connection to spirit

Each nurse had their own spiritual beliefs which were mentioned incidentally during the interviews but some of them shared experiences with rapport that pertained particularly to spirituality. "I mean a lot of families and patients say, "How do you do this?" I say, "...by faith I can deal with death better." When asked Nurse E offers her faith as the reason she can work with dying people in hospice. Nurse D has a passion for identifying patients' spiritual connections, she was told many years ago "Spiritual Care, if you can't find a spiritual connection, find an idiosyncrasy that's really special to that person", and so she does, she looks and encourages others to look for each individual's expressions of spirit.

We had a blind man once and he was an atheist. He was s a bachelor man and he was older. No one visited him. He had no family. So, I thought, mm, wonder where his spiritual component is or what lies within. So, chatting to him and no, he's an atheist. I thought, okay. But I thought he lived in a lonely dark world. And I did talk about that, as because you're blind is that a lonely dark world there? And yes, it is. And so, I thought he's an atheist so how am I going to go from here? So, I asked him if he'd like one of our staff members, L to visit, "He's got time to come and visit you. Would you be comfortable with that?" "Oh, I'd love that". Nurse D.

This experience is about Nurse D looking holistically at a patient and feeling what it must be like for him in his dark and lonely world as he is dying. She did not let the label of atheist stop her from finding a deep and caring connection with one of the team who just happened to be an Anglican minister. Her own rapport with the patient was such that he was able to say yes to the "special visitor" and trust her recommendation. This was a skilled, thoughtful and kind intervention created by Nurse D. It validates her belief to subtly present the spiritual question to patients and have the courage to revisit it. Nurse D knows the value of connection and was willing to work with the patient's belief around atheism to connect him to a team member who also valued connection and would understand and respect his beliefs. She feels it probably provided him with a "great inner peace" at the end of his life. Nurse D talked about the importance of the role of Pastoral care, which in her example is not concerned with religion.

Nurse B talks about not being religious herself.

Because I'm not religious or anything like that at all. I respect people. I respect you've got the Catholics with their rosary beads and all their pictures and all that. I totally respect that but it's not for me. But that doesn't... and they don't know that. They don't know that I don't. Sometimes people will ask you, and I suppose maybe they'll say, "Are you a Christian?" I've had a couple of questions like that which is quite confronting. And I'll say, "No." But I say, "I'm a good person," because I am. Nurse B.

It is the sense of being a good person rather than being a good nurse that matters here for Nurse B. She tucks away her beliefs when talking with patients about their spiritual beliefs. She acknowledges she finds it can be confronting to be asked about her own beliefs, so this is not necessarily a connective subject for her. She goes on to say though,

A lady said to me once that her dad had been sitting there beside her. I didn't know he'd died, and I said, "Oh really?" I said, "Has he gone?" or something and she said, "No, he died." And she had seen him. And I believe that. That's what I want to believe. It just seemed normal to me, but I didn't think a lot about it at the time. But once again, I've never forgotten that conversation. Nurse B.

Nurse B is reflecting on how she connects with patients around pre-death visions and spirituality, describing a formative experience around this topic of pre-death visits from relatives who have died, and its impact on her connections with patients today. Sometimes though, formal religion is the right vehicle to connect to the patient with. Nurse D recognised that not she but her colleague had the right skills for this agitated dying man:

We had a man really, really agitated, he was dying, and he had this brief lovely moment in the middle of the night and he was holding his rosary beads and I said, "Would you like me to get my colleague to come and have some rosary time with you?". Nurse F was on. She went down and did that with him and absolutely magic for Nurse F. It was just such a special, special time for her and for the patient. I couldn't do that with him but if Nurse F wasn't on I would have sat there and asked him, "Would you like to say your rosary to me?" But with Nurse F there, it was amazing. You work with the right people at the right moment sometimes and you can share what the patient needs. They said a rosary together. He was so settled. And she just so connected with him. It was lovely. Nurse D.

Nurse D spotted a moment of lucidity for the patient holding his rosary beads and offered him someone to pray with him. It was a special connection for the nurse and patient praying together in the middle of the night. He settled, and they all benefitted from this interaction including Nurse D for putting them together so beautifully.

Nurse C had a strong connection with a patient, but their spiritual beliefs differed:

She actually made it clear, at times, that she had no religion or spiritual affiliations at all. And that had come up during admission and other chats and things like that. Whereas for

me I'm spiritual on the inside; I don't share it with every single person. But there's certain feelings and things that I feel like come from somewhere else, not from me; you know, that there's something else that helps me along, every day. So, we didn't necessarily have that in common, but definitely there was a gap that was filled with something other than nursing tick boxes, and care plans, and have I completed all of these daily things for this person. There's always something else I think that draws people together, one way or another.
Nurse C.

Despite their differences in spiritual beliefs Nurse C and this patient found other things to connect with. There was an acceptance of the differences. What is revealed here also is the filling of the “gap” with the things that connect and draw people together. This gap between people that can be filled with connection. Nurse C is sure that connection is not achieved through tick boxes and “to do” lists.

Connection and rapport make things easier

The nurses thought connection with patients and families made palliative care nursing easier. Nurse B says exactly that: “Nursing is easier with connection”. This is echoed by Nurse D.

Yes, so much easier when there is rapport. They're pleased to see you come in and you sit down in the chair. That's the most important thing, sit down with them just to observe the patient, and the conversation goes whichever way it goes. But you're included, and they want you to be there and they want your support and it just flows freely. But I think the difference is they are comfortable that their loved one's dying and they're accepting of them dying. Nurse D

Nurse D reveals here how the relationship and care is so much easier for the nurse and the family when there is rapport. There is particular reference to the nurse sitting down in a chair in the room with the patient and family and how important this is as a barometer of connection for Nurse D, to be able to sit and observe the patient and be part of what is happening. “It just flows freely” which is referring to the dialogue and the connection being light and inclusive for all parties. Nurse D has a theory developed over years of nursing that the families that are comfortable and accepting of their relative dying are more available for connecting with nursing staff. This implies that the families that may benefit most from connection with nurses are stuck in their own fear and grief around their loved one dying.

It makes everything just easier. I don't know if it is all nurses, or is it just me? You know you find it a bit of a personal challenge sometimes to break that, and to get that, because you want that connection. You want that, I don't know if it's your nursing ego, or what, you know? You want that reciprocation, connection. Nurse C.

Here Nurse C is clear she wants a two-way connection with the patient and will work to get it. She questions her “nursing ego” as a motivator, the implication is the nursing ego will want the connection as it is what a good nurse does perhaps. Nurse C finds it is rewarding to overcome

some resistance to connection with patient or family. It is meeting a personal challenge for her, and ultimately making “everything just easier” for them all. Patients also benefit from connection with the nurse according to Nurse B.

For the patient I think it's quite important because if you've got a connection with that patient you may be inclined to make the time to sit for a little bit, talk to them. A connection is sort of trust. So, if they've got that trust they'll talk to you about what's bothering them or what their worries are. Nurse B

Nurse E talked about how connection makes it much easier to interpret and understand what the patient or family is trying to say. It is easier to meet patient needs. For her, connection helps the nurse advocate for the patient.

It's vital; it's vital. I believe it is because it's the heart of your assessment. You can only do so much with what you know on paper. Person to person connection is vital. Nurse E.

Nurse C refers to her strategy of spending time with patients at the beginning of the shift which makes everything easier,

If I've got that, sort of a snapshot, with me and my patient, at first, before I end up spending time elsewhere; then that's important, to grab it, and I've gotta make it important; I've gotta make it right; right and special, you know. Which is what I want for everybody. Nurse C.

Nurse C has learnt the importance of taking time at the beginning of each shift to make a solid introduction, setup the plan for the shift and how they will work together to meet her patient's needs, and hopefully agreement to ring the bell if they need anything. If these things are done well and made “right” and “special” for the patient, it means if unexpected things occur later in shift and take the attention of the nurse elsewhere, she is more likely to keep connection with her patients because they have made a connection at the beginning.

Here, they probably stand out for making connections more so than out in the community. Yeah, I think so. A couple of the staff possibly here have made a real point of trying to make me feel better; or feel better about myself, I think. Patient C.

Patient C was struggling with shortness of breath during this admission and she was feeling vulnerable because of this, needing a hand with the shower and cares generally Patient C felt the nurses were caring for her nicely but “they stand out for making connections”, which she implies is different to what happens elsewhere. The significance of the comment “to make me feel better, or feel better about myself”, is to reflect what the nurses were saying about giving more than physical assistance. Patient C felt seen and supported as a person, helping her to cope with the distress of her symptoms. Connection can be experienced in the most unlikely places:

I still love the radiation place; in between patients. People normally don't talk when you're sitting at the bus; but they're talking while they're waiting to go into radiation. "Hi, how are you?" They want to talk; they want to have a connection. Family One.

Reference to the "radiation place" as a time when patients want to connect and do connect in between appointments as opposed to the silence that can happen while waiting for a bus. It is a place where connection with others makes treatment easier. This ease is a feeling that Patient A describes like this,

It's just you know that the person cares and truly wants to help and they do make a difference. You can feel it. There're a lot of good examples. Patient A.

Patient A knows what it is like to have rapport and connection with a nurse who cares and wants to help. It does make a difference and is something he can feel. Connection makes him feel better.

Summary

This chapter was spent exploring "being connected" and looked at how the nurses, patients and families experienced being connected to self and being connected to other. Being connected to self, had the subthemes of a sense of safeness and self-awareness, and being real and present. Being connected to other had the subthemes of safety and confidence, of being conscious and deliberate, genuine personness, acceptance and inclusion, lightness, kindness and friendliness or being like family. Connection to place as hospice and connection to spirit were also explored. The finding that summarises this section is connection and rapport makes things easier.

An individual needs to feel safe to connect, safe with themselves and their immediate environment. Feeling safe also had some sense of awareness of self. One patient rang the bell in the night and felt vulnerable doing so but knew in herself she needed help and trusted she would be safe. Being present and putting aside the details of their own lives to be with the other, required the person to connect to themselves first in some way. Being present was considered by one of the nurses as "the key to unlocking it all" as far as connecting with patients and families goes. The need for safety extended beyond self when a person wanted to connect to others. This created a need for social safety. For one of the patients it meant feeling safe in hospice and watch her husband go home and not worry about him or herself. She had not felt safe in hospital previously. She attributed the feeling of safety to the place and the people of hospice. Patients felt heard and seen and listened to and the nurses described their experiences applying conscious communication to create connection. There were also deliberate or intentional actions to connect with patients even when they were unconscious or connecting with partners as they cared for their loved one right up to the last minute of life and beyond.

The need to be genuine was important for the nurses and appreciated by patients and families. Being genuine means to be congruent as a nurse and as a person. Genuine personness was

perceived to help with connection. The family member and patients felt deeply about being accepted and included. One family member summed it up with advice to treat family members as “individuals and speak to them as equals” and a reminder to offer hospitality evenly to everyone, even a biscuit will do. It helped family to feel included. The tone of connection was kept light when looking for connective subjects to develop mutuality. This was done by looking around the house or the room and picking up clues of person-ness, like blueberries in a bowl and asking about gardening or children. Humour was used sensitively. The nurses were all aware of the tension of person-ness and giving too much of themselves and professional boundaries.

Kindness was considered by all participants to be necessary to connection. To be kind and to have kindness shown was a key way to create rapport, it was attractive to each person in different ways. One patient described kindness as being able to ask a question without fear of ridicule, another recounted unkindness to her mother 35 years ago and its lasting impact on her. “Kindness goes a long way” and so it seems does unkindness. There were unfortunately unkind words and actions experienced by the patients, prior to hospice as patients receiving palliative care. The nurses had three ways that they felt made kindness indispensable for connection. Firstly, there is kindness with patients and families, and secondly kindness with each other as nurses. There was a feeling that kindness from colleagues helped with sustainability of the job. Without at least one connection with a colleague, it was speculated that the work was harder, and the care of patients was affected as a result. The third way for kindness to be helpful was with new staff to the area. The other quality described and desired by patients and families was for the nurse to demonstrate friendliness or being like family. Families were wanting the nurse to create an ease in the room and to “fit in” with them. As one family member said, “You can’t nurse without loving people”.

There were many comments about Hospice from patients and families about the sense of pleasant surprise and the profound sense of safety people felt due to the physical surroundings and the people who work there. It was recognised that communication was valued as part of the hospice experience. Two patients felt so safe and relaxed there they felt they could come back to spend their last days there. For the nurses the connection to spirit is a deeply personal experience but the nurses described when they felt some kind of spiritual connection was made with the patient, like saying the rosary in the middle of the night with a patient.

The nurses, patients and families found that when there was connection and rapport between them, they found managing each day was much easier than when there was no connection and no rapport present. The nurses all cited connection with patients and families as vital to their work as palliative nurses. It was being connected and having rapport to either the patient or loved ones or both that meant they were *being* palliative care nurses. The rapport and connection experiences were described as “fantastic,” “tremendous” and “really good”. The interviews revealed the sense of the patients having been through so much already, on every level, physical emotional psychological and spiritual. Their vulnerability and courage were

evident as was their absolute need for safe and kind connection. The way that care is demonstrated by the nurses was perceived as important for them too. For the families it was optimal to be seen and heard and treated as real people themselves and to see their loved ones genuinely cared for. From the patient and family transcripts comes this interpretation of what makes connection easier for them:

I am grateful I can ask a question and not be thought stupid

I am pleased I can ring the bell and a nurse comes and wants to help me

I am relieved to be engaged as an intelligent human being

I like it we can talk like normal people

I need you to listen and not talk over me or tell me you know better

It is nice that you get my name right

Chapter 5: Phenomenological Meanings of Rapport

Being Disconnected

The process of thematic analysis of all the interviews revealed there to be two essential themes, that of being connected and being disconnected. Chapter 4 has already focused on the experiences of “being connected”. Chapter 5 will focus on the experiences of “being disconnected”. It is clear from the interviews that rapport is highly valued by the palliative care nurses, patients and families and that it occurs in conjunction with connection. The ideal for the participants would be for each interaction in palliative care to feel connected and rapport be present. It was strived for by the nurses and desired by the patient and families. This ideal is however not always the case in clinical reality. Disconnection occurred and was considered unsafe and uncomfortable for all groups interviewed. In addition, it seemed as if rapport was not possible in these experiences of disconnection. This chapter has an in-depth look at the experiences of disconnection as described by the participants under the following headings.

Theme: Being Disconnected
SUB-THEME: BEING DISCONNECTED FROM SELF
Related to- <ul style="list-style-type: none">• feeling unsafe and vulnerable• being not present or partially present
SUB-THEME: BEING DISCONNECTED FROM OTHER
Related to- <ul style="list-style-type: none">• feelings of separateness• belittlement• a sense of uncertainty or not known-ness• one-sidedness

The theme of being disconnected had the two key aspects of being disconnected from self and being disconnected from other. The aspect of being disconnected from self related to feeling unsafe and vulnerable, and being not present or partially present. Being disconnected from other seemed to relate to feelings of separateness, belittlement, a sense of uncertainty or not known-ness, and one-sidedness. When these were present there were feelings like sadness, anger, anxiety, frustration, and dissatisfaction, with an overall sense that disconnection makes things uncomfortable, with no rapport experienced.

