Why do community healthcare professionals find some conversations difficult?

Janet Nadicksbernd

October 2022

Royal Holloway, University of London

Professional Doctorate, Health and Social Care

Declaration of Authorship

I, Janet Nadicksbernd, hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

9th October 2022

Acknowledgements

Prior to this academic journey there were two mentors, Frank Ferris and Charles von Gunten, who inspired and encouraged me and I want to recognise them for seeing my potential.

I am very grateful for each one of my supervisors along the way for provided guidance and feedback. I acknowledge Scott Reeves, who helped me realise the importance of not taking on more than I could chew. I acknowledge Tony Evans, who recognised my struggles and helped me formulate my next steps after Scott's death. Tony's perspective always pushed me to consider things from a different lens. I recognise Frank Keating for his thoughtfulness to always start with the positives before getting into the constructive feedback. His kindness went further than he probably realised. And I recognise Jennifer Cole, for her honesty and practical approach, who whipped me into shape there in the end to make sure I was ready for submission.

I thank George, Monica, Cecilia and Ana for putting up with me over the long years of study.

I am indebted to and so incredibly grateful for my study buddy, Maria Brent, who shared the struggles, the highs and the lows, who pushed and supported me. Although we were often at different stages and had different issues, Maria was someone who could really understand what I was enduring and helped me see it through.

This study was possible due to the physiotherapists, nurses and general practitioners who participated. Their time and candour made this study possible and is much appreciated.

Abstract

Community healthcare professionals can find discussing life-limiting, deteriorating health, and end-of-life difficult to navigate. As a result, communication is limited or poorly done. With the lack of communication, patients/families are more likely to have negative experiences. Also, professionals often avoid conversations, leaving patients/families uninformed and uninvolved with treatment and care decisions, which is at odds with the patients' legal rights.

Although there is much research on communication, generally, it is either about the patient's/family perspective or education or training but little on professionals' perspectives of difficult conversations. This qualitative research explores professionals' perspectives of conversations that become difficult. It includes professionals' perceptions of how they interact during these conversations and the differences between the three disciplines under this study: nurses, physiotherapists, and general practitioners.

The methodological approach is interpretivism employing grounded theory approach for analysis. The data collection is in-depth interviews with thirteen professionals, a research diary, and field notes to give a comprehensive understanding of participants' views.

Findings are that professionals do not see difficult conversations as clearly definable, but they see them within certain contexts and with difficulty levels. Findings indicate that professionals' thinking, attitudes, and perceptions about difficult conversations are due to patients'/families' adverse reactions or their own, or both, and/or due to differing expectations between the patient/family and the professional. Other influencers are time, professionals' mortality, and the uncertainty of a diagnosis, prognosis, or treatment.

A crucial complexity is that professionals find their feelings and emotions dominant influencers, with fear standing out as the main one. Other influencers are work experience, a duty of care, and wanting to feel helpful.

The thesis gives new understandings about professionals' personalised accounts of having difficult conversations. They help explain why professionals often avoid these conversations which may have implications for education and training, and practice.

Table of Contents

List of tables, figures, and abbreviations

List of abbreviations:

ACP   Advance Care Planning

CCG   Clinical Commissioning Group

CPR   Cardiopulmonary Resuscitation

GP   General Practitioners

HEE   Health Education England

NHS   National Health Service

PCT   Primary Care Trust

QOF   Quality and Outcomes Framework

Foreword

In the UK, 19 million adults live with one or more conditions impacting their quality of life

(ONS), 2020). In 2019, there were 604,707 deaths (ONS, 2021). Of those, the National

Institute for Health and Care Excellence (NICE) (2015) suggests that ~75% were expected.

Identifying when someone is at the end-of-life can be challenging. Care Quality Commission

(CQC) (2016) suggests professionals should change their focus from 'only identifying people

who are clearly in the last year of life' to engaging in conversations early on, even when the

prognosis is uncertain, about the patient's 'wishes and preferences for care' (p.6). The

General Medical Council (GMC) (2022) suggests that unless harm will come to a patient,

doctors should inform patients about their condition. NICE (2015) guidelines state that

professionals should tell patients who want to know about their prognosis and end-of-life

care and to engage patients in decision-making. However, there is a debate about harm,

with some believing that telling the patient that s/he is dying can be detrimental and cause

them to give up hope (Blackhall, 2013). UK medical schools started offering communication

skills training over twenty years ago, varying from patient history taking to breaking bad news

(Hargie et al., 2010). Communication skills, where they are taught vary from lectures to

simulations, integrated within course topics or as separate courses sometimes as little as one

hour per academic year (Hargie et al., 2010). Physiotherapist schools tend to teach general

communication skills through lectures, without much patient exposure (Parry and Brown,

2009).