Exploring being disconnected

One way to know what rapport is like is to explore what it is like when there is no rapport. An important part of this study was finding out from the participants what it is like for them to

experience either no rapport or poor connection as nurses, patients and families in palliative care. Each of the participants was able to cite examples of disconnection and the stories were readily shared. Without an actual tally of how many times disconnection happened for them, the impression is that it is not uncommon for the nurses to have rapport and connection difficulties with patients or families. When there was little or no connection with patients the nurses were reduced to task orientated nursing that left them feeling unfulfilled or frustrated. The patients were left feeling unsafe and the families disenfranchised under an “objectifying clinical gaze” (Benner, 2000). Nurses may not feel an affinity with every patient (Lazenby, 2017) and patients and families may not feel a connection with every nurse. As Gulino described it, they may be “like two ships passing in the night...completely missing each other” (1982, p. 354). Even when there is no connection there is always communication however. The patient with their back turned, eyes averted, hiding behind a screen, not talking, or asleep, is still communicating with their nurse. They are potentially expressing information about themselves or how they are perceiving the nurse caring for them, (Stein-Parbury, 2014). The family member with their arms folded and a grim look on their face or silently watching and ignoring all attempts at engagement, is also communicating something. These communications just happen to fall outside the usual social realm, which can be partly due to the patient’s and their family’s approach to dying.

Disconnection from Self:

At some point in the dying process, there can be what Julia Lawton (2000), refers to as the “liminal” way of death. When the person with the life-threatening illness comes to a period of time that is between living as they have known it and dying. It is a state of in-between-ness (Bruce & Davies, 2005) With the chronicity of many illnesses the person can be in this liminal state for some time. A prolonged liminal state can see the person become disconnected from their body, their social life and their family (Lawton, 2000). The sub-themes under this heading are feeling unsafe and vulnerable, and being not present or partially present.

Unsafe and Vulnerable

The need to feel safe for each of the palliative patients before any connection of significance could be made was essential. Lazenby (2017), reminds nurses that patients are just the same as nurses and are simply vulnerable people in need of care. Indeed, nurses are in the ideal position to help reduce the patient and family vulnerabilities (Stein-Parbury, 2014). If Maslow’s need for safety is not being met, the person is likely to be fearful of death and the kind of death they, or their relative may have, or it can be a fear of prolonged suffering (Zalenski & Raspa, 2006). The participant patients each had physical and emotional scars from their experiences with their disease, the health system and some personnel along the way before coming to hospice. They lived with the questions: Will you hurt me? Will you be late? Will you leave me in pain, or take me to the toilet in time? Will you laugh at me if I ask this question? Will you think I am stupid? Safety is important for people who are dying: the need to feel safe with the people around them, safe to sleep, safe to let staff undertake procedures, safe to be left alone, safe to

say whatever they need to say and, in this section, sadly when all of this is unsafe. Having no connection with the nurse “caring” for them, opens patients up to being vulnerable to physical and emotional hurt. Protection strategies are used by patients and nurses when there is no connection or trust, one of which is avoidance.

If there was a problem with communicating with a doctor or nurse, Patient B says she would be "more inclined not to speak up" and that if “patients avoid you, then you will know" you are doing a poor job of connecting. She would also “restrain myself about expressing opinions”, if she perceived a nurse as not being there for her. To with-hold opinions rather than giving feedback is her way of expressing dissatisfaction. So, for patient B the less she interacts and the less she says, conveys her avoidance and desire for less contact with that person.

Nurse B thinks that deciding to not look after someone where there is no connection after best efforts made, is one way to manage self-care. "Yeah, because we give. We're giving and we're absorbing a lot of sadness and grief and all that stuff, so it is a form of protection". Not being listened to is a barrier to connection. Patients will disconnect from self to retreat and wait out the disturbance. Nurses who do not listen reveal their own fear and their need to control others. Not listening is perceived by patients as heralding unkindness, and means the nurse is something other than “I am here with you”. To one patient not listening to him means wanting to control him, and over-ride his knowledge, experience and self-authority.

The big thing is that certain people listen to you and other people, they want to control. They won't listen to anything that you say. They interrupt you; they tell you, when you know better. Like this peg, I know more than a lot of people know about the peg; and I know what works and what don't work. But some of them will listen and they'll genuinely want to help and see what you have to say; but the other ones, they act like you don't know, "I'm the nurse. I know" whatever. When I said, "No", they laughed at me "No, we don't do that what you're saying" like you don't know what you're talking about. No, she didn't listen. Patient A.

This is a difficult story to hear as a nurse, this man was so hurt and angry about this violation to his whole being. He is incredulous that nurses can behave this way, his experience is that when nurses don't listen, he is physically and emotionally unsafe. When he protested “No” and was overridden and laughed at, he felt violated and disempowered. As a result, it is clear to him that when someone is interrupting and “telling” him and assuming they know better than him, they are to be avoided as they will hurt him. This has been his experience pre-hospice.

They don't care, and it hurts. They can hurt you. I've had quite a few who don't care. Patient A

Another sign of feeling unsafe was shown as a keeping the other at bay. Patient B says she would keep someone "sort of at bay". Which meant she was keeping that person and their behaviour at a safe distance so as not to hurt her or dissipate her vulnerable and limited energy. She makes herself unavailable until she feels safe. As does Patient A,

But then again, if they... I need to keep up, and sometimes I can't be bothered if you're just going to be a downer more or less. Yeah, I'm just going to kind of avoid the situation if I can.
Patient A

Patient A is saying that he assesses people's energy, if they will be a downer for him, they will drain him. He admits he would try and avoid that situation. This must be difficult in a clinic or ward where there is no real choice about which nurse will care for him. Patients are powerless to choose who looks after them, the nurses choose at shift handover. Patients wonder who is going to come into their room and wonder if they are really going to care for them. Will they be friendly, kind, funny or serious, quiet or loud, will they leave me to rest, will they sit and talk? These palliative patients also shared their vulnerabilities about wanting to connect, they each had an innate desire to connect to people despite their illness, fatigue or pain.

The nurses related experiences where they felt ill at ease or vulnerable being in a patient's room. The common thread here was the experiences were often as new palliative care nurses. With these experiences they found their boundaries of safe practice and were quickly in the unknown. There was a disconnect from their nursing-self as they wondered what to do or say. Nurses learn on the job to feel safe with what they say and how they say it, each and every time they go into a new patient or family, it is ongoing learning.

But, I definitely had, in the very beginning, situations where you feel like you're out of your depth. You know, you walk into a room and you just feel like, "Oh, my gosh; this wasn't quite what I was expecting." Or, I don't know the information; I should know at this point about what was happening; and I've missed something. Nurse C.

Nurse C describes her learning curve when she began nursing in palliative care, especially when entering a room and being unprepared for what is encountered. Being out of her "depth" is her way of describing the new limits found in her communication practice and experiencing the feeling of being out-of-control, of being in the unknown.

To be honest when I first started (in palliative care) I was unsure about how to connect. I suppose if it is a bit more of a complex patient I'm always a bit hesitant and just very cautious as to what I would say. I would be a bit more cautious when I come in; being cautious meaning being more watchful with my words. Yes, because I know sometimes you might make say a side comment about the weather's been really rainy today or something like that. Sometimes I don't do that, because I would rather that they focus on, not really me, but if there were any sort of concerns that may come out that is more important than me causing a bit of a distraction. Nurse E

Nurse E said there was only on-the-job learning regarding rapport and how to connect with patients, and she thought that nurses have to find their own way in palliative care. She also talked about needing to trust her own feelings to keep herself and her patients safe as she cautiously found her way. She has learnt there are times when small talk like the weather is not needed or appropriate as it can distract from what else might come up from patients or

families. She listens to nursing handover with the filter of communication needs, then tries to adapt her behaviour and speech to assess and meet patient and family needs.

Sometimes there is a patient who despite the amount of nursing time spent in the room there is a challenge to make connection and rapport due to high and complex needs. The patient in this scenario wants to disconnect from his physical self, due to constant pain and strong medication effects. For Nurse B there was a moment or two of connection after many days of care.

He did. He did take me in. And it took a while. Love looking after them but wow, it's hard work ...It's great, because there's been a bit of a breakthrough with him and I got a smile last night. He's a complex young man. Can't walk. He's bedbound. Gets a lot of pain, pain, pain, pain. Nurse B.

These words reveal the suffering which was a daily state for the young patient and how difficult it was for him to have attention for anyone else as his suffering was so intense and continuous. He was only available for a moment or two to make a connection with those outside of himself or his intimate circle. Mostly though, those moments did not occur, and it was hard graft with so much focus on alleviating his suffering. This patient became an important teacher of taking the moment of connection when it occurs, cherishing it and sharing it with colleagues. Every tiny connection had big impact for the nurse.

I said, "Night, night Patient X," and he goes, "Night, night," and I stood at the door and this great big grin came over his face as I walked out. I went home feeling just good that we had a laugh because there's not a lot of laughter in that room. Nurse B.

This is the currency of moments of connection. Nurse E also describes a connection that was real in the moment and gone when she next came back into the patient's room.

And then I talked about piano and she responded with smiles. She said, "Oh I haven't been playing," and that was quite clear. "I haven't been playing, not for a long time now." I just talked about, "Oh that must be really hard, because it's part of your life," and she nodded. I said, I can't do chores without singing and she had a laugh. Nurse E.

For this patient to respond with smiles was significant and that she connected and actively engaged in the conversation about piano was amazing for Nurse E, and she recognised this as a significant connection for a usually uncommunicative patient.

Yes, she responded to me. And then the connection was gone as soon as I came back with the pills. All she said is that, "I don't like it, what do you want me to do, what do you want me to do. I don't like it," and her demeanor changed. As soon as I said, "Look that's alright, if you don't like it I'll just take it back and we'll come back later and see how you feel. You could see the relief – "Okay." But I feel for me that because we didn't have that connection anymore, we were unable to communicate; she was unable to communicate or articulate

exactly what is going on. I feel like I'm not able to do what I should be doing for her. Nurse E.

The connection was gone as soon as Nurse E came back with the pills, and they seem to get into almost the opposite of rapport. Nurse E says it was like "A wall, with guns." She felt the patient's defense, with walls and protection to prevent intruders from entering her space. Defending her space with guns to use if needed. It felt to Nurse E in this case like her patient was saying "I do not want that medication, take it away. I will withdraw or get agitated if you keep trying to make me take it" This is still communication of course, just more coded and different to when there was connection. Nurse E felt shut out, barricaded against, when her intention was to relieve pain and yet she inadvertently was causing a different kind of pain for her patient.

Nurse A describes a last visit with a patient whom she had a "tremendous rapport" with. Unknown to her he had become disconnected from his increasingly debilitated self. His sense of vulnerability was so profound he had decided to die.

We'd had a good morning. We were talking about the fact that probably within the next two weeks he was going to go into care. And then he said, "You're gonna go in a few weeks." He said, "I just want to give you a wee pressie" ... I said, "Okay, okay, yeah. Thank you very much." And thanked him and what not. Talked about what I was going to do and the fact that I'd got a job lined up and went off sort of thinking, okay. I actually didn't click. Nurse A.

What Nurse A "didn't click" to was that this was to be the day her patient died by killing himself after her visit. He did this in a pre-planned way, with a gun he had hidden, saving up ammunition and arranging the time place and equipment in a way that he was able to carry this out himself, despite his debilitation. They had the usual visit with Nurse A with even reference to future care and plans. The extra-ordinary thing that happened during this visit, was he wanted to give a present to Nurse A as she was leaving in a few weeks to live somewhere else. He was adamant that she received his gift, it was an important giving gesture for him and in hindsight a farewell and ending of their relationship in so many ways. This relationship was important to him, Nurse A had made a significant connection with him that he valued and wanted to acknowledge with a parting gift, even on the day he was planning to die. This connection has also had a lasting impact on Nurse A as a person and as a nurse.

Not present or partially present

As connection requires presence of the self and other, disconnection has absence or "not presence" as a feature. One or other of the relating parties has withdrawn or is not available to connect. Without connection to self it is difficult to connect to the other. Nurse A describes a visit with no connection, her own fear and intimidation had her disconnected from self before she went in. It was difficult to be present.

No connection is traumatic and upsetting. The person I was relieving for the day, had a good relationship with the patient, which made us all terrified of going in there. I was absolutely shaking in my boots going in there. Anyway, I tried to play it safe and do the right things and just be nice and do what I had to do but that didn't connect at all and the feedback I got was she didn't want me back which I found I really dwelled on. Obviously, I hadn't been able to connect with her. So, that was traumatic for me. I was really upset by that. But I thought, well, she has the right to that and that was okay. Nurse A.

Nurse A was not feeling well resourced for this visit. She was in a relieving role, and not able to offer the continuity she prefers for establishing connection. The nurse she was relieving for had a relationship with the patient that “made us all terrified to go in there”, which suggests an unusually strong and perhaps over-involved relationship. Nurse A was shaking in her boots going in to visit the patient - a difficult place to create a connection and inspire trust from. Rapport was not established, and it was clear there was not a connection. This created a situation for Nurse A which took some reflection, support and time to put in perspective as it was “traumatic and upsetting”. Nurse E describes her strong sense of frustration when patient symptoms can block rapport as the patient is not present.

With regards to connecting I find it harder when there's barriers; when there's cerebral involvement or like delirium or hallucinations or memory loss. If you've got a patient who does have that I feel like the next best thing would be to connect with the person closest to them, which can only happen if they're present; which I found challenging with one of the current patients who is unable to express herself. So, I just feel like I have done her an injustice. Nurse E.

Nurse E sounded disappointed when talking about this experience. She felt like she was neglecting her patient, even though her physical cares and medications are done. Not being able to nurse holistically is frustrating for her. The use of the word injustice implies a lack of fairness with time and needs. For Nurse B, rapport and connection is:

“...less likely if you just buzz in with the pills and buzz out - which seems to happen quite a bit now because we're so busy. The difference, the busyness? You don't have the time. There isn't as much time. You try to make it. I'm inclined to think with this busyness, if you've got someone who's come in for maybe just respite or who is quite independent, I find you just don't seem to have the time to sit and be with that person. But do you know I've only just realised it right this minute. Nurse B.

The “too busy” nurse is not as present for the patient. Nurse B is realising the change in acuity and busyness of hospice has changed her nursing practice and she cannot recall when she “just sat and talked” with an independent care person. She was surprised and shocked by this realisation that the change in acuity has affected her time management and by implication the time needed for rapport with a certain patient group. The busyness factor is raised by Nurse C

as well, she identifies there are “definitely” opportunities to connect with patients missed due to being too busy.

You know you miss opportunities for connection sometimes because it's so busy, and because you're running in and out; and you miss those opportunities, actually. Oh, definitely. Because I'm aware that things can change at any moment, you know, somebody could get really sick, unexpectedly; or somebody could have a fall. Things just change really quick, and all of a sudden, your time and attention is spent somewhere else. Nurse C.

Disconnection from Other:

There are times when “we may feel alienated in our embodied being, if body experience and situated experience are in conflict or disharmony” (van Manen, 2014), as when someone is diagnosed with an illness that will accelerate their dying. This sense of alienation is lurking for patients as “alienation from human relation and alienation from lived body relation” (van Manen, 2014, p. 341). This alienation causes a disconnection from other and shows up for the patient in ways including withdrawal from loved ones and reluctance to connect with nurses. The themes under this heading were separateness, belittlement, uncertainty and not knownness, and one-sidedness.

Separateness

When individuals do not connect they are separate. Being separate can be isolating loneliness or contemplative aloneness. For some people being removed from their usual social, family, and cultural contexts due to illness, poor symptom control and admissions can be isolating. On top of this people suddenly find themselves being put in a “patient box” which can also create separateness. This separateness can inhibit the nurse's ability to fully understand the patient's beingness or humanity (Minicucci, 1998). There may be feelings of guilt and shame which contribute to separation, as “shame isolates one person from the other” (Brown, 2007). Family members can also be shocked, fatigued or afraid resulting in separating from their loved one themselves. Nurse B describes an admission interview with a wife who thought her husband was coming into hospice to die.

I had a patient not so long ago who came in. He was really unwell, and his wife was very, very tense, very tense. Sat with her arms folded throughout the whole admission process. Wouldn't smile. Would barely look at me. That was awful. I went through all the paperwork and that and I said to her, “Is there anything you want to know, or I can help you with?” She said, “Has he come in to die?” And I said, “No.” And she thought coming into the hospice meant he was going to die. And I think he did end up going home, I can't quite remember the ins and out of that, but once I said no and then talked about that, you just saw her loosen and she smiled a bit when she went. But there was no smile really. It was such hard work. There was that small breakthrough, and I didn't know there'd be a breakthrough until she said that. So, the whole time she was there answering these questions she was just

glaring at me because she thought he'd come into die. So, she wasn't angry at me, she was angry at the whole thing, but I was the one representing the hospice, I suppose. Nurse B.

This reveals a challenging dynamic with a patient's wife whose body language screamed anger and fear. With arms folded, no smiling, no eye contact, holding herself separate from the nurse and even her husband, the patient. Nurse B found it "such hard work" trying to connect, to try and find out what was causing this separation. The tension continued with the wife glaring at the nurse and reflecting her anger onto her. Nurse B persevered by not taking it personally and asking more questions. She could eventually see the wife's anger was at the whole situation and that it was not necessarily directed at her personally but at what hospice potentially represented for the wife -that her husband was there to die. Which was not the case. Nurse B also commented that their rapport remained limited for the duration of the patient's stay. Nurse B was philosophical about this,

No, it either happens or not. When I meet someone, I introduce myself the same way each time, "Hi, I'm Nurse B. I'm your nurse today," and just take it from there.

Nurse B has no presumption of connection made when meeting a patient for the first time. She uses the same introduction and believes it either "happens or not". Rapport is not something she initially has control over, but she has the confidence and experience to "just take it from there", wherever there is. There are times when this confidence and experience is not enough. There are times when the patient does not welcome the nurse into their lives (Lazenby, 2017).

I looked after a chap recently who was always looking at his laptop or his screen. Every time, even asleep, it was on and in front of him. So, that was all that and he barely looked when you went into the room, barely looked at you. Would say "Thank you," but didn't look up. I thought, time, he needs time. I looked after him for about four days I think, and then I just thought, no, no, no. I don't know what. He wasn't rude, but he wasn't available. So, I stopped looking after him after my days off. I'd go in and I'd do checks and he would just, "Hello." He would look as if he'd never seen you before and then one day, he said, "Oh, your name's P isn't it?" and I said, "No, it's Nurse B." So, I knew. When you look after someone... he had never once mentioned my name. Nurse B.

This man apparently used his laptop to shield himself to protect himself from external interactions and Nurse B also thought it shielded him from his own fear of dying and his emotions. She persisted to look after him as she believes time can sometimes help break down barriers, but after four days of no eye contact and minimal speaking she decided he was unavailable for connection with her. His way of being disengaged, monosyllabic and his lack of recognition of her name or her face told Nurse B that this patient was not looking for connection, or at least not wanting it from her. He was able to receive functional service from her but was unavailable for any connection on a person to person level.

No. And that's fine. And I knew that. So, I thought, I can't do anything for you to help you through this, which obviously he was struggling with dying, but there was just a brick wall

up. There was an invisible glass wall around him that he didn't even look through. He didn't even see me. So, I thought if he can't see me, how can I help him to talk about anything?
Nurse B.

The mixed imagery here of a brick wall and a glass wall, that he is sitting behind shows the impenetrable nature of his protective barrier. She can see him “obviously struggling” and feels unable to help him. This block to connection means for Nurse B that her usual ways of helping him by talking and listening and connecting were just not possible.

I thought someone else can do that better than I can, or give someone the chance to do it better. And somebody did. Somebody learnt a lot about him, but I didn't. Nurse B.

Nurse B felt this patient was choosing to keep himself separate and felt there no intention from the patient to connect with her. By stepping away from caring for him and allowing another nurse to take on his care proved to be useful as the other nurse was able to make some sort of connection with him which Nurse B felt was good. Nurse C had a similar experience.

And sometimes you just have to realise, actually, whether it's just me as a person that they don't quite connect with, and they connect with other personalities better. I mean, that's fantastic, you know. But it does happen from time to time where people don't look you in the eyes; or they just, yeah, shy back, just kind of grunt and grumble at you and you just feel like you're not really getting anywhere. So, it's slightly uncomfortable you know. Nurse C.

Despite her best efforts and techniques, Nurse C has a realisation that sometimes she has a patient that does not connect with her. She feels this could be personality related and that this person may connect better with someone else. She describes the lack of eye contact, monosyllabic responses and shying back as uncomfortable for her but accepts it as the patient's choice.

And so, we had a guy in here... And he had had some history of drug abuse and other things going on. So, he wouldn't make eye contact, and kept sort of looking out the window; and kind of gave me a “Huh, yeah, huh” sort of thing when I “Oh, hello. My name's Nurse C, I'm your nurse today”. But that, I mean; you take it personally or you don't. You know, I'm still there in the end to do my job and do it well. I mean, that's just what it is. Nurse C.

Nurse C is saying here she has a choice to take his lack of response personally or not and thinks she has a job to do and wants to do it well, even without his connection.

Things could be so much better for that person, I guess, if they could find a way to open up. Not necessarily to me, but to other nurses and people around that could probably be quite helpful. And you wonder, too, what else is going on in that person's mind to be so shut off. Is it me? Or is it everybody? And usually after a few days, and talking to different nurses at handover and things, you get a bit of an idea of how that person's personality is coming across to people. Nurse C.

She describes wondering what is going on for this person to be so “shut off”, she believes connection would make things “better” for this person, but appreciates it is his choice and someone else may be able to connect with him. It seems this man did not “open up” to any of the nurses on this admission as “you get a bit of an idea” from colleagues referring to whether someone else connects or is he left alone. Nurse C mulls over whether this is what he really wants, ironically without connection the nurse does not get to know for sure if being alone is what he wanted but has to assume it is. Nurse E shared the frustration of how not speaking a shared language can inhibit connection:

Just not able to communicate because of language barrier. I've had a few. I felt frustrated. So, you go in and you know what you want to say and...and you can't. We did use the charts. But you know how when it comes to pain. Yes, because I mean the type of pain or discomfort and it's easier for us to explore it if we can communicate effectively because we understand each other's words, but for somebody you can't understand— and he probably didn't understand me either – it's harder to pinpoint what is causing this distress. Is it just the usual pain, the chest pain, the physical pain, or is there deeper existential or emotional pain? Which I find really hard to assess if you can't talk, you know. Nurse E.

This lack of shared verbal language provides a real challenge to Nurse E's example of assessment of pain. The feeling is one of distance from the patient, a disconnection. The care is there but not the rapport and connection. Nurse E describes feeling frustrated as the combination of lack of language and the lack of connection makes effective care more difficult. In another instance Nurse E felt having no connection as “frustrating and disappointing”, citing not enough time and conflicting workload at times.

To be honest, I just feel like I couldn't really connect as well as I would have wanted with this young person. I just have not established that connection. And I think because there's so much other stuff to do that I've not been able to really sit down and, you know, yeah. I've just not had a chance. Yes, also don't want to really stir things up. There's nothing coming from their side. Nurse E.

Here Nurse E talks about not connecting with this person as well as she wanted to. She felt like she had not really connected with either the patient or the partner. She cites the complex cares and the time taken to undertake the cares, leaving little time for relational connection. Nurse E recalls talking but there being no response to her attempts at engaging. She feels she was able to care for him physically but there was little connection to enable her to care for him in the other domains. In a different example, Nurse E felt not actually seeing or touching or connecting with the person before a phone-call added an extra challenge to connection.

Because we've never actually met before and there was an absence of the person. Nurse E.

This lack of analogue (person to person) data can be difficult when making a connection via digital (Watzlawski, 1967) modalities such as phone or email and social media.

Disconnection can also happen in a room full of people, Nurse D talked about what it is like to not connect with patient's families, when they keep themselves separate.

There is the patient with the family who sit around the room and you could cut the air when you walk in, they'll ring you if the patient twitches or wants medication. But you haven't got that little bit of banter that usually goes with caring for the families to reassure them. You can't get anything out of them. You just have to deliver the service. Nurse D.

Here Nurse D is describing being in "just-delivering-a-service" modality for the family who are having difficulty connecting.

Yes. I probably have several examples of that over the years. Nobody can attach to the families and it's just uncomfortable. That to me is when we're just delivering the service. They're in the hospice, we're looking after them properly. Tender loving care for the patient in this setting is a given, whether awake or unconscious but you're not able to give that to the family because they're sitting around so tense. Nurse D.

The challenge she is describing here is when the family avoid connection with the staff generally. "It is just uncomfortable", implies that the connection with families is usually comfortable. Without that connection it is difficult to conduct care and comfort to the family members. Nurse D muses over these non-connecting families and how that experience in hospice was for them. Her experience leads her to speculate they are feeling afraid and separate.

I think the ones where they're sitting around the room are frightened, they haven't been through this dying process before and maybe they don't want their loved one to die. But because they're not expressive we've not got there. If you talk too much in the room, you just hear yourself. I would say when you hear yourself, I hate that feeling. I just hear it going right through the walls. That's the hardest thing in palliative care for me is hearing that voice of mine with no connection. So, usually I say very little once I realise. I say less and less because it's wrong. But I'm nursing outside my comfort barrier. I don't like when there's no rapport with the families. Nurse D

Nurse D suspects the families are frightened, and despite her significant experience and skill she cannot make a connection with them. She also talks about the idea of hearing herself, hearing her own voice in the room sort of reverberating around not being taken in by anyone, when no one is available to connect or communicate with. "It is the hardest thing in palliative care to hear that voice of mine with no connection". This highlights how much she values and needs connection with patient and families in her day to day work.

Patient B did say she has techniques to keep herself separate, one is to say, "no thank you" and refuse cares. While Family One said this when asked how it feels to not be connected:

You feel lonely. I feel the patient in the bed feels lonely and feels isolated. Of course, we're happy your family is around but the family most of the time is not around 24 hours; so, who's in charge is really the person that's taking care of them. Family One.

If there is no connection from staff, there is a sense of loneliness and isolation for the patient. Family One views it as the nurse's responsibility to ensure there is connection with the patient when the family is not there.

Belittlement

Belittlement is to put someone down, to depreciate their dignity or sense of self. This can be done with words or actions with the effect the other person feels little, or less than the other. Some of the patient's experiences were uncomfortable to listen to as a nurse, it was challenging to hear about the poor treatment and communication dished out by fellow nurses in other areas. It was worse to hear and sense the effects this had on patients. As a researcher I was grateful for the honesty from the participants. None of the following negative experiences were had in hospice, but all happened to these people as palliative care patients.

I've been stuck with needles, where it was like... you know what I mean? It was just...shoved in. Patient A.

While telling me about this Patient A was visibly upset and pointing to the place in his arm where the blood was taken. He thought this was a callous technique rather than a difficult cannulation as he had had many before. He was surprised and hurt it was a nurse doing this to him.

But it's like with the peg, making sure, you know what I mean? Because I'm not always 100 percent awake, you start putting stuff in this peg that I don't know about, there's a good chance it could get plugged up, even though you're a nurse. I've done it for two years, so I know what works and what doesn't. I always like to keep on it, 'cause I've had some people forget or they've given me the wrong medicine if I wasn't watching. Oh yeah, I've caught it all. I've seen it all. So, I try and pay attention but sometimes I'm groggy. So being on the same page and just being, "Hey...". If you realise the patient can't talk that much, you just lean down to him, "This is what I have for you. It goes in your peg. You tell me if this works" and you read off what you're going to do and what pill it is and that's at least a precaution. Just because we have what we have, we're not dumb. We've been through a lot. Patient A.

Patient A rightly considers his peg tube to be part of him. His trust has been damaged with wrong medication, poor technique and carelessness around his peg. He says he has not been woken up and talked to when being given medication and he is saying that nurses have presumed to "know" more than him about the care of his peg tube. He is asking for alignment and partnership with his nurse, to wake him up, and work with him. What is not said here but implied is he needs help and he wishes that he did not. He needs connection to trust his nurse. Patient A also describes a "clique" for some nurses where he felt it can be unsafe to complain if

he was hurt, as nurses can and do stick up for one another. I asked about the “clique” and he gave this description:

"Yeah, they're like in little cliques; certain ones they stick together. The one who drew blood, I tried to tell that she did it wrong 'cause I knew it... You know when you take blood out, it's like a gravity flow? Well this one injected it out, which is to me... Like pulling. Yeah. And when I said that she stuck up for her and blamed it on me. I said, "look how black and blue that is and it's been that way for three weeks" and you just couldn't tell her anything. That's a clique, where they stick up for each other. They're pretty easy to spot. You can spot them by simple things. It's just like letting the other person do things; Lazy, you know? ...and some of them, need to start mopping the toilets and get out of nursing. You just don't treat people like that, especially in this situation. Patient A.

His meaning seems clear, that there is a threshold to nursing behaviour and attitudes below which Patient A considers is not nursing and should not be tolerated. His advice is to leave nursing rather than hurt patients, especially dying patients. The following is an excerpt from Family Two, about a Doctor appointment that rated very poorly for rapport and connection by them, it occurred in a clinic in the last 2 years. It was NOT a hospice doctor but one who is associated with palliative care patients.

The Doctor example, yes. We went to the appointment and during the appointment questions were asked. The doctor almost brushed them aside as unimportant. The doctor is of the older guard and certainly didn't treat us, myself and my relative, as intelligent people. He basically brushed aside anything she tried to put to him. That particular doctor certainly gave the impression we were encroaching on his time; that we weren't important enough to spend enough time to actually sit down and have a proper conversation with. Yes, he belittled my relative. Somebody with a terminal illness does not need to be treated like an imbecile and be pushed aside with their questions and that sort of thing. Family Two.

Family Two further described the doctor as an “arrogant ass” who treated her relative like an imbecile and pushed aside her questions and concerns. Imbecile is such an emotive description, a word that is out of vogue clinically and even colloquially; it is used to describe someone of "moderate mental retardation" as per Merriam online dictionary (2017). Meaning Family Two felt that the dynamic was so distorted that the doctor was treating his patient as mentally retarded. They were given the impression they were “encroaching on his time” and not “important enough” to have a proper conversation with. This was a deeply disturbing interaction for Family Two and the implication is she thinks he should not be caring for terminally ill patients. A complaint was made.

For Patient C being able to ask a question without being judged as silly or the question being thought of as silly came up three times in her interview, it was clearly very important for her.

"...sometimes you think you're being silly by just asking a simple question".

"...they don't make fun of you for asking perhaps, a silly question"

"Oh, yeah; I can ask a question even if it sounds silly to me, they get what I am trying to ask".

Each of these statements is revealing a different aspect of her fear of being thought less of by Health care professionals. Patient C is judging herself as silly for asking a simple question and is afraid that the other person thinks she is not intelligent. She is grateful no one in hospice makes fun of her for asking a silly question, implying other people do or have done. When she does take a risk asking a potentially silly question, having it heard and interpreted correctly is important. All three of these statements reveal her hidden hurt and fear to ask, in case of being made to feel belittled and thought of as silly as has probably happened before elsewhere. She added,

I'd have been home 3 days ago if this was public. Yeah, you're just another number I think up at public. Patient C

Her previous experiences at hospital had left her feeling depersonalised as a number and this was not the case at hospice.