Communication skills trainings available for professionals focus on actively listening,

engaging, speaking with patients, reading and using body language, and demonstrating

empathy (Tan et al., 2021; Brighton et al., 2018). However, they are not compulsory and do not focus on the professionals' emotions.

During my career I worked for many years in the USA as a social worker with a hospice. I had many difficult conversation experiences, from supporting a parent telling her children she was dying to talking with patients about their preferences for end-of-life care. Sometimes another professional or I initiated the conversations; sometimes, the patient would. As a member of an interdisciplinary team, I attended many patient/family meetings giving bad news, such as life-altering information. Frequently everyone involved would describe these conversations as difficult, hard, frustrating, or sad and often demonstrated emotions by crying, anger by raised voices, or confusion by stating, 'What does this mean?'.

I was usually involved in conversations with a hospice nurse telling a family that their loved one was actively dying. The approach was gentle and paced. The nurse would lead with enquiry each time asking, 'What has the doctor told you about her condition?', 'Can you share with me what you are most concerned about?' Sometimes negative emotions were demonstrated but providing the space and permission to express those emotions was effective, with the individuals often expressing reassurance and gratitude. Often plans were made, and compassionate care was then the focus for everyone involved. Although sad and challenging to navigate, these conversations felt effective when the family could make informed decisions and implement patients' wishes. Those were the good difficult conversations. But conversations were not always good.

Once, I remember having a patient who was terribly angry that he would not be going home from a nursing home. He was independent before but could no longer manage his care. He was verbally abusive, and I remember saying sorry and walking out as fast as I could. I felt

horrible afterwards, and the experience stayed with me for a long time. This, for me, was a difficult conversation. The care home staff dismissively called him a challenging patient, and I remember agreeing with them yet feeling guilty about it. I saw him a couple of times afterwards, but always with other professionals present and avoiding the topic of him going home. He deteriorated quickly. When he was no longer able to engage in conversations, I remember feeling relieved and guilty at the same time; guilty for not doing more for him when he could talk as we did not know his preferences except to be at home.

I also witnessed other conversations that did not go well. Many were when patients/families were either not given information such as a short prognosis or when they did not understand the full implications of the information. For example, I was called in as a representative from the hospice to attend a patient and family meeting. The hospital doctor quickly said, 'You are not going to get any better, even if we keep throwing medicines at you. You will just have to face it' and left. The patient was shocked and later explained he was sorry for being such a burden. The family was confused and asked, 'Okay, so he won't get better, but we just keep on doing what we are doing then, right?' The family was left uncertain and confused since the word dying was not spoken.

I had a challenging conversation with most of the patients/families on my caseload (approximately 25-30). The really difficult ones occurred perhaps once every other week. These experiences influenced me to get involved in education, programme development and evaluation to try to help improve experiences for patients/families and professionals alike. In 1999 I trained as a social worker, obtaining a Master's degree in social work with a concentration in health and a specialisation in management, in the USA. I was promoted to manager, and then later, due to successfully implementing a major service delivery change

strategy, I was asked to be a co-principal investigator for an educational research project. I became a special projects manager using education interventions for quality improvement. With mentorship I was involved with evaluation and research and learned as I went on how to select, monitor and report outcome measures such as changes in attitudes and knowledge. For example, one programme we trained hospice staff how to conduct bedside teaching with care home staff about pain and noticing changes in condition to improve quality of care.

I moved to the UK in 2010 and worked as a project manager within a Primary Care Trust (PCT), later called a Clinical Commissioning Group (CCG). After the National End of Life Care Strategy (2008), the PCT developed a local strategy across health and social care to improve end-of-life care. In this role, I used my experiences from when I was in the USA to help implement the strategy. I conducted focus groups with social workers and care home staff and evaluated services such as bereavement care and a rapid nursing response for care homes. I piloted an electronic record system that captured patients' preferences for treatment and care at the end-of-life (defined as being in the last days, months, or years of life) (Department of Health (DH), 2008). I found the challenges of end-of-life conversations to be universal. Within the CCG we were aware, based on previous experience, that learning the technology involved was one thing. However, professionals also needed to have training on how to start and engage patients/families on this difficult topic. In 2012, using my knowledge and experience from my hospice days, I helped develop and taught experiential communications workshops (professional training independent of my doctorate) titled Difficult Conversations to address this need. Workshops were for groups of five to 25 attendees, targeted at community multi-professionals. From the pilot phase, we learned that community professionals identified more with the terminology and had more conversations

about deteriorating health than end-of-life care. The workshops aimed to build participants' knowledge, skills and confidence in having difficult conversations about deteriorating health and end-of-life care. Workshops used short video clips of poor and effective communication to stimulate discussion and taught the essentials for good communication. We taught a mnemonic to help guide professionals through a difficult conversation, and attendees practised in simulated role-plays and received feedback.