The nurses recognised that some of their own values and beliefs can sometimes be judgemental and a barrier to connection. Judgements are akin to belittlement as they both put down the other.

I mean, how many times do we hear, you know, that we shouldn't judge people; we know not to because things can be completely different, depending on what we're thinking. I mean you have to keep that in mind; we don't know what makes people tick and think. Nurse C.

Nurse C is mindful that keeping an open mind is useful while caring for a person, and that judgements can corrupt assessments. One of the nurses relates a story about judgements.

We had a patient come in screaming recently, in terrible, terrible pain and she'd bled into her abdomen, so it was really acute. She was obviously going to die in the next few hours. But the comment because she was from a certain culture, it was comparing it to noisy expression of feelings. This lady I had met before and she was very stoic. So, I knew this was quite different behaviour for her. She wouldn't have acted that out. So, I found that I was really cross with that comment and stuck up for the patient. I think we have to watch that because sometimes we're always trying to work out what's happening for people so that we can manage their symptoms better but sometimes in doing that we also make judgements. Sometimes without the assessment. That's the key. Sometimes you hear the judgement fly at a meeting when they haven't even met the person or haven't really any understanding. That concerns me. I think that could be a bit of compassion fatigue for some people.

This is an example of myopic viewing of a patient in hospice, of judgements and potentially cultural ones made. This example was challenged by the nurse as she had met the same woman elsewhere, and the impression of her was stoic as opposed to histrionic. She expresses concern for colleagues with regard to judgements about patient symptoms without assessments and she makes a link with judgements and compassion fatigue. Nurse C talks about judgements too.

Sometimes what you're seeing in front of you with different relationships between our patients' families, is just not necessarily what it seems. We might think, oh, there's a lot of tension in the room today; oh, so-and-so wasn't communicating much with so-and-so. And, actually, we might have just walked in on a bit of a hard moment. You know? Maybe at that time they were having a hard conversation; things are dealt with, and it's okay after that.
Nurse C.

This comment reveals, it needs some listening and asking just the right questions to enliven the clinical notes to reflect actual current relationships for the patient. Nurse C stresses the value of not judging with an example of what may look like a tense family scene, she suggests it is better to observe and notice it but frame it with more possibilities, like a provisional diagnosis.

Uncertainty and not known-ness

As it is part of the nursing function to "establish rapport" with patients, it seemed reasonable to ask the nurses how they know when rapport has been created. When this question was posed, it caused a pause, it was a new consideration to assess the type and quality of connection they experienced and to verbalise it. The impression is that the nurses don't know for sure how the patient feels about the connection the nurses think they have. Nurse A looked thoughtful and asked herself:

"How do we know from the patient's side if there is rapport?" and her answer was "You don't know". She then wondered, "Hopefully someone is connecting with them if I am not".
Nurse A

Based on the idea that rapport seems to be difficult to assess from the viewpoint of other, I asked Nurse A to consider the patient if everyone's not sure or not connecting with them. "That's dangerous". She means dangerous in terms of, patient emotional safety perhaps, there is no real mechanism to check who is connecting with patients or how well. There are times when nurses do not know if rapport and connection are there for the patient.

Sometimes I think you make a connection and you don't realise. I looked after a girl - god, it's all coming out. This is a long time ago. This would be probably when I maybe first started in the hospice. I looked after her, but she was just quite, not cool, but polite. Polite would be the word. I'd looked after her for about three days. Everyone used to say how lovely she was, and she was, but there was just that politeness barrier. This particular day she was walking down the corridor and I said, "I'm not looking after you today." She said, "Oh, aren't you? I like you looking after me." Yeah. So, sometimes you don't always read it. I have thought about that and sometimes the obvious isn't obvious. Nurse B.

The feedback from the other person can be subtle when rapport is established, it can be moments and micro reactions as a person who is sick or dying is not always well enough to speak out to anyone. So, when this young woman simply said, "Oh aren't you? I like you looking after me", this gave Nurse B feedback that she had made a connection, even though she had been unaware of it. Nurse B had only felt politeness, which she considered respectful but not connected. "The obvious isn't always obvious" is from Nurse B's reflection and hindsight which provide her with a valuable learning about connection. Nurse C attempts to describe the uncertainty of rapport:

It's a feeling; I don't know how to describe it. It's a feeling, and you hope that you are on the same page as that person; that it's reciprocated that what I'm feeling; I think this person is okay with me being their nurse, and likes me genuinely as a person, in that I'm not a hard nurse to work with. So, you hope that what you're feeling is correct. Nurse C.

Nurse C hopes but is uncertain of how the other person is feeling about her in the connection they may have. She hopes her feeling of connection is correct. She hopes they are on the same page and seems to presume they are. Ultimately Nurse C is not sure how the other person feels and hopes this feeling of connection is reciprocated. The impression during the interview was she had not consciously considered this "How do you know?" question before. There are times when it is by reflecting on an experience that the nurse comes to some sense of knowing if the connection is there or not. In terms of uncertainty sometimes families sit and wait for information, it may be the family are naturally reticent or paralysed with not sure-ness as Nurse C points out,

Because I think this family were not asking enough questions in the beginning to really recognise what was happening. They were all too scared; didn't have the language; they felt a bit shy; felt like their questions might not make sense. And the questions, they didn't know who to direct the questions to". Nurse C.

When relatives are quiet, it is not always considered that they may be scared or shy or not have the language. The initial feeling Nurse C had walking into this room was that this was going to be a really challenging setup, with no-one smiling, no talking and wide-eyed stares. The first impression she had was that they were cool and disconnected, but she paused and interpreted their non-verbal cues to mean that perhaps the family felt scared, and this gave her the courage to stay standing in there despite her discomfort.

And some Pacific Island families are standoffish in that way; they think that, well the doctor has already explained, or that we should know already. You know? But, it's having that confidence to say, can you just tell me again what's happening now? Maybe they would not have rung the bell. You know? Maybe they would have just looked at each other and gone, "What's happening? You ring it. You go get that nurse. You tell her to come". Nurse C.

Nurse C gives her insight into the reluctance some families have to ask a question or ask a question again. This family tended not ask, so as not to disrespect the doctor or not to not

appear stupid. Nurse C gave this family space to ask their questions and to facilitate the family to be able to be with their loved one as he died. If there had been no connection with the family and the nurse, she speculated they would have sat there and waited by his bed and urged each other to ring the bell or ask the nurse something or maybe not. Even when the nurse felt she had created rapport with a patient she was not able to say how it was being perceived by the patient, there is an uncertainty to the reciprocal nature of rapport. Culturally we do not ask patients “this feels like a good connection for me, how is it for you?” Nurses rely on interpreting linguistic and behavioural cues and their own innate knowing and hope it is ok for the patient. One of the patients indicated it was similar for her, Patient B was asked if the ease of connection she felt with a nurse was a two-way thing,

Oh, I don't know from her point of view, but it worked from mine. Well, you can't really judge other people's opinions, can you? Patient B.

Patient B was not sure if the nurse felt the same way, she was unaware of the nurse's point of view on the connection, but it felt nice for herself and that was good enough.

We just see this person sitting here in front of us with this file, and we have a quick look, and we go in and say hello. We don't know anything else, really, about this person's life. And sometimes we can look at the genogram and we know this and that; or we think we know this and that. Nurse C.

Here Nurse C talks about how very little is known about the person being cared for, so little of their life before hospice. There is often a folder full of information that holds discharge summaries, clinic letters, treatments, medications and notes and a genogram but these are not from the patient's point of view and often piecemeal to the whole story of their illness and lives. The data is two dimensional and she is wary of what “we think we know”. An example of real unknown-ness comes from Nurse A.

I was devastated that I'd missed the signals. Absolutely gutted. But I guess for him that's what he had to do, and I accept that for him it was just too, too hard, too, too hard. But I must admit there was... a lot of guilt there for a while. Nurse A

Nurse A experienced complex feelings of guilt at not being able to divert her patient from suicide. There was also shock at the suddenness of his death, when he was on a long slow decline otherwise.

That's a tragic end and I never want to have another one of those, but you never know do you? Nurse A.

Nurse A reveals a little of the impact on herself when she says, “I never want another one of those”, meaning I never want to have another intense relationship with a patient hell-bent on killing himself in a such a graphic traumatic way and live with the wondering and guilt. I never want to be so powerless that I can't alleviate his suffering enough to feel he had no other choice.

It was a tragic one, but it was a very special one. Nurse A.

She uses the words "tragic" as in causing extreme distress or sorrow and "special" as in greater than what is usual. These words may seem to clash but they also seem to be a fair way to describe the impact of how this man's life ended, and to describe their relationship as patient and palliative care nurse.

This example from Nurse E is about uncertainty and the dilemma created by having no connection with a family, for a middle of the night phone calls to relatives of a deteriorating patient:

The "I wish I had done it" is more like a phone call at nights. You know, Do I? Don't I? Especially if it's like two o'clock in the morning. And because it's more than once that you're just not sure; because there were no clear instructions as to whether the family wanted to be phoned or not. So, in my experience since then, if I know that somebody is dying I always ask. Nurse E.

A new patient dies in the middle of the night and no family have stayed. Because there was no connection with the patient or family due to the short time at hospice, Nurse E was left wondering and worrying about not ringing during the night. The lack of connection with patient and family with Nurse E and her colleagues, meant she was feeling uncertain as to what was the best thing to do. She wished she had called. However, because Nurse E is clear that she doesn't want "to end up going through that again" she has since developed different ways to ensure she knows what communication a family would prefer. Her practice has been altered by this experience, to provide clarity to families and to safe guard herself.

One-sidedness

Connection can be unilateral from either the patient or the nurse, there can be a one-sidedness (Morse, 1991; Stein-Parbury, 2014) that defies the presence of rapport, as mutuality is stressed for rapport to be present (Tickle-Degnen and Rosenthal 1990). At times the nurses felt that to have a one-sided connection with their patient was the best or only option. The strategy here was to presume a relationship and act as if the patient might respond at some point, continually allowing the possibility to create two-way rapport, even when this does not eventuate. Nurse E prefers the relationships to be two sided but admits there are times when that is not achievable.

So, if the other party is not able or willing or there's something that's preventing them to connect further then that connection's not going to get any deeper than it is. Like you've got to have both ends, both sides, to meet in the middle to connect. Nurse E.

Here nurse E explores the preferred dyadic nature of rapport, it is really challenging to consider one-sided communications as it can only get her so far. But sometimes that is all that is possible, when that is the case Nurse C keeps going into the room.

So, I still will sit down and ask the questions that I need to ask. And I think that's important too, that even though they're probably aware that they're not giving a lot away, and they are trying to maybe cut the communication short; that it won't stop me from trying, I'll still smile, I'll still pop in the room, "How are you going?" Even though they might be, "Oh my gosh, go away." To me it's still building rapport even though it's not showing up in the way it might with other people. It's the same thing that I want my patients to know: who I am, that I'm here, I'm going to keep checking on you, and I'm going to do my very best, and that's it. Nurse C.

Nurse C offers the same rapport creating verbal and non-verbal communication to each person, even those who are clearly not wanting to connect, she offers this intentionally as she sees it as "still building rapport" it just looks different. At a minimum if she feels like the person is "shutting her down" she will stress her simple mantra of care and follow through, maintaining one part of the relationship at least.

Being as genuine a person as you can; you know, whether or not that person really wants to be your friend, or whether or not that person really wants to engage with you as their nurse; that's something you can't control. You can't control how that person feels, but for me I'm satisfied if I know I've put it all out on the table in that way, and people will do with it what they will. Nurse C.

Nurse C realises that not all patients want to be a friend or even engage with her. She is "satisfied" if she has met the patient and their family and they are aware who she is and that she is there for them in whatever way serves them. She is aware the only thing she can control is her own behaviour. Nurse D on one sidedness:

I always think we'll get there in the end, but if I haven't really, I will praise the family for being so loving and so supportive and for being there. You still hear yourself saying that and no words and not even a nod, maybe just a look back at you. Nurse D.

This reveals her sense of holding out hope for there to be a connection with the family, at some point maybe at the end. At the end in hospice usually means as someone dies. For some families in her recollection even at the end there is no sense of having connected with the family. She acts as if there is connection though and despite their lack of response, she has praised them anyway. Mutual rapport and connection is a driver to these nurses, so they may persevere with unilateral connection to encourage any chance of rapport. How a patient dies can also be a one-sided affair, this example is from Nurse A.

But looking back in journeying with him, with the family, I think it was an incredibly special time and although it didn't end the way I'd like to have seen it end, it was probably the right way for him even though that sounds a terrible thing as a palliative care nurse to say. Nurse A

Nurse A acknowledges the “incredibly special” connection with this person and family with a reflection of the complexity of emotions and reactions. How he died was troubling and uncomfortable for her as a nurse. However, she could see he was going to be challenged by his deterioration and by going into care, and she could see how he viewed suicide as a way out of this. By saying it was probably the right thing for him, she reveals an uneasy relationship with suicide “as a palliative care nurse”. He died his way.

Disconnection and lack of rapport makes things uncomfortable

The need for belonging is universal, yet it is not universally achieved. No one seems to get what they want when there is no connection. Certainly, there is no comfort or joy in everyday activities, it is more likely to create a dis-ease and dis-comfort between people, that is hard to overcome. Even though nursing care activities bring a nurse and patient into close physical proximity, this does not guarantee genuine connection, (Paterson and Zderad, 2008). Family Two describes a nurse coming to their home, where rapport and connection are challenged from the first visit.

If the doorbell goes or there's a knock at the door I tend to answer it, but this particular nurse will actually not knock and just walk in. Especially if I'm not expecting them, I don't find it very polite. Even if I go to a sibling's house or a friend's house I'll knock first. If I'm coming around a corner I'm confronted with this person I didn't expect. My back gets put up a little with that one. Mm. That happened the first time she came, actually. I didn't think that was appropriate. It would be different if my relative was on their own and unable to get to the door very quickly; then that could be acceptable or more acceptable. But when it's known that my relative wasn't on her own. So just walking into somebody else's house with no relationship, I find it quite confrontational. Family Two.

There is a sense of boundaries breached and offense given by the nurse entering the family home without knocking and not waiting to be shown in. For Family Two it is an affront to the values of safety, privacy and sanctity of the home. This is a threshold both for the family home and for rapport building; the opportunity for the nurse to begin with respect has been not taken and is now gone. The threshold of a home is a portal into family intimacy, it is not the right of the nurse to cross this threshold without invitation. I asked what happened to the families trust with this nurse. Family Two began shaking her head,

I certainly would query what she would have to say. I'm sure she's highly qualified in what she's doing and knows her stuff, but it's just the way it comes across. It might come across as a bit judgmental or confrontational; just the way she interacts with me anyway. Family Two.

There is acknowledgement that the nurse is trained and knows her stuff BUT has a manner which does not allow connection for this family member. A lack of connection in this instance has made trust difficult and has called into question the nurse's advice or knowledge as potentially judgemental or confrontational. Connection is further hampered by the power

dynamic of a professional who is not respecting a family's wishes and they feel unable to say anything to her. There is a high level of discomfort with this interaction.

For Patient B though, it was really hard for her to articulate exactly what it was that created the lack of connection with a particular nurse visiting her at home, she described it as:

There was one particular nurse that came in and just sort of, almost like a... not a full barrier but just a little barrier. We get on reasonably well, but...I don't know. Maybe she comes over a little bit officious. I'm not too sure exactly what it is but there's just something there. She is caring but just in an almost stand-offish way. I'm not too sure how to describe that one. Well, yes, she has said some things about her life but not a lot, but it's almost, that little barrier there, I think. At times, it could feel awkward. Not all the time. I'd be happy not to see her again.