These experiences eventually led me to embark on a professional practice doctorate to gain a better foundation in research approaches. In 2013, I became a part-time student, allowing me to continue working. In 2014, although the workshops were popular, the CCG could not continue to bring in commissioned work. The co-developer and I were advised to establish a social enterprise so the delivery of the training could continue. I moved on from the CCG but continued to co-run the social enterprise part-time. The role involved preparing and supporting new facilitators and designing other training and teaching workshops. My involvement fluctuated due to other work commitments. I was not actively involved in the organisation when I had completed gathering this research data. I officially left in 2020 due to the pandemic when most education and training came to a halt.

Once when I was teaching a workshop, a doctor attending told me about his role by saying, 'I'm in it to find out what's wrong so it can be treated, to cure the person, to make it all better, but what I have learned is that sometimes, no, many times, that is just not possible'. This comment raised many questions for me about how professionals deal with difficult conversations in practice and how one copes with this disappointment, this duality of expectations on oneself. I thought about what may go through their heads when behind closed doors/curtains when this happens. I continued to be curious and looked for answers

to more questions with each workshop. Questions such as: 'How do professionals perceive how they have difficult conversations?' and 'What helps them move past the instinct to avoid them, and how do they feel about it when they avoid one?' These questions then became about me. Was I missing any easy wins, some golden nuggets of truth that could help others? Were the complexities and the barriers professionals face appreciated? Did I appreciate the complex nature of these conversations? Were my expectations realistic of what professionals should or should not do in practice? I decided that I wanted to explore these questions further in my research to gain a better understanding.

Working through these questions and developing my research focus, I read the book *Researching Your Own Practice: The Discipline of Noticing* by Mason (2002), which opened my eyes to being 'sensitive to' my own experiences. I was intrigued to find out if my assumptions were accurate and if so, were there missing pieces? I could not ignore my experience and beliefs about the topic; that would be counterproductive as an insider researcher because I inevitably play a role in the research and my experience and beliefs would seep into it. Mason (2002) helped me shape the idea of 'Noticing a possibility for the future, noticing a possibility in the present moment and reflecting on what has been noticed before in order to prepare for the future', influencing how I approached my study (p.175).

Originally, I intended my research study to evaluate the Difficult Conversations workshops. Over the process of reading and discussing with my supervisor my observations, the various questions and my interest with a more explorative approach, the research changed to a mixed-methods study to better understand the experience of professionals. Ethics review approved this version of the study: part explorative, part evaluative.   It changed again as participants' responses kept dividing my thinking between evaluating the workshop and

exploring their perceptions. As an insider researcher, I was split between my interest in the

effectiveness of the training and wanting to better understand professionals' experiences and

views. In the end, this thesis focuses on the qualitative explorative approach.

Chapter 1: Introduction to the study

1. Introduction to perceptions about difficult conversations

At the beginning of the Professional Doctorate, the professors said, maybe even warned, 'Choose your research topic wisely'. I remember hearing, 'May it be something you are really interested in because you are going to focus a lot of time and energy on it. You want to end still being friends'. Heeding this warning, I needed my research to be interesting and convenient, which steered me towards my inquisitiveness and where I was spending a large amount of my time: work. Therefore, as an insider I designed this thesis to explore how community healthcare professionals (professionals) characterise conversations with patients/families as difficult and to capture my learning along the way.

In working in palliative/end-of-life training, I often used and heard the term "difficult" or "challenging" conversations, referring to conversations about discussing patient wishes, treatment options, and delivering bad news and end-of-life information. Therefore, I came to this research with a preconceived idea that certain conversations are difficult. This chapter introduces the thesis by explaining the context and research focus. Then it justifies the study and concludes with a brief overview of what to expect in each thesis chapter.

2. Context[1]

Long-term conditions such as dementia, hypertension and other chronic diseases are not curable but can be managed; however, many can be debilitating and life-limiting. There are predictions that the number of people with a long-term condition will increase over time, as

---

[1] This research took place prior to and does not include the COVID19 pandemic.

will the number of conditions (Department of Health and Social Care, 2015). People also live longer, but with this longevity comes increased morbidity (ONS, 2018). These conditions result in patients/families engaging with professionals for their health and well-being.

The form of communication most used is talking, i.e. having conversations between patients or individuals close to the patients (referred to as "family" in this thesis) and professionals. Conversations range from the practical, such as giving information or advice, to the supportive and comforting. Due to the complexity of health, treatments, relationships and emotions, these conversations can sometimes be difficult, which is the focus of this research.

The National Health Service (NHS) tasks professionals to give patients control and choice, aiming for 'The principle of "shared decision-making" to become the norm: no decision about me without me', making patients partners in care (DH, 2012, p.9). Doing this well takes good communication (DH, 2016a). Although professionals are required to have communication competency (GMC, 2019; Nursing and Midwifery Council (NMC), 2018; Health and Care Professions Council (HCPC), 2013), there is a lack of clarity around who does what (Oishi and Murtagh, 2014), and disagreements remain about what patients need to know around end-of-life and the value in truth-telling (Hinshaw, 2022). The difficulty in knowing an individual's disease trajectory is linked to this, leaving professionals navigating uncertainty (Ahluwalia et al., 2013; Selman et al., 2007). The NHS sets out guidance that staff need to have training (NICE, 2019), but prior to 2017 there were no specific standards for training in communication around deteriorating health and end-of-life care, leaving it to the discretion of the service provider.

"Difficult conversations" is a common term in palliative and end-of-life care, education and training literature for improving communication skills around such conversations (Marcus

and Mott, 2014). The workshops, where participants for this study were recruited, had an explicit title, "Difficult Conversations", and were advertised in the context of deteriorating health and end-of-life scenarios; therefore, participants were aware of the idea from the outset. Through my observations of workshops, though, I recognised that not all participants consistently had the same understanding of difficult conversations. For example, for some the difficulty was more about dealing with angry patients or telling someone they have a new, life-changing diagnosis such as diabetes or Crohn's disease. For others, it was talking with patients about how they were no longer progressing and therefore stopping rehabilitation treatments. All these examples involved emotions. These professionals opened helpful discussions around various issues such as dealing with uncertainty, not wanting to cause harm, responding to emotional patients, and how to engage. All of these are components of difficult conversations. I thought these definitions were important to recognise and interesting to explore further to allow space for and broaden understanding of these characteristics of conversations in these different contexts, which was my motivation for this research.

Based on this learning, I chose the working definition of difficult conversations for this study to be discussions where participants felt the conversations were hard, usually uncomfortable, challenging, needed extra effort and in which they often needed skills to navigate through them, in other words when a conversation was about a tough topic to bring up or engage in, based on the emotional content. However, I recognised it could restrict participants' thinking about how they saw difficult conversations. Wanting to explore further, I explicitly said to participants that although I provided a definition, they did not have to agree, and I wanted to know what they thought and what they considered difficult. Understanding how participants

view conversations that become difficult is a key part of this study. To note, I do not explore conversations with those with cognitive impairments.

To help understand why some conversations become difficult it is helpful to know the historical and traditional roles of professionals and patients because they compete with the concept of partnership in care. Historically professionals have the role of authority, and patients are the sick; therefore, the patients listen to and obey the professionals (Parsons, 1991). Traditionally, conversations between a professional and a patient are centred around giving instructions, not engaging in dialogue (Parsons, 1991). The dialogue previously was not a priority because the professional knew what was best for the patient; therefore, they made decisions about patients without the patients' input (Parsons, 1991). However, as Milton (2004) points out, critics of Parsons believe this to be short-sighted since the sick role does not include chronic illness (Friedson, 1970), and these roles are not as straightforward as Parsons describes (Turner, 1973). However, some studies showed that professionals did not think it was in the patient's best interest to know if s/he was deteriorating and dying (Glaser and Strauss, 1965; Oken, 1961). Societal shifts over the years found patients taking more ownership of their care alongside the move toward healthcare consumerism (Brown, 2008). These culture shifts have impacted communication between patients/families and professionals, especially difficult conversations.

Research suggests that professionals have facilitators and barriers to difficult conversations (Fulmer et al., 2018; Best, Butow and Olver, 2016; You et al., 2015; Griffiths et al., 2015; Prouty et al., 2014; Mellor et al., 2013; Slort et al., 2011). The facilitators are trust and relationships which occur through communication and are what patients value most in the patient-professional relationship (Owens et al., 2017; Best, Butow and Olver, 2016; Berglund,

Nassen and Gillsjo, 2015; Almack et al., 2012). Relationships have ranges of familiarity, with good relationships considered influential in supporting patients and being catalysts for communication (Owens et al., 2017). Studies argue that the relationship and trust between the professional and the individual help when the communication content becomes challenging (Owens et al., 2017; Best, Butow and Olver, 2016; Berglund, Nassen and Gillsjo, 2015).