The adjectives used are telling: officious, stand-offish and awkward; these are adjectives that no nurse would want to hear about their practice with patients. Patient B is really searching for what is causing the "little barrier", she is not able to pin point it exactly but these adjectives she has used might give some clue. Patient B is left feeling so uncomfortable about these home visits that she would be "happy not to see her again". This should be mortifying feedback for a nurse to receive, but it is unlikely to be given.

Nurse D describes an encounter with a patient where an attempt at humour from her fell flat. It resulted in a deterioration of any rapport they may have had to the point where the nurse felt uncomfortable and "like an elephant walking in the room".

I know those times because you go into the room and you just feel like an elephant walking in the room. So, I know that feeling. Sometimes, if you've been picked up wrong, and you never meant that at all. But it depends where the patient's at and why they think that. That's really uncomfortable and you've sort of got to tread a bit carefully. Sometimes I find it's difficult. But usually that patient is difficult for other people too, but you feel really uncomfortable that they've picked you up wrong. They've perceived you were saying something, and it wasn't your intention at all. Nurse D.

There was little hesitation to think of an example of not having rapport with a patient. The experience was vivid enough for Nurse D to use the metaphor of an elephant in the room to describe the amount of discomfort she felt with the patient and their lack of connection. They had a misconnection, a misunderstanding, leading to her being picked up wrongly which left Nurse D feeling she had to tread carefully with this patient. She felt it was hard to be so careful with every word and meaning and difficult to come back from this place of disconnection. She was shocked things went so awry. I asked what that was like for her.

Horrible, that he was perceiving something that wasn't meant but I kind of felt I couldn't engage with him. And sometimes when you can't engage with a person, if you're a bit more light-hearted that might work but didn't work on him at all and I felt very uncomfortable. I

did go back to see him again. I just made extremely sure that I dotted my I's and crossed my T's with absolute professionalism. In hospice we do things professionally, but you've got to be a bit light-hearted a good bit of the time. But no, not that person. Yes, I did look after him again, but I was business as usual. I don't like business as usual, but it was better for him. Not for me. I could have been a shop assistant. In a shop they're delivering you a service and sometimes you can get warm, friendly shop assistants but they deliver a service and you move along - the next one comes. Nurse D.

The usual repertoire of connection like using light humour to try and make a connection, did not work for Nurse D and this patient. He perceived some other meaning in her words and this created discomfort for them both. Nurse D was able to keep caring for him maintaining "absolute professionalism" and caring for him like "business as usual". This is a superficial connection only, which Nurse D takes to be like a shop assistant delivering a service. She recognises it is better for him that she remains distant, polite and clinically perfunctory, but it is not better for her. Nurse D does not like operating in a "business as usual" way, seeing it is as demeaning, as in, de-meaning or away from the real meaning of nursing for her, which is that of connecting with her patients. There was also a sense of the patient missing out on the "whole service" on offer from hospice nurses by not connecting, she felt that rapport and connection with the patient would have been a way to ease his pain and discomfort. A similar business-like reference is used by Family Two.

She has spoken with me as she's gone to see my relative, but I don't get the warm feeling as I have with the other nurse; and some of the others. She's certainly not as bubbly or cheerful. She comes across as there to do her job. I almost get a cold feeling from her. I know that sounds funny saying you get a cold feeling from her, but it's what I experience. So, she comes and does her job. It's very business-like and not the same interpersonal skills that the other nurse displays. Family Two.

Family Two uses temperature to describe her experience with this nurse "I don't get the warm feeling" as compared to another nurse, later saying it is a "cold feeling" she gets from this nurse. The nurse is not bubbly and not cheerful, she is business-like and there to do a job, with a perceived lack of interpersonal skills compared to the other nurses. Nurse C shared this experience about the way a situation can change in a moment, Nurse C went from hitting what she called an "absolute unknown" to an amazing connection that transformed the experience of dying for this patient's family. Nurse C's patient was unconscious and imminently dying when she met him and his family for the first time.

I had no idea of what I'm walking into. I knew this man has deteriorated. He is in the hospice, and now he's dying. I walked in; there was literally about 10, maybe 15 people in the room. And I couldn't remember, for the life of me, what his wife's name was. As soon as I walked into the room, it had just gone; I got a bit of a "Huhh" moment when I saw all the people. Looked around, said, "Hello, my name's Nurse C." And everyone's just kind of looking at me; and there was no, nothing. And then someone tapped me on the shoulder,

and said, "Oh, Nurse C." And I thought, oh, my goodness. I saw her face, and I knew her. Her arms flew open and gave me a big hug; and it just, everything broke. That - not tension - that unknown distance, I should say, in the room broke. Nurse C.

An abyss with nothing, a "Huhh" moment, a kind of freeze, and no feedback from the group. Nurse C told me she felt insecure and awkward at this time. She was disconnected from self in that moment. When she finally was able to say her name someone recognised her and she was given a warm greeting and the "unknown distance" in the room broke. In that moment of connection, it was like the scales fell away from their eyes and multiple connections were made in a short time, they all wanted to connect with Nurse C. She was known and accepted and trusted in that moment of embrace. From this moment rapport began. Nurse C still had to figure out who was who in the room, but she was aware it could have been so much harder without that first connection.

From Family One came this comment which was among the most surprising ways of describing disconnected nursing.

But there are nurses and workers. The workers do the nursing, but they don't love. That's what I think. Not all the nurses are the same. They could also be going to KFC and do the same thing. The only thing is that at KFC the chicken is already dead. Family One

Family One holds the view that people who say they are nursing without loving people, may as well work in KFC. This was based on their recent experiences at an aged residential care facility post hospice. When families witness this kind of nursing they are on guard, they are less comfortable to go home, they want to protect their loved one from belittlement, lack of care and feeling unsafe and unhappy.

Summary

This chapter focused on "Exploring being disconnected" and looked at the examples from the interviews that described being disconnected from self and being disconnected from other. Being disconnected from self, had the sub-themes of feeling unsafe and vulnerable, and being not present or partially present. Being disconnected from other had the sub-themes of separateness, belittlement, a sense of uncertainty or not known-ness and one-sidedness. Followed by the finding for this part of the study that disconnection and lack of rapport makes things uncomfortable.

Being disconnected from self is the possible reason for some patients in palliative care not connecting, it may be that they cannot connect due to the dramatic changes they are undergoing physically emotionally and spiritually. There is a complexity to the relationship with self, that affects the nurse patient relationship. As when the "tremendous" rapport experienced by a nurse and patient was ending alongside the patient's decision to commit suicide. It may be as one patient says he is so wary of others he withdraws into himself to keep safe which is a change from his well-self and cheerful connectedness. The nurses recalled being inexperienced

in palliative care and the vulnerability they felt talking with the dying person and fear of making a mistake. The nurses were less likely to be fully present in this type of situation and identified busyness as a hamper to being fully present. It was difficult to connect with patients and families if they were not present, as when in their own process of grief. There were definite times of patient disconnection by separating, as when the patient was using his computer screen to avoid eye contact and when another patient looked out the window and made monosyllabic replies to his nurse. Both were communicating indirectly but the messages were hard to interpret, and the nurses felt shut out. There was a theme of belittlement from the patients and families, it was a word that was used and implied often. All the examples given were pre-hospice but still recent and fresh in the minds and bodies of the participants. This was summed up one patient saying, “we are not dumb” just because of illness, and the nurses behaving in this belittling way should “start mopping the toilet and get out of nursing”. There was a sense of uncertainty or not known-ness which related to not knowing if there was rapport for the other person. Reciprocity was uncertain, as one person may feel there is connection and has no confirmation if it is so for the other. There was concern from the nurses about the approach to patients when judgements were made in lieu of assessments, as when the family may have been afraid rather than aloof or when the patient may have been in intense pain rather than histrionic. One of the possibilities for connection is the state of one-sidedness that the nurses offered some patients when all else did not create a connection. Rapport was not possible in this state, but the nurses felt this was the best way to keep potential of two-way connection possible.

To experience less than connectedness was uncomfortable and unfulfilling. The nurses described their examples of no rapport or connection as traumatic and upsetting, frustrating and disappointing, awkward uncomfortable and wanting to run away, horrible or feeling like an elephant in the room. Apart from the discomfort they felt, the nurses also said their work was affected by not having rapport with their patients, they were left with a “business as usual” or task orientated nursing approach and a sense their work was unfulfilling without connection. One of the nurse’s experiences expressly mentioned how the lack of connection with patients and families meant their work felt unfulfilled and that she may as well be a shop assistant. This was echoed by patients and Family One and Two who felt when there was no connection, this was not nursing, and the nurses may as well “clean the floors” or to work “at KFC”. They shared the sense that it was uncomfortable and unsafe when there was no connection. The nurses felt nursing was less fulfilling for themselves when there is no connection and they also felt that something was missing for the patient and family when the service and care provided is not connected with rapport. There is reference to experiencing different levels of rapport and connection with patients and families, and there is reference to realising there are different levels of care linked with the level of rapport they experienced. It was experienced as difficult if not impossible for nurses to offer holistic care when there is no connection. From all of the experiences in this section is revealed a sense that rapport cannot be created when connection is not made. A case could be made that no connection is close to not nursing.

The synthesis of the participant voices in the last two chapters, of being connected and being disconnected, gives rise to insights into meanings and implications for practice which are discussed in Chapter Six.

Chapter 6: Discussion of Meanings and Implications for Practice

“...and when we meet each other, something extraordinary happens” (Lazenby, 2017).

Introduction

This chapter is concerned with seeking meaning and understanding of rapport in palliative care by discussing the findings from the analysis of being connected and being disconnected. Also considered here are the possible clinical implications of these findings and understandings. Part of the function of this chapter is to ensure the purpose of the study as stated in Chapter 1 is being aligned to.

The Purpose of the study is to explore the research question using a phenomenological approach with the three main aims being:

1. To develop an understanding and in-depth description of the lived experiences of rapport from the viewpoint of the nurse, the patient and the family in palliative care.
2. To explore rapport and connection in relation to the quality of care given and received in palliative care.
3. To report findings and their implications for improving nursing communication practices in palliative care.

The first aim of the purpose statement will be synthesised throughout this chapter. The second aim of the purpose statement will be addressed in the section “Rapport and links to care”. While the third aim of the statement will be addressed in the “Implications for Practice” section.

Interpretation of findings

This study has been researching the phenomenon of rapport with the findings that in essence, being connected allows rapport to be present, and that the state of being disconnected seems to impede rapport to be present. This is the pared down simplification of what in reality is the complex interrelating of human beings (nurses, patients and family members) meeting in palliative care. When considering a wider focus and interpretation of the study as a whole, a Meta-theme of “Between-ness” came into being. The interpretation of this Meta-theme has three aspects: the first is related to the between-ness of living and dying, this is the liminality that the patient lives with (Bruce & Davies, 2005; Lawton 2000). This liminality affects not only the patient but by association the family and indeed the nurses who work in this area. Each patient is in the between living and dying phase of their life and as such has a particular need for safety and protection (Chapter 5), genuine care and kindness (Chapter 4). Each family member is experiencing their relatedness to this liminal state in their own way, as a daughter may be heard to say, “that is not my mother in there, that is her dying body”. For the living and

the dying are experiencing different life-worlds with different expectations of the future (Baird & Rosenbaum, 2003). The nurse knowingly meets each person in this twilight space to make a connection and create a rapport. The second aspect of the Meta-theme of between-ness is related to the space between connection and disconnection. The interpretation of the interviews and thematic analysis suggest there is an in-between level that this study has called Passive/transient. The following section on “Rapport and links to care” highlights all three levels of relating and their characteristics are listed there. (see Table 1.0). The third aspect of between-ness is related to the space between two people when there is rapport, referencing ‘the between’ of Humanistic Nursing according to Paterson and Zderad (2008). A profound statement from Paterson and Zderad (2008) that, “Each comes to meet the other with all that he is and all that he is not, at this moment, in this place” (p. 24), has reverberated through the writing of this chapter to find expression. In the context of this study it is taken to mean, with the creation of rapport and between-ness is also existing the potential for no rapport and separate-ness. Each is possible with every nursing encounter.

From this meta position comes an exploration into the meaning of two areas considered important to bringing an understanding of rapport as lived experiences. Firstly, in the interviews and through thematic analysis, there are links to rapport and the type of care nurses provide and patients receive, found in the section “Rapport and links to care”. Secondly, the concepts of between-ness and separate-ness are explored in relation to rapport.

Rapport and links to care

The second part of the purpose statement for this study says, “To explore rapport and connection in relation to the quality of care given and received in palliative care”. This part of the purpose statement is referring to the lack of literature found that provides evidence that the quality of the nurse-patient relating has an impact of the quality of care achieved. Epstein and Street (2007), made the claim that this is an under-researched area and that the literature infers there are links with little evidence. Based on the interviews data, this section makes a link with rapport and holistic care; and a link to no rapport and physiological cares. A table has been created (1.0), to simplify the viewing of the information, with acknowledgement that this is an imperfect vehicle for something as intangible as rapport.

Nurse Patient Family Rapport and Links to Care			
Level of relating	Static	Passive/Transient	Dynamic
Type of connection	Disconnection Remain as separate individuals	A workable connection One-sided or mutual moments	Connected Mutual and times of one-ness

Quality of connection (Dutton and Heaphy,2003)	No or Low Quality Connection (LQC)	Low Quality Connection (LQC)	High Quality Connection (HQC)
Rapport experienced	No rapport	Intermittent	Rapport present
Simile of cellphone bars	No bars of reception	Reception cuts in and out and poor quality	Full bars
Model of nurse-patient relationship (Halldorsdottir, 2008)	Biocidic-life destroying Biostatic-life restraining	Biopassive-life neutral	Bioactive-life sustaining Biogenic-life giving
Experienced as:	Traumatic Unfulfilling Not rewarding Not satisfying Frustrating, upsetting Isolating Unsafe “not nursing” Affective Dissonance (Ricard 2015)	Sense of OK-ness/ fine Not rewarding “Delivering a service” “Not what is hoped for” Superficial “Business as usual” Dissonance/resonance	Enlivening Rewarding Satisfying Personal growth Transcendent Deep lasting effects Positive resonance (Fredrickson 2014)
Level of nursing care possible/given	Physical cares, medications	Physical cares, medications and perhaps more	Holistic care
Consequences	Strategies to connect or disconnect applied	Strategies to connect or disconnect applied	Partnership

Table (1.0)

There were levels of relating found in the study represented here under the headings of Static, Passive/Transient and Dynamic. These names were chosen to reflect some of the elusive movement and energy described in the interviews by participants when talking about rapport and connection. In this table, Static describes a lack of movement and low energy in the way two people are relating, and it is likely they remain as individuals. It is characterised by having no connection or a low-quality connection (LQC), (Dutton & Heaphy, 2003), no rapport, and being a biocidic or biostatic relationship as per Halldorsdottir (2008). The words used to describe this level of relating included traumatic, unfulfilling, frustrating and a sense of “not nursing”. Ricard (2015), also used the term “affective dissonance” with its meaning of a lack of harmony. The level of nursing care perceived as possible or actually given was related to

physical cares, and giving medications only. There were strategies used by the nurses and patients (and to some lesser degree families) to try to connect or to disconnect as it was uncomfortable to stay in this level.

The Passive/Transient level of relating has limited energy and movement. The two people may have a workable connection at times with possibly no connection or one-sided efforts made and moments of mutuality. Rapport was therefore intermittent at best. Dutton and Heaphy (2003), label this a low-quality connection (LQC) and Halldorsdottir (2008), would call it bio-passive, meaning life neutral. The description of this level included having a sense of OK-ness or being fine, not particularly rewarding, and the nurses felt they were delivering a limited service. There was also a sense of disappointment as in it was “not what is hoped for”, and it had a superficial feel. This translated into nursing care at the level of physical cares and medications with the possibility of more domains of cares being accessed. The Passive/transient heading had as its consequence, that strategies may be applied by either the nurse or patient to try to connect or disconnect rather than stay in discomfort and uncertainty.

This Passive/transient level has emerged over the time of this study. It was not part of the original project design to have an in-between third state. The interview questions were primarily asking what it is like to experience rapport or to not experience rapport. The interviewees however threw up description of this intermittent workable state that has a sense of OK-ness to it. There is not much in the way of literature apparent on this topic and it may require further study.

The Dynamic level of relating has both movement, energy and connectedness with times of oneness for the participants. It is a high-quality connection (HQC) according to Dutton and Heaphy, (2003) and rapport is present. The Halldorsdottir model would call this level either bioactive (life-sustaining) or biogenic (life-giving) (2008). The descriptors included: good, really good, fantastic, tremendous, amazing, rewarding, satisfying, there was associated personal growth, pleasure, satisfaction and deep lasting effects. These fit with Fredrickson’s (2014) description of “positive resonance”. The nursing care was likely to be of a holistic nature. The Dynamic heading has Partnership as a consequence because the patient-family- nurse experiences in this connected realm had a sense of mutuality and acceptance of each other which meant there was an easy platform for working together as partners to achieve patient goals of care. The dynamic column is perceived as optimal nurse-patient-family relating.

The table also has a reference to cellphone “bars” that show how much reception there is to make a call, send a text or check a message. As we know the bars can change by moving rooms or by moving your head in a certain way, and then suddenly there is enough “reception” to connect or it may just as easily disconnect when the next corner is turned. It is a useful digital imagery to demonstrate the etheric nature of rapport under these headings. Static has no bars, Passive/transient has poor quality reception that gives unreliable service and Dynamic has full bars. It may be something nurses could think about when reviewing their day with patients.

From this table it is evident that rapport and connection have an important impact on care given and received in palliative care. The more connected the nurse is to patient and family the more holistic the care. Connection and rapport is how holistic care can be delivered and partnership is likely. From one of the nurses, “Holistic nursing is my passion” and is linked with being life-giving. Nurses who understand the life-giving nature of holistic care, bring their love of helping others into their practice with warmth, humour and a positive “lightness of being” (Halldorsdottir, 2008). This level of nursing supports the “moral imperative for nurses to focus their attention on patients during their interactions” (Stein-Parbury, 2014 p.56). The nurses interviewed were motivated by the dynamic relating level on this table and felt thwarted when the patient or family member did not want this level of connection.

The findings suggest that the less connected the nurse is to the patient and family, the less holistic the care. No connection and no rapport reduce the care level to physical cares and holistic care is unlikely. It makes sense of the nurse’s cry “I can’t look after him, if there is no connection” and it makes sense of the patients’ and families’ bewilderment and withdrawal when rapport is not created. There can be a certain amount of tension around the low-quality connection levels. The nurse who feels that by connecting with a patient or family that they may be of benefit in some existential way (Watson, 2008) has a challenge when the patient is not ready or too afraid or angry or sad, to just hand this potential connection over. The family member who is angry or fearful of the unknown and hit by massive waves of grief may also not want to connect. The nurses can see the pain of the other and feel they are “missing out” on all of the services available by not connecting. Their sense is that their own therapeutic agency (Stein-Parbury, 2014) is not being utilised, by the patient and/or family and it can be frustrating. It is necessary to consider the context of the patient’s life, and it is wise for nurses to be sensitive to the patient’s “relationship world” (Minicucci, 1998). This is helped by an understanding based on “openness and acceptance of the “otherness” of the patient” and the family (Benner, 2001, p.68).

Rapport: between-ness and separate-ness

So, instead of asking “what did you do?” in a nurse-patient interaction, Paterson and Zderad (2008) suggest asking “What happened between you?” as nurse and patient or as nurse and family member. Paterson and Zderad, (2008) write, “The patient and the nurse are unique individuals meeting for a purpose” (p.24) and ideally the nurse has an existential awareness of self and the other to fulfil that purpose. In palliative care the “other” includes the family. This between-ness is akin to the interhuman sharing that this study calls rapport. Rapport is the vehicle into the experience “with the other” and it is the way to enter the between. There is no entry without it. Without it is separate-ness.

This separateness can be accompanied by intense emotions and reactions. Saunders (2005, p.23) reminds us, “the greatest sorrow of a dying patient is the ending of relationships and responsibilities”. The hospice nurse also holds in mind the enormity of the transition for the patient and family coming into hospice, as it often brings focus on palliative care and dying as a

reality. This can affect behaviour in many ways, it can be very confronting and frightening for the patient and/or the family to bring their dying loved one into hospice care. Fredrickson (2014) suggests the feeling of being isolated and disconnected from others does more bodily harm than actual isolation. Disconnecting from a previous perception of one's body is what van Manen refers to as, "the moment when our wellness is disturbed, then we discover, as it were, our own body" (2014, p. 329). The dying person can therefore reflect on their body in a different disconnected way and for some this is a confrontation with non-being (Baird & Rosenbaum, 2003). Paterson and Zderad (2008), ask the nurse to consider what that must be like for the patient when bodily functions change during illness and dying, and how this changes the way "the patient experiences his lived world" (p. 19).

Reflecting on my own rapport with patients in hospice, I have become aware that there is a particular level of connection that can occur when working with a person who knows they are dying. To describe it is like trying to hold a beam of light but what comes to mind is there is a level of realness that is hard to get when dealing with people in the rest of our lives, there is a joy that is healing and a lightness that is relieving, and a facing of human mortality including my own which is liberating. It can last a moment or two or it can imbue the whole day. The example of the blind man and holding hands as we met, at the very beginning of this study is an example of this connection and rapport. I felt his love, his vulnerability and anxiety and his heart, just by holding his hand, there were no barriers. In that moment I too felt "seen" as a person and a nurse. His daughter was part of the connection holding his other hand and I felt her relax. We all had softened, and with moist eyes we felt what we felt. Trust was bestowed upon me as their nurse and advocate, just by the way we connected in meeting. When that kind of connection is made it means everything else becomes very simple in terms of care and a deep sense of peace in the room ensues. This is rapport. It is also what Paterson and Zderad (2008), call "the between" and akin to what Watson (2008), calls the caring moment and Fredrickson (2014), calls love.

To say this is common or usual would not be true, but it is more than unique. It is certainly not in any way formulaic. If I tried to recreate this particular connection with someone else, by going in, sitting beside them and holding their hand wordlessly, they may think I am crazy! So, it is an artful process of experience, knowing and not knowing and an openness to each person each time that allows the possibility of this kind of connection. This level of connection cannot occur as a unilateral offering. The nurses, patients and families interviewed all know something of this rapport and it is treasured when it occurs. Paterson and Zderad (2008), said, any nurse who has experienced moments of genuine connection will agree that these moments exist, and they are what gives meaning to nursing. The nurses interviewed all had a sense of this same rapport and between-ness with their patients and families that allowed them to broach difficult subjects, like partner intimacy; acknowledging dying and grieving; and the challenge of transferring to hospice. Despite the challenging nature of these topics this rapport allowed the nurses to be able to stay in connection with the people involved. The nurses each relayed a sense of accomplishment, an overcoming of an obstacle within the connection that was special,

and through reflection, this had added to their nursing practice in some profound way. The examples given were when a nurse can literally and metaphorically speak the same language as their patient, and when a nurse is given a farewell gift from a patient planning to commit suicide, or when a family writes a letter a year later to acknowledge care given to their mother, or when a shower scene marks the transition to dying in hospice, or when two mothers meet and realise one is going to live and one is going to die soon.

The notion that two people experiencing being connected have created a “between-ness”, is described in *Humanistic Nursing*, (Paterson & Zderad, 2008). This has synergy with rapport, as there is mutuality, positivity and being in-sync together. The nurse is inherently professionally responsible (Davies and Oberle, 1990) for the two-way transactional relating required to make relationship, just by being a nurse aware of herself and the other (Paterson & Zderad, 2008). The two-way-ness is equated to mutuality and is necessary for rapport to be created (Goleman, 2006, Tickle-Degnen & Rosenthal, 1990). The neuroscience of what happens in the between-ness is complex and evolving quickly. An example from Fredrickson (2014), quotes evidence that the neuropeptide oxytocin is a contributor to connection. Two people having a mutual positive engagement will have their oxytocin levels come into sync with each other (Fredrickson, 2014). Once created rapport is considered essential for the nurse-patient relationship, as it brings warm and harmonious qualities and creates an easeful partnership of care. This was borne out in Chapter 4 “Being connected” where the participants had many experiences of this type of connection, it was the preferred way of interacting for all the groups.

However, there was a darker cooler side to the findings. When two people are experiencing not being connected or “being disconnected” they do not have a between-ness and no positive emotions can be conducted. There is instead a separate-ness. This separate-ness is revealed in the humanity of the nurses with their pain, grief, frustration and disappointment when connection was not made. There was the utter vulnerability of the patients in their metaphoric and literal pyjamas wanting basic civilities met to feel safe to be present, let alone connect. For the families who were passionate advocates and supporters of their loved one, they just wanted to be seen and spoken to as intelligent people and witness kindness and care of their dying relative. All felt the separateness of disconnection at various times. This disconnection is hidden and muttered about but not really given any nursing research attention.

The need for belonging on Maslow’s Hierarchy can be disturbed by the liminal state that many dying people enter into (Bruce & Davies, 2005; Lawton, 2000). This liminal in-between living and dying state not only affects their connection to self but also affects the relationship the patient has with the others in their life including family. The daily experiences of social loss and physical decline which cause increasing dependency, can result in the dying person disengaging (Glaser & Strauss, 1964). It can also prevent them from engaging with new people no matter how well meaning. For the nurses this provoked them into feeling challenged and shut-out sometimes. They also found it difficult to conduct the “whole service” of palliative nursing

without connection. Conversely, Halldorsdottir (2008) makes the link with disconnection by nurses referring to it as “the wall” and patients feeling disempowered. It is what Brown, (2010), calls the fear of disconnection and links this fear to feelings of shame. This disconnection was felt by the participants as the de-meaning of palliative care nursing.

When rapport is not present and there is no connection or no hope of connection, is this nursing? The families did not think so, seeing it as the nurses’ job to connect with the patient when they are not there, and calling for the nurse to work at a fast food outlet instead, when not showing love. The patients did not think so, when there are cliques who talk over them and pretend to know better and called for the nurse to clean the toilet floors instead of “not nursing”. Sometimes the nurses did not think so, with one saying she may as well work in a shop when there is no connection. If the connected caring relationship with rapport is foundational to professional practice, then it is a valid question to wonder what happens to “nursing” in this situation. Watson is clear, without attending to the core connection of nurse and patient then “nursing would cease to be a profession” (2008, p.76). Her view is that each nurse needs to reflect on their own behaviour especially when there is a failure to establish rapport, or create an alliance with another (Watson, 2008). This disconnection happens clinically probably more often than is thought about or certainly written about and was common in the interview data with an entire chapter devoted to this content. Paterson and Zderad (2008), say that every nursing event is unique and dependent on the individuals and there is no guarantee it will work,

Since both persons are independent subjects acting with their human capacity for disclosing or enclosing themselves, there is no guarantee that the availability and presence necessary for a genuine confirming encounter will come forth. P. 16

So even though the nurse is called to the patient to “help” them, each may have very different ideas on what kind of help is needed or wanted. There are many examples in the interviews of just that, where the nurse makes a joke that falls so flat it spirals their connection into separateness, or the nurse who does not wake her patient to give him medication into his peg tube generating mistrust and frank unsafety. There was also the experience of feeling like “the elephant in the room” when the family were silently observing, and no connection made despite every known strategy tried and re-tried by the nurse. There is a difficult quandary here, Minicucci, (1998) says that “presence is inhibited when nurses focus only on the patient’s body or behaviour” but what of the times when this is all the patient, or the family for that matter, is willing to offer, and the “fullness of their personhood” (Minicucci, 1998) is simply not available. This is a nursing dilemma.

Implications for practice

The third part of the purpose statement for this study is “to report findings and their implications for improving nursing communication practices”. To do this the most potent sub-themes from the thematic analysis have been chosen to consider how they may improve

connection and rapport in palliative care. These sub-themes are: Kindness, Safety, and Belittlement of patients. The section following these is entitled “Rethinking rapport as moments and micro-relationships”, which suggests reviewing the language and thinking around rapport to make it more achievable clinically. Recommendations for action are then made.

Rapport and Kindness

Kindness is transformational and ordinary and necessary in palliative caring. It has been established that rapport requires mutuality; the I connected to the thou (Buber, 1959). Whereas Ricard tells us that Kindness or altruism “is an unconditional benevolence, not necessarily mutual, and which does not depend on the way the other treats us or behaves” (2015 p.68). This makes it a useful part of the nursing repertoire when the patient or family are struggling to connect. It was described by the nurses as transformational, but this transformation can be off-putting. Real kindness changes people in the doing of it, and can therefore be perceived as risky (Ballatt & Campling, 2016).

Patients recognise kindness (O’Brien, 2016), they see kindness where the nurses may only see they are doing their job. It is the way the job is done. If it is done with presence and full of care for the other, then it is likely to be perceived as kindness; if it is done absently and ticked off a mental task sheet then it is not likely to be perceived as kindness. Patients remember unkindness (O’Brien, 2016), and the inter-generational effect was proved in the interviews by the patient talking about the unkindness shown by a nurse to her dying mother 35 years ago.

Patients need kindness. In her article “What whānau need at the end of life”, Tess Moeke-Maxwell, (2014) says, “A culturally sensitive nurse who deals with the patient and their family with kindness, patience and respect for their traditions will help preserve the mana of the whānau at this vulnerable time”. Included in this preservation of mana is the nurse being aware of the wairua and the mauri. The wairua is the spiritual dimension that is fundamental to care of the dying and the mauri which she says is “particularly salient as the dying and their whānau embrace the interface between life and death” (Moeke-Maxwell, 2014). This is caring for the person and their whānau holistically, with every act of kindness and respect potentially increasing the mauri. One way for the nurse to do this is to embody manaakitanga as respect, hospitality and kindness (Moeke-Maxwell, 2014).

“Making attentive kindness part of everyday practice can have the effect of reducing anxiety and building trust “(Ballatt & Campling, 2016 p.37). Kindness was considered by the nurses in this study to be a key way to connect with patients, as it eases and transforms situations to allow rapport and connection to be created. It allows trust to be formed and patients feel safe to ask questions and feel confident to ring the bell, knowing the responses are going to be kind. There is a link here to suggest that a connection with rapport cannot occur in the face of unkindness as when a nurse rolls their eyes. It would be very challenging to pursue rapport with a person showing obvious disdain or impatience, let alone a vulnerable person interacting with a perceived authority figure. The nurses had no stated expectation of the patients being kind to them, they knew kindness needed to be nurse initiated.