However, communication can become difficult even with excellent relationships and established trust. For example, when professionals must discuss other care options for a fiercely independent, deteriorating 90-year-old or discuss preferences for someone diagnosed with end-stage heart failure or a new cancer diagnosis. Professionals can struggle and stumble in having these types of conversations and often shy away from having them at all (Piggott et al., 2019; Lazenby et al., 2016; Pfeil et al., 2015; Ahluwalia et al., 2013; Almack et al., 2012; Selman et al., 2007). Avoidance increases with uncertainty about a patient's prognosis (Ahluwalia et al., 2013; Selman et al., 2007). Also, professionals often wait to introduce sensitive issues, thinking the patient/families will bring it up, whilst patients/families believe the professional will initiate it if needed (Almack et al., 2012). In addition to this disconnect, is a mismatch of expectations, for most patients/families want to know what is happening so they can make informed decisions (Schattner, Rudin and Jellin, 2004).

Avoiding difficult conversations can result in patients not receiving necessary information about their disease progression, resulting in uninformed decisions about their treatment, care, life and well-being (Lazenby et al., 2016; Griffiths et al., 2015; Ahluwalia et al., 2013). Without engaging in conversations, how can patients be true partners? Bernhardt et al.

(2010) said these conversations also impact professionals and their job satisfaction, resiliency, and mental health. Exploring how professionals approach these conversations in practice also gives us a better understanding of the complexities, motivators, and barriers they face.

Many argue that professionals should not avoid difficult conversations because they are essential to upholding patient-centred care and having a true partnership in decision-making (National Palliative and End of Life Care Partnership, 2022). Others argue that conversations about future decision-making, such as preferences for treatment and care, including preferred place of care up to death, are also crucial for preparing for what is to come (Fulmer et al., 2018; Ahluwalia et al., 2013).

When communication is lacking or poorly undertaken, patients report negative experiences and dissatisfaction with care (Appleby and Robertson, 2015; Fisher and Ridly, 2012; Ogden et al., 2002). Dissatisfaction and negative experiences often lead to complaints (Parliamentary and Health Service Ombudsman (PHSO), 2015). Furthermore, there is a link between inadequate communication and inadequate care (Almack et al., 2012; Amiel et al., 2006; Clayton et al., 2005). The King's Fund (TKF) (2014) reports a link between patients involved in decision-making about their care with patient satisfaction and good patient outcomes (Foot et al., 2014). The consequences of not having these important discussions can result in patients not being invited to make decisions about their own life and death.

Patients engage with various professionals, especially if they have a long-term or debilitating condition. These professionals play similar yet different roles. Existing research around difficult conversations is generally about breaking bad news or end-of-life care planning. It often occurs in hospitals and predominates with patients or doctors as study participants.

Different professionals work in different settings, with 'hospital care' and 'community care' being different environments. Care in hospitals tends to be conducted in a single institution with different professionals working side-by-side, diagnosing, treating and caring for acute ailing patients. On the other hand, care in the community tends to be more disparate, involving a range of people in different settings such as a General Practitioners (GP) surgery, an outpatient clinic or a patient's home, and for the most part, patients are generally not as critically ill. Community professionals work independently, interacting with other professionals more over the phone or through clinical letters and documentation. This research focuses on the healthcare professionals working in the community.

Conversations become difficult in both settings. They are hard and are often avoided, and I wonder, do we really know and understand why? In running workshops, I thought maybe there was more to it than what we were teaching. Did we understand the professional's perspective? How do professionals even define what a difficult conversation means? What stops them from having them or helps them when they have them? What influences their practice? The focus of this study is to explore these questions.

3. Research focus

This study uses qualitative research to help understand the world around us, recognise social complexities underpinning individual perspectives and make sense of a phenomenon (Ormston et al., 2014). The epistemological approach underpinning the study is interpretivism, recognising more than one side to a story. The objectives are to explore the individual realities of how professionals (community nurses, GPs and physiotherapists) define and characterise conversations as difficult around deteriorating health and end-of-life, their perceptions of what makes conversations difficult, including how they interact with

patients/families during these difficult conversations and any differences between the professional groups.

Exploration included a grounded theory approach to investigate this societal phenomenon within its context and investigate relationships by singling out entrenched patterns to understand the complexity and depth (Robson, 2011). It explores how professionals approach these situations to capture their exhaustive knowledge and experience, allowing a closer and in-depth examination.

4. Justification

Existing research does not often focus on the professionals' points of view (You et al. 2015). The focus tends to be more on training or process evaluation or the perspectives of the patients or families (explained more in Chapter 2, section 4). This research addresses a gap in understanding professionals' points of view about conversations that become difficult.

Other research focuses on specific forms of 'difficult conversations' such as 'giving bad news' and particular professionals, predominantly doctors (Griffiths et al., 2015). However, difficult conversations are wider than this, and doctors are not the only ones to have them (Griffiths et al., 2015). Other examples include actively dying, preferences for care before dementia worsens and when a patient is going against professional advice.

This research strives to contribute to the literature by exploring professionals' perspectives, and with more research on doctors already available, I was motivated to include other disciplines. As conversations are typically initiated by the professional, it is important to understand how they approach it or the perceived barriers to engagement when they do not, to help tackle the barriers and improve experiences. This research sought to take a step back

to try to understand more about how professionals are affected by such conversations and what their experiences are in real-life practice. The importance of this is that although professional guidance and policy expectations exist to help professionals engage in conversations that can become difficult, there are inconsistencies in education and training to help them have these conversations effectively. Understanding could lead to better training for the professionals and future research which could lead to new opportunities to help professionals tackle the daunting task, which can have a knock-on effect of helping the patient/family.

5. Thesis overview

The following gives an overview of this thesis. The research question for this thesis was to explore the individual realities of how professionals (community nurses, GPs and physiotherapists) define and characterise conversations as difficult around deteriorating health and end-of-life. The objectives were to:

- Define and characterise conversations as difficult;
- Explore their (participants') perceptions of what makes conversations difficult;
- Examine participants' perceptions of how they interact with patients/families during these difficult conversations; and
- Explore any differences between the professional groups (community nurses, GPs and physiotherapists) in having difficult conversations.

This chapter provided context, an overview of the approaches used and the study's rationale. Chapter 2 is a scholastic literature review with the aim of understanding 'the different contributions that have been made' about this topic and to 'make interpretations' (Hart,

2018, p.95). The review includes policy and practices over time, an account of the search

strategy and the screening methods used to investigate difficult conversations in practice.

Chapter 3 explains the study's methodology, including the epistemological approach of

interpretivism and the use of grounded theory within the research design. It then covers the

data collection, analysis, reflexivity and ethical considerations.

Chapters 4-6 each relate to the three main research objectives presenting the findings

related to each and include a discussion within the same chapter. In these chapters I draw

on the literature from the review and Parsons' (1991) account of the patient and professional

relationship. To help interpret the findings, I use other theories to provide further

understanding focusing on three: Luntley's (2009, 2011a, 2011b) activity-based concepts

theory, Burkitt's (2002, 2014) work on the complexity of emotions, and emotional labour,

originally by Arlie Russell Hochschild (1983) with other contributing authors.

Chapter 4 shows how the original research term develops from "difficult conversations" with

an expectant binary response with definitions to a gradation with examples of conversations

that can be characterised as difficult — trying to understand how professionals see these

conversations can give us great insight. Chapter 5 explains what makes conversations

difficult in practice. It includes professionals' perceptions of patients'/families' reactions,

differing expectations and other complexities such as limited time. Chapter 6 then dives into

the professional's way of thinking and their perceptions of self in difficult conversations. It

explores the complexity of emotions between professionals and patients/families.

The last chapter, Chapter 7, is the conclusion of the thesis. It summarises the key findings,

explains the study's strengths and limitations, expounds on how this research contributes to

knowledge and provides suggestions for future research. Following the chapters, the

References and Appendices which includes the Search output table, the Information Sheet,

Consent Form and Interview Schedules used with participants can be found.

Chapter 2: Literature Review

1. Introduction

Chapter 1 explained my motivation for undertaking this study and how it influenced my research question. This chapter is a literature review exploring how professionals view conversations that become difficult and what influences their practice when having them. It includes how one characterises and defines them, what makes conversations difficult, how one interacts during these conversations and if there are differences between disciplines. This review does not include studies focusing solely on the patient/family perspective, specific clinical care or education and training.

2. Approach, search method and screening

Literature reviews help inform studies by identifying what is written about a certain topic, including similarities, differences and gaps between studies, to help inform research (Robson, 2011). They can have different forms with a common distinction between interventionist and scholastic. An interventionist (systematic) review focuses on 'what works' giving 'supportive evidence for translating research into practice, to address a particular need' (Hart, 2018, p.99-100). A scholastic (traditional) review aims to 'acquire greater levels and degrees of understanding' by learning the various contributions and then interpreting their meaning (Hart, 2018, p.95). The intention is to compare and contrast these meanings or 'arguments logically, look for and resolves contradictions, challenge propositions and make inferences through rigorous conceptual analysis' (Hart, 2018, p.93). This literature review is a scholastic review. The search method was a rigorous process of searching policy and empirical evidence related to my research question and critically analysing the evidence to

account for the arguments. Then I interpreted them around my research question, using the literature to challenge my assumptions and widen my view (Hart, 2018, p.95; Blaxter, Hughes and Tight, 2010, p.124).