Importantly, the nurses interviewed thought being kind to each other as nurses, was fundamental to being able to provide quality palliative care nursing and indeed to be kind to their patients. They felt kindness to each other helped make the work sustainable for them as practitioners, as knowing there was a kind supportive colleague helped to make the work more enjoyable, safer and released a tension in the nurses to be able to focus on the patient and their needs. The issue of kindness to new nurses, drew a strong response from two nurses. The impression is that kindness is necessary for new staff coming into palliative care work as the transition is challenging and takes time to assimilate. It appears there is a need for established palliative care nurses to be kind, supportive and mentor new colleagues as they make the transition to becoming palliative care nurses. As supported by Ballatt and Campling, (2016. p. 3), "To fail to attend to the promotion of kinship, connectedness and kindness between staff and with patients is to fail to address a key dimension of what makes people do well for each other". The benefits of kindness are both for the person giving and receiving the kindness (Ricard 2015, Pressman Kraft and Cross, 2014, Buckman Tulsy and Rodin 2011).

O'Brien (2016), asks "How can we practice kindness in our clinical work?" It is a good question and there is no doubt that we can up the ante on kindness as nurses in palliative care, there seems no danger of over-doing it as long as it is genuine. One place to start is to value kindness in our workplace, to see it as important and beneficial, to create a language and culture to support kindness being talked about, and demonstrated. All the while observing and reflecting on the difference it makes to patients, families and outcomes. Outcomes that have been supported with research are hard to find at present but Ballatt and Campling have created models to support what is possible and to encourage research to be done in this area. Their hypothesis is that kindness as a systemic cultural change that includes policies, places and people applied to patient care will improve "symptoms, well-being and satisfaction" (Ballatt & Campling, 2016, p. 45). Intelligent kindness is a virtue, that requires practice and intelligence and skill (Ballatt & Campling, 2016). Nurses practice kindness already but it is this "intelligent kindness" applied with consciousness and skill that will make the difference to creating rapport and connection. It is kindness or its absence which is remembered by patients and their families and nurses and new nurses. Intelligent kindness is what they are all wanting to experience as captured in the mantra from one of the nurses, "be kind, be kind, be kind".

Rapport and Safety

Patient safety is usually considered as preventing avoidable errors and adverse effects (Dy, 2016) particularly iatrogenic medication and treatment errors and falls (Tice, 2007) even in palliative care. This is necessary body safety. The kind of safety found in the interviews and analysis though, was of a far more existential nature. There was a concern for safe-ness to be present and safe-ness to connect to self or other, which applied to nurses as well as patients and families. There was also the safe-ness of place as hospice which was particularly related to patients and families. The application of Maslow's Hierarchy of needs to palliative care by Zalenski and Raspa, (2006) refers to safety as physical, emotional and social which allows more scope for safety needs to be met. It could be argued for this to include person-ness safety or

existential safety, as after all these are people facing the threshold of life and death, with ultimately a need to feel safe to die.

Holistic safety for palliative care patients then, needs to include their personal physical safety, their psychological, emotional and spiritual safety. It is also considering their social safety, and to be aware of the safe-ness of the place they are dying whether that is hospice, home, hospital or residential care. Not just the cords on the floor and the fire exits type of safety but a safety-of-place that allows being able to relax into dying. As part of this holistic safety nurses will need to consider the patients lived world view (Paterson & Zderad, 2008; Gulino, 1982). The dying-as-lifeworld can mean a body and mind that are no longer trustworthy, that are affected by disease, drugs, dehydration, poor diet, delirium, mental illness, anxiety and or fear. When safety needs are not met holistically, the patient may exhibit signs of anxiety, nightmares, fear of falling, fear of how they might die and what happens after death, (Zalenski & Raspa, 2006) These are urgent messages for the nurse to assist with patient safety.

Judgements are also unsafe in palliative care. Patients desire to lessen their vulnerability (Lazenby, 2017), not to have it amplified. "Patients are exquisitely sensitive to unspoken and perhaps unconscious appraisals" (Hill 2010). Cameron (2002), relates this to a patient who is dying with a keen sensitivity to the sincerity of individuals. Patients are therefore perceptive to the nurse's congruency and if they can trust them. "Feigned concern, forced and insincere, can be as detrimental as no concern at all", Raphael-Grimm, (2015). Mistrust from previous health experiences caused the patients interviewed to be cautious when coming into hospice, they had experienced feeling unsafe and having no connection. Being unsafe to connect is a vulnerable place to be and makes it difficult for the patient to disclose their true state of being (Cameron, 2002). The judgements which the nurses interviewed referred to were experienced as concerning when they happened. A judgement is likely to come from the amygdala which fires off rapid stereotypical responses. The pre-frontal cortex is meanwhile processing more nuanced responses which arise quickly but later, (Hill, 2010). One suggestion to temper the amygdala's reactivity is to distract the brain by being interested. It is hard to make judgements when feeling curious or interested (Hill 2010; Raines & Ewing, 2006).

Therapeutic use of self (Stein-Parbury, 2014) is one way to promote safe-ness for the patient. It is the nurse's use of self including their skills strengths and competence to creatively respond to the uniqueness of each patient (Stein-Parbury, 2014) and each nursing event. By being fully present as the nurses described in their interviews, enables access to the repertoire of skills, experiences and confidence, to be real as a person and a nurse. By doing with and being with (Paterson and Zderad, 2008) in this way the nursing presence can bring comfort and build trust. This sense of safety is necessary for the family members too. "Care must be taken to ensure each person and their whānau feel as safe as possible" (Moeke-Maxwell, 2014). As Nessa Coyle (2013) writes in the foreword of Wittenberg-Lyles et al, "Effective Communication creates an environment of safety". It is also likely that the safer the environment, the safer the person and family feels, the more likely rapport and connection can flourish.

Belittlement has no place in nursing

One expression of feeling unsafe, as related from the interviews was belittlement. Belittlement of patients by nurses and doctors exists today and is a result of disconnection and separateness. In this study there were three patients and they each had stories of being belittled, intimidated and one was subjected to physical insult disguised as a procedure. One patient suggested this was not nursing.

and some of them, need to start mopping the toilets and get out of nursing. You just don't treat people like that, especially in this situation. Patient A.

The words and actions of belittlement were mostly perpetrated by nurses and some doctors, all of whom were aware that the patients are dying. However, all of the stories were from pre- or post-hospice care. Another patient recently showed me her dramatically bruised arm from a venipuncture pre-hospice and she was furious about how she was treated. The nurse involved did not speak directly to the patient suffering the injury, the nurse instead told the husband it was his wife's fault because she moved! These patients' stories are not uncommon, and it is a sad thing. It is impossible to have rapport when any of these behaviours are present. Belittlement is biocidal and life-destroying (Halldorsdottir, 2008) and what Dutton and Heaphy (2003) described as "a little death with each interaction".

As an escalation of this, it is belittlement that has been attributed to at least one nurse suicide as reported in the Nursing Review June 2018. The nurse's mother uses the words "belittled and bullied by management" as the workplace behaviour that led to erosion of the nurse's self-esteem, the drop into hopelessness and deciding to die. There is much research over the last 10 years which uncovers the dark secret of nurses bullying nurses, (Adams & Maykut, 2015; Castronovo, Pullizzi, & Evans, 2016; Dellasega, 2011; Longo & Hain, 2014) and even patients abusing nurses (Hutchinson, 2014) There is little (if any) research into nurses belittling or abusing their patients and yet this happens. The incidences of abuse and neglect of patients by staff, that were reported in The Francis Report (2010), are what has led to the focus on kindness from Ballatt and Campling. They have insights into the complexity of "the pull away from kindness" (2016, p. 51) that contributed to the travesty of Mid-Staffordshire NHS Trust and suggestions for the health sector as a whole to reconnect to kindness as a result.

Lee and Botheridge, (2006) conducted a study identifying workplace bullying as verbal abuse, work being undermined and belittlement. Their findings showed belittlement was related to self-doubt, indirect/passive coping and ignoring the bully. Self-doubt was related to burnout and ill-health (Lee & Botheridge, 2006). This could be applied to nurse-to-nurse bullying or as indicated in the interviews for this study nurse-to-patient bullying. The patients described avoiding behaviours when they were concerned about a nurses demeanour or to preserve their energy. Like the clues from a patient "when we go quiet" "patients avoid you, then you will know", indicating there is a problem with the connection.

This is an emphatic truth: Belittlement has no place in nursing, ever. At its best belittlement is essentially gross unkindness. Both Ricard (2015) and Ballatt and Campling (2016) refer to the competitive individualism of our western societies as one of the reasons we are prone to unkindness, and that we have forgotten to consider the other as the same as ourselves and we have lost sight of the divine in ourselves and the other. What of Levinas's moral imperative of the other (2003)? What of Paterson and Zderad's Humanistic Nursing (2008)? What of Gadow's bringing the whole nurse to care for the whole patient (1980)? These are all the antithesis of belittlement. As is making human to human connection that "deepens and sustains our shared humanity and helps to avoid reducing another human being to the moral status of object" (Watson, 2008 p.5) or "an assembly of parts" (Gulino,1982). As a place to start, this study makes a call for nurses to admit to their tendency to put others down and to reflect and write and talk about what is needed to make a change, personally, professionally and culturally. A change needs to happen, seriously.

Rethinking rapport as moments and micro-relationships

One thread of a solution is to reconsider rapport as moments and as micro-relationships. Instead of establishing or building or maintaining rapport like great edifices, it may be useful to rethink the language used clinically and create rapport as moments. It certainly sounds more achievable to create rapport as a moment and would place greater value on the moments of rapport as they do occur. The concept fits well with what the nurses currently practice with checking in with themselves and preparing to meet a new patient and family, to go into the room with the idea of creating moments of rapport. The flash of a smile and eye contact made can be the start. The intention to "be here for you" and connect with light subjects and gentle humour and kind gestures and touch, can all help to accumulate moments of rapport. On leaving the room there can be reflections of those moments when connection and shared positive emotions are felt. It will make assessing whether some sense of rapport has been created easier. By recalling the holding of a hand as a procedure is done, an exchange of kind words, free flowing tears, maybe the odd belly laugh and the marvels of a smile. Creating moments of rapport also supports the idea that it is necessary to create rapport each and every time the room is entered. This is attending intensely to the meaning of the moment being lived (Easter,2000) by the patient and family and the nurse.

In her work as a scientist who studies emotions Barbara Fredrickson (2014) has worked with the concept of love as micro moments and not the romantic ideal we have grown up with. Love in her research is literally "transitory powerful emotions that occur and are health and life giving "essential nutrients" for our survival" (2014, p.24). She discards the term rapport as "optional and superfluous", as it distracts from her focus on love as the "Supreme" emotion. Rapport is not an emotion, rapport is defined as a relationship. As a term in nursing, rapport has value and it is understood as the something that helps connection with patients and is linked to both communication and relationship competencies. What may make it more user friendly and relevant is to borrow the term "micro" from Fredrickson, (2014) and apply it to the concept of rapport as a micro-relationship. It means when the nurse and patient have the joy of

connecting with the harmony that characterises rapport, as when the nurse talked about the piano with her patient, that they are having a micro-relationship. They both had that fleeting experience, it was rapport. It would make sense to value it just as it was experienced as a micro relationship with a beginning middle and end; just very condensed. Their next encounter minutes later had no rapport, as happened often with the young man in intractable pain, rapport one moment and then gone for a myriad reason. If each instance of rapport was considered as a whole and tiny micro-relationship this may well reflect the reality of the participants better. Being held to some ideal construct of “establishing rapport” with its implications of once done it has been “achieved” and with “maintenance” should last the distance of the nurse-patient relationship leads to disappointment and frustration and a sense of not doing the job well for the nurses. It does not reflect their lived reality.

Recommendations for action

The following are suggested action points that have arisen from the findings of this study.

Talk about this more: as colleagues share both the brilliance of connection and rapport and the frustration and grief from no rapport and disconnection. Making it real and normal to talk to each other about rapport experiences and learnings. Developing relationships skills is a lifelong work and it is enormously rewarding personally, professionally and good for nursing consciousness to share these experiences.

Talk about this more: Belittlement of patients. What does it look like in your place of work? Is it subtle, or is it overt, or is it like bullying in the playground when we pretend it does not happen? Acknowledgement helps with behaviour change. Consider conducting study on this subject in your area of work.

Talk about this more: Kindness-in-action, looking at ways to be and do kindness in the workplace. Start small and keep going. Use the word kindness. Notice and encourage kindness-in-action in others.

Make goals of Being-Nursing that include these:

- Embedding kindness- aspire to intelligent kindness
- Expanding the concept of safety- consider safety holistically.
- Eliminating belittlement- has no place in nursing, let's be bigger than that.
- Endeavour to create rapport - even as moments

Summary

Taking a step back from the intensity of the interviews, thematic analysis and the oceans of text that this produced, enabled a meta-theme to come into being. The meta-theme was Between-ness and had three aspects as related to rapport. This was the liminality of existence that is experienced as between living and dying, it affects patients, families and the nurses caring for them. It is a key concept of care that could be articulated more explicitly for the benefit of

those in the dying-as-lifeworld. The second aspect was the between-ness of levels of relating, the third was the between-ness of two people in rapport.

One of the important findings of this study is the link with rapport and levels of care. The link is essentially the more connected a nurse patient or family member is, the more rapport is likely and the more holistic the care. Between-ness is cited from Humanistic Nursing and has real relevance to this topic of rapport. When there is connection, rapport is the entry into the between space. This allows a depth of inter-relating and trust that creates partnership with the other, in this context it allows holistic care and is mutually beneficial to nurse and patient and family.

The existence of between-ness calls into being the polarity of separate-ness. This is when the self and other do not meet, there is no between-ness and they remain separate beings. This is a challenging place for the nurses to be in, as they felt their therapeutic sense of self was not being utilised which was frustrating, and the patients and families interviewed were uncomfortable and vulnerable if they found themselves separate.

Implications for nursing and communication practice considered the sub-themes of kindness, safety and belittlement as related to rapport and palliative care. The intelligent kindness of Ballatt and Campling (2016), is suggested as a facilitator of connection and is thought to be the transformational force of sustainability of nursing relationships, including mentoring new staff, and the salve that patients and families are wanting in palliative care. Safety is usually thought of as physiological, though the interviews revealed the existential unsafe-ness that was experienced without rapport and connection; It was difficult to connect to self or others without safety. The inverse was true; with safe-ness it was possible to connect to self and others. Belittlement was a theme for patients and family, it was experienced pre- or post-hospice and it was experienced by known palliative patients. The harm from this belittlement was both physical and emotional, impacting on the already vulnerable patient and the protective family and is perhaps inter-generational. This aspect of the study was disturbing to uncover, as was the lack of research to highlight the non-nursing behaviour of judgements and belittlement that exist.

One way to re-focus on the importance of rapport is suggested by using “create” to describe rapport instead of “establish”, and to consider rapport as a moment and even a micro-relationship, complete in itself. The palliative patient sometimes literally has a small window of consciousness to connect with eye contact or a smile, so being real and present are incredibly vital to making that moment matter. That moment can be the rapport that connects self to other and bring ease to both. It is the responsibility of each practitioner therefore, to be fluent in creating rapport and to be aware of its impact on care.

With more now revealed about the meanings of rapport and implications for practice, Chapter 7 provides a context for this research and highlights the key findings.

Chapter 7: Concluding Thoughts

At times, the nursing relation is a relation beyond relation. This means that it is a relation of self-other where the self is erased (passed by) in the ethical experience of the vulnerability of the other. Here, caring is experienced as an ethical encounter that is beyond relation. (van Manen 2014, p340).

Introduction

This chapter is a review of the research and findings that have been reached as a result of the interviews with nurses, patients and families in palliative care about rapport. This chapter, therefore is a drawing together of the findings of the study and their meanings and importance. It begins by considering the strengths and then the limitations of the study, the researcher rapport learnings, the suggestions for future research, and concluding thoughts.