There is much to consider when looking at communication as a topic. It can include verbal (words used), non-verbal (body language, active listening) and visual communication (pictorial, written information, documentation) (GMC, 2019; Chartered Society of Physiotherapy, 2013). In addition, communication can include, paralinguistic (aspects of communication without the use of words such as tone, speed, and non-linguistic sounds such as sighs or gasps) and methods for communication such as telehealth with the use of video. For this research, communication is about the verbal and non-verbal conversations or discussions between professional and patient/family, mostly face to face, but can include over the phone (without the non-verbal communication). At the time of this research, participants were not engaging in telehealth. The literature is vast and ranges from studies on the patient's point of view, such as satisfaction in care, to ones that focus on professionals' views, such as interprofessional working or training evaluation. There appeared to be limited research that addressed my research question; therefore, I needed a robust and organised approach with clear search terms to navigate the sea of literature, which the following section explains.

As my research question concerns professionals' perspectives, I searched extensively for community healthcare professionals' views. First, I started with what I knew professionally, as Glaser and Strauss (1967, p.252) recommended, so as not to ignore one's professional experiences when conducting research. I also tried to remain open to the possibility of

chance, a development or direction change and look at it as an 'opportunity to change the research' (Hart, 2018, p.301).

I first considered the research question's main overarching words and word associations to develop search terms. For example, I used "difficult conversations" and "significant conversations" and the basic overarching terms "communication" and "communication skills", focusing on "professionals perceptions", "professionals views" and "professionals experience". I manually searched for policy and reports on Google and Gov.uk. These searches helped me to develop further search terms such as "giving bad news" and "emotions". Aware that my professional experiences could bias my approach, I used various databases for empirical studies to address this bias: AMED, PEDro, Medline, HMIC, EMBASE, and PsycINFO. A Search Output table in Appendix A incorporates a detailed list of search terms, numbers retrieved per search term and databases used. Further details about the search are in Appendix B.

Although with multiple studies on communication skills, specifically training or the behavioural application of communication skills, it became evident that there was little empirical research examining professionals' perspectives regarding communication hindrances (You et al., 2015). Historically, studies have focused on "breaking bad news" in the context of giving a patient a terminal diagnosis/prognosis, mostly researched in hospitals and about doctors and usually as one-off conversations. However, breaking bad news should be expanded further to include other disciplines and the home setting (Griffiths et al., 2015). My experience has shown me that challenging emotional conversations do not only occur when delivering bad news, so perhaps looking at communication issues in this light is new, and the characteristics of conversations that become difficult also need to be broader.

Although this thesis is in the context of deteriorating health and end-of-life, it expands to include broader issues that participants consider challenging. Therefore, my search too extended to include other topics where conversations can be difficult, providing a useful lens through which to interpret professionals' understanding of conversations that become challenging. However, my research remained within the context of healthcare.

Overall, hospitals dominate the settings, and doctors dominate the studies' participants, requiring me to search further. Many sources selected for this review have mixed representation of hospitals and community participants: this and the underrepresentation of physiotherapists in the literature results in a limitation of this review. The domination is most likely due to the history of focusing on how to improve delivering bad news about cancer or end-of-life through education (Baile et al., 2000). Patients'/families' perspectives dominated the search results but were not included unless the study contained professionals' perspectives. Less is on the research agenda for difficult conversations with nurses and physiotherapists, which is a limitation of this review. Gender is not explored in the literature, and only one study mentions the age of participants. I used Hart's (2018) adapted main and secondary questions to appraise the literature. The following are the main questions:

- Is this a question that can be addressed through research?...
- How defensible is the research design?...
- How well defended is the sample design/target selection of cases/documents?...
- How well was the data collection carried out?...
- How well has the approach to and formation of the analysis been conveyed?...
- How credible are the findings?...
- How coherent is the reporting of the research?...

- What evidence is there of attention to ethical issues?

- How adequately has the research process been documented? (p.87-89).

The main themes in this review are examples of difficult conversations, the barriers professionals face and facilitators when having those conversations. Throughout the review, I will reference study participants as professionals; however, I will also disclose the disciplines involved when it helps to provide context.