Strengths of study

This study has created a unique access to how rapport is experienced clinically for nurses, patients and families. The participants were willing and committed to sharing in-depth their lived experiences of rapport and importantly their experiences without rapport. By being phenomenological in intention and design this study allowed the hidden meanings of the encounters given as lived experiences to emerge. These meanings have clear messages for nurses on how to improve their practice of rapport. The situating of the study in a palliative care setting was to provide insights about rapport and also in response to calls for more study to be undertaken between practitioners and patients and their families in this area.

Limitations of study

The nature of the phenomenological study is to have a small sample size, there were five nurses and three patients, and four family members interviewed. This may mean that although the data obtained is in-depth, it may be considered to be not representing the majority of experiences of rapport. There is a specificity to the palliative care setting which may be perceived as not applicable to other areas. However, it is an encouraging platform from which to conduct more research into this area of clinical rapport, it may be replicated or expanded upon.

Researcher rapport learnings

This heading has been included to cover a number of observations made and experienced by myself in the role of researcher which may add to the findings of this study. There were some surprises along the way, mainly the prevalence of unsafeness experienced by patients and families and its impact on rapport, the theme of belittlement was not anticipated, and the strong suggestion that disconnection happens often clinically. Along with this the most impactful aspect of the interviews was the lived experiences were offered in such a deep and profound way that as a researcher I was struck and perhaps overwhelmed by my sense of

responsibility for what was said. Each person and each interview have been received as taonga or treasure.

Interviewing each of the nurses I noted an ease with establishing rapport, there was an existing relationship with each of them and I had worked alongside them at some stage as a palliative care nurse in hospice. The change in context from colleague to interviewer was effortless on my behalf as I listened to their stories or asked a question for them to share further. The nurse as storyteller was noticeable with a tendency to include me in their stories, “you may know this person” or “you were there”, it seemed to enliven their stories to have a shared experience with me as nursing colleague listening. Instead of denying this relationship to them clinically, I would nod and smile or say I remember, or I was there, or I know who you mean. This seemed important to keep the flow of the story going. My role was as an observer of the example they were exploring. An example of this is from my notes at the time of interviewing:

Nurse E remembers a special connection with a young patient, it was almost instant as they were from the same place and spoke the same language. She asks me if I was around, she wants to include me in the story, as we have rapport as nurses as well as interviewee and interviewer.

There was a very different way of working with the interviewee when it was a patient. The three patients interviewed were all new to me in every way, I had only met them in the course of consent process and the interviews themselves. The rapport I just “had” with the nurses was not there initially with the patients, I needed to create a warm connecting safe space for the patients to share into and I needed to do it quickly each time. As Pitts and Day (2007) are aware in their researcher-participant study, there is a need to introduce, manage impressions and establish trust in a short time. This was a draw on my own experience of creating rapport and a challenge as I was self-consciously aware of both the tape recorder and the phenomenological approach needed for the interviews. It was helpful to have interviewed the nurses first for my confidence and interviewing style to become more established before interviewing the patients. It was helpful to consider the epoché suggested and required by van Manen (2014) For me the epoché became a practice and I likened it to having a mindful attitude and expansive listening before and during the interviews. The patient interviews were markedly shorter than the nursing ones, due to the patients’ fatigue or breathlessness. There was also a sense of getting to the essence of their experiences quickly. At all times I was acutely aware of the privilege of being offered the descriptions and feelings shared. From my notes:

The interview with Patient A was only 16.49 minutes long and we covered in-depth subjects including his relationship with God. For the last minute or so we found ourselves holding hands as he talked of hope in the face of his obvious illness, with tears in his eyes. We stayed holding hands for a moment or two after the recorder had stopped, nodding our heads together and smiling as I moved away. After such a short time rapport was created and we were able to conclude with a heartfelt connection made and released.

The family member interviews were different again, I had a previous nursing connection with one family member, so rapport was easily created for that interview. Another family member not previously known to me had a lot to say about rapport and connection and was really pleased to have the opportunity to share it. I felt our rapport develop over the period of the interview, with smiles and laughter at the end. The rapport was instant in the case of the short interview with the fourth family member as he was so emotionally available and had such a deep understanding of love and connection himself, this interview was the shortest as I was respectful of his obvious sadness. He was very clear about wanting to speak and express his gratitude though. The third family member was the husband who sat in with his wife who was relaxed and happy to add his comments. The interview with him and his wife proved to be a useful rapport building exercise for getting to “know” each other as coincidentally I became their nurse the following day. I held a question for myself as the interviews began and while they were underway, “How is my rapport with this person, do they have what they need to share deeply and safely?”. I have taken this question into my nursing practice as well as an acute consciousness of the value of rapport as a result of this study. From my reflection diary:

I have seen a wide-eyed student nurse look on in amazement as the patient we have just met, says “you are kind”. On the surface it looks like we have just given him breakfast and his tablets, but what has also been happening is a conscious creation of rapport, with an acute awareness of body language- his and mine, a real listening for what he was saying and not saying, an assessment of his physical and emotional needs all while letting him know “I am here, for you now”. The cue for connecting was when he said, “I don’t know” after I had asked about where he felt the discomfort he was experiencing. I asked, “What is it like to not know?”, he looked at me directly and said, “It’s awful”. His worries came tumbling out with that admission, and he began to tell us about his fear of the unknown and his fear of being out-of-control as he faces the reality of his dying.

It would seem having an awareness on rapport and connection has also been a useful thing for the nurses who participated in the study. There has been feedback of the value of reflecting their experiences, including having more courage to try things with patients, a willingness to acknowledge their impressive abilities and their desire to keep learning and to highlight the power of kindness and connection with each other as a source of refreshing energy to do this work. It has been a useful process to undertake this study in the place that I work, as it has allowed a sort of informal follow up on the impacts on individual nurse rapport practices. Just being aware of the study and my passion for this subject has raised interest from some of the other nurses as well. I have had moments with colleagues in the corridor, with “I have got there”, as they have made a hard-won connection with a patient, a joyful smile and a sharing of the experience, and an acknowledgement from me of good work, well done.

Future direction of research

The sub-themes of kindness, safety and belittlement explored in the implications for practice section of this chapter have an inter-relatedness with each other. It could be hypothesised that

If there is safety of a holistic nature established and there is genuine kindness offered, connection and rapport are likely with positive patient and family and nursing outcomes as the result. If, however safety is uncertain, and kindness is not offered, then the door is open to belittlement and no rapport and disconnection with poor feedback and outcomes likely. From this hypothesis there are many possible research questions to answer, including:

Quantitative and Qualitative: connection vs disconnection how frequently does disconnectedness happen for nurses and patients and families? How big a problem is it? Looking at feelings of shame and links to disconnection especially in palliative care.

Qualitative: How Ok is OK? The Passive/transient level of relating and the OK-ness of its nursing.

Qualitative: Belittlement of patients- what does it look/feel like and how can we change behaviour to protect patients?

Qualitative- Holistic Safety- physical, emotional, psychological for nurses, patients and families in palliative care.

Concluding thoughts

This study was intended to bring description and understanding to the phenomenon of rapport to shine a light on the uninspected way nurses, patients and families meet in palliative care. The taken-for-grantedness of rapport had hidden the deep importance of connecting the self to the other with the warmth, harmony and mutual benefits of rapport. It is an everyday occurrence that can operate on auto-pilot as we meet and greet the other or it can be a vivid life changing moment.

Rapport is the experiencing of the moments of between-ness for the nurses, patients and families. It can be as simple as a smile, an exchange of names, maybe a handshake, a warm friendly presence that offers time and space to listen. This can be the gift of rapport that is given and received. Rapport is the vehicle, the micro-relationship that allows transpersonal experience with the other. It is equalising, two humans, being and doing. It is transformational, with it there is ease, and resonance without it there is dis-ease and dissonance. This study has shown that rapport is not a given, it must be co-created with the other. Sometimes the meeting is a synchronised affair with biochemistry attuned and little effort required. At other times it is a conscious effort of finding a way to connect and persist with care and attention to create rapport together. At still other times it is like two birds flying in different directions with no connection made despite the best of intentions and efforts.

Having rapport was desired by all participants and yet there were particular needs and wants for each group. Patients wanted rapport to feel safe, to be themselves, to relax, to think, to feel, to be alone, to be connected or to accept dying. Families wanted rapport for them to be treated with respect as equals or family-like, to see their loved one being cared for in such a way that allows them to relax, to talk, to express their feelings and ask questions, to go home, or to accept the dying experience of their relative. Nurses wanted to have rapport so that the

patient and family receive the “full service”, which includes impeccable care and a bringing of the nurses-self as therapeutic beings into their care; and by doing so feel they are making a positive difference in a person’s dying and for their family.

What is more clear now than at the beginning of the study, is that rapport and connection are essential to nursing and to holistic palliative care nursing in particular. The shadow side of this finding is that no connection and no rapport teeters perilously close towards not being nursing at all. The main conclusions that are reached by this study are:

- Rapport is important and gives meaning and fulfilment in palliative care nursing.
- Rapport and connectedness are linked to holistic care.
- There are different levels of care given related to the quality of connection created.
 1. The more connected the nurse is to patient and family the more holistic the care. Connection and rapport are how holistic care can be delivered and partnership is likely.
 2. If there is no connection and no rapport the care level will be physical and holistic care is unlikely.
 3. There is also an in-between level of relating, the less connected the nurse is to the patient and family, the less holistic the care, it may be workable or one-sided and not fulfilling for anyone. It may also be the secret majority of nurse patient family interactions and requires further research.
- All participants had examples of disconnection and this maybe a common occurrence which requires research and understanding.
- Patients have a need for holistic safety in palliative care
- There are nurses not practicing with care and connection (not reported in hospice) resulting in judgements, belittlement, bullying and abuse for palliative care patients and families. This is a matter for urgent concern, research and culture change.

As a result of this study, I now have a mental checklist of questions for each patient and family encounter. Have I connected with this person and how well? How is my rapport today? Does this person have what they need to connect safely? Am I being kind? These questions are prompts to be present, to be genuine, to be myself, to meet the other in the best way I can.

In conclusion, are the words of a patient who understood the moments we meet in rapport. She gave permission for her words to be used in this project before she died. She was a nurse.

I know what rapport is. It is the giving of yourself to the other

It is knowing that they may accept you or reject you. And both can be difficult.

Knowing this you go ahead anyway and be present and open and there for the other.

It is not for the faint-hearted; but it can be life-giving. A.C. 2017.

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Appendices

Appendix i



During the month of April 2017, a small group of patients and whanau in hospice will be interviewed about communication and connection. The interview will be about 30 minutes long. This is part of a Master's thesis being undertaken at University of Canterbury. It would be great to have your valuable input to help create meaningful findings.

Contact Wendy for more information

Research Project

"The Moments We Meet"

Wanted: Patients and family to interview for research project.

Benefit: to capture your stories that help us as nurses to be more aware of how we communicate and connect with you while offering palliative care

WENDY ENGLISH RN

021 800214

wendy.english@
pg.canterbury.ac.nz

nurse researcher

Appendix ii

RESEARCH PROJECT INFORMATION SHEET



Department: Health Sciences
Telephone: 021 800214
Email: wendy.english@pg.canterbury.ac.nz

The Moments We Meet: The lived experiences of rapport for nurses, patients and family in palliative care.

Information Sheet for participants

This study is being undertaken by Wendy English RN, as part of a Master of Health Science degree at University of Canterbury. The purpose of the research is to explore the experiences of nurses and patients and family as they form rapport and connection in the hospice setting and how this impacts on care. Central to the project are interviews with the researcher with individual patients, family members and nurses.

Thank you for showing interest in this project. If you choose to take part in this study, your involvement will be making time for an individual interview approximately half to one hour in duration, which will cover topics around connection and communication for nurses and patients and family in hospice. The interview will be audio recorded and later transcribed to be analysed for completion of the thesis. As a follow-up to this interview, you will be invited to read through the written transcript of your interview, making any changes so it accurately represents what was said and meant.

In participating in the interview there is a small risk that thoughts and feelings may arise that bring an emotional response, to this end you are welcome and encouraged to bring a family member or friend with you to the interview. At any point, you may discontinue the interview and support will be offered.

Participation is voluntary and you have the right to withdraw at any stage without penalty. You may ask for your information to be returned to you or destroyed at any point. If you withdraw from the study, I will remove information relating to you, however, once analysis of raw data starts on (estimated) July 2017, it will become increasingly difficult to remove the influence of your data on the results.

The results of this project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation. To ensure confidentiality, no information that identifies person or place will be included in transcriptions and all related electronic files will be password protected with access limited to researcher. Backup files will be stored in locked drawers in the researcher's office. The only people with access to raw data will be the researcher and supervisors; additionally, the person transcribing will have signed a confidentiality agreement. Data obtained for this study will be held as per UC guidelines for

5 years. Please note a thesis is a public document and will be available through the UC Library.

The project is being carried out by Wendy English under the supervision of Kate Reid, who can be contacted at kate.reid@canterbury.ac.nz; they will be pleased to discuss any concerns you may have about participation in the project.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you will be asked to complete the accompanying consent form which can be handed to me directly or returned via email to wendy.english@pg.canterbury.ac.nz, otherwise to the reception desk at Hospice. Please indicate on the consent form if you would like to receive a copy of the summary of results of the project.

With sincere thanks for your consideration,

Wendy English RN

CONSENT FORM – APPENDIX II



Department: Health Science
Telephone: +64 021800214
Email: wen19@uclive.ac.nz

The Moments We Meet: Experiences of rapport for nurses and patients in palliative care.

Consent Form for participants

- I have been given a full explanation of this project and have had the opportunity to ask questions.
- I understand what is required of me if I agree to take part in the research.
- I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- I understand that any information or opinions I provide will be kept confidential to the researcher and supervisor. A transcriber will sign confidentiality agreement. I understand that any published or reported results will not identify the participants or place. I also understand that a thesis is a public document and will be available through the UC Library.
- I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.
- I understand the risks associated with taking part and how they will be managed. Including counselling services may be accessed if I require this support.
- I understand that I can contact the researcher Wendy English, at wendy.english@pg.canterbury.ac.nz or supervisor Kate Reid, kate.reid@canterbury.ac.nz

- For further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)
- I would like to receive a copy of my transcript to check for accuracy
- I would like a summary of the results of the project and have supplied contact details to receive this.
- By signing below, I agree to participate in this research project.

Name: _____ Signed: _____

Date: _____

Address (*for report of findings, if applicable*):

To return this consent form you may email to wendy.english@pg.canterbury.ac.nz or hand into Hospice reception.

Appendix iv



HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 364 2987, Extn 45588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2016/112

4 November 2016

Wendy English
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear Wendy

The Human Ethics Committee advises that your research proposal “The Moments we Meet : Experiences of Rapport for Nurses, Patients and Families in Palliative Care” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 28th October 2016.

Best wishes for your project.

Yours sincerely

R. Robinson
pp.

Jane Maidment
Chair
University of Canterbury Human Ethics Committee

Appendix v

Ngāi Tahu Consultation and Engagement Group



17/08/2016

Tēnā koe, Wendy

Re: Māori Consultation Experiences of rapport for nurses, patients and families in palliative care

This letter is written on behalf of the Ngāi Tahu Consultation and Engagement Group. I have read and considered your proposal and acknowledge that this is a worthwhile and interesting project.

It is well considered and the researcher is clear about how they ought to take participants' (cultural) needs into account.

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement. It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Nga mihi
Nigel Harris

A handwritten signature in black ink that reads 'Nigel Harris'.

Acting Māori Research Consultant
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