3. Background: policy and practice drivers that affect difficult conversations

There is a shared belief in Western societies that communication is significant in healthcare between professionals and patients/families (Vermeir et al., 2015). However, when it comes to deteriorating health and end-of-life, the approaches and theories differ; some say disclosure is important (Brighton and Bristowe, 2016) while others say disclosure is not necessarily required (Blackhall, 2013). Over the past seventy years, the patterns of beliefs in healthcare changed due to many contributions including a decrease in paternalistic treatment of patients/families and an increase in healthcare consumerism (Foot et al., 2014). Setting the context for this study, the following section provides an overview of key arguments that have informed the current climate around patient care and what may inform current practice around deteriorating health and end-of-life conversations. The NHS stresses the importance of patient-centred care (DH, 2013) and professionals are required to involve patients in decisions if they want to be involved (GMC, 2019; NMC, 2018; HCPC, 2013). The NHS Constitution for England (2021) reads, 'Patients, with families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment' (p.1). Involvement is fundamental. NICE Guidance (2021) states:

Shared decision making is a collaborative process that involves a person and their

healthcare professional working together to reach a joint decision about care…

straightaway or care in the future, for example, through advance care planning (p.5).

Linked to this is the difficulty of predicting the disease trajectory for an individual and the

impossibility of knowing when someone will die, leaving professionals navigating this

uncertainty. Many recommend 'A health professional who is confident and experienced and

has a good rapport, often the person's GP or specialist nurse' should be the one to tell a

patient/family s/he is dying (Marie Curie, 2022). Doctors also give new diagnoses, and to

help them navigate this and prognosis uncertainty, the GMC (2020) provides guidance stating

that one 'Must give patients information they want or need to make a decision' (p.11). To do

this, one 'Must answer patients' questions honestly and accurately, and as fully as is practical

in the circumstances' and be open about one's limits of knowledge and explain any

uncertainties (p.16). The guidance also suggests that doctors should 'Explore in advance

what options the patient might prefer in the future, depending on how treatment progresses,

and the factors that might influence their choice' (p.16).

For patients to be involved, communication must occur; if not, professionals could risk

violating the law regarding consent (Chan et al., 2017). NICE Guidance (2012) states, 'All staff

involved in providing NHS services should have demonstrated competency in relevant

communication skills' (p.15). For terminal diagnoses, NICE (2015) states that patients should

be told if they want to know. Although many doctors agree that patients should be told, they

often do not disclose terminal illness and end-of-life (Hancock et al., 2007). There are also

debates about what or how much patients need to know, as well as when they need to know

it, which links to professionals' perceptions of patients' openness to uncertainty (Portnoy et

al., 2011). Some believe it can be detrimental for patients, and telling them could cause

harm (Blackhall, 2013; Pollock and Wilson, 2015).

Healthcare research on patient-centred care and communication points to a correlation

between the way professionals communicate with their patients and their satisfaction with

care (Vermeir et al., 2015; Appleby and Robertson, 2015; Beck, Daughtridge and Sloane,

2002; Johnson et al., 1988). Communication impacts continuity of care, patient safety,

professionals' time and use of investigations (Vermeir et al., 2015, p.1265), as well as

patients' perception of 'Trust, rapport, comprehension, compliance and adherence, and long-

term health effects' (Beck, Daughtridge and Sloane, 2002, p.26). When professionals do not

communicate with patients/families regarding health deterioration or end-of-life, there is

mistrust and lack of confidence in the professional, accompanied by low satisfaction (Fisher

and Ridly, 2012; Ogden et al., 2002; Johnson et al., 1988). Furthermore, when

patients/families complain, those complaints often correlate directly to poor communication

(PHSO, 2015). Next, I will describe the patient/family and professional relationship.

3.1 The relationship between the patient/family and the professional from the 1950s to the present day

In the past, society saw professionals as experts, with the patient as the recipient of the

expertise. In the 1950s, Parsons (1991) argued that in addition to a medical diagnosis or

disease, patients also played a societal role, the 'sick role' defined as 'The sick person is

helpless and therefore in need of help' (p.269). Moreover, the expectation was for patients

to obtain and adhere to professional guidance. Patient choice and involvement in decision-

making were not common. It was acceptable and common practice for the professional to

"do to" the patient, leaving communication as less essential and, therefore, off the list of

priorities. Not all agreed and some criticised Parsons' work. Friedson (1970) said that the sick role did not include the different dynamics of a chronic illness, nor give tribute to the role family and friends play, from legitimising the illness to providing care prior to seeing a professional (Milton, 2004). Turner (1973) stated the roles are more complex than Parsons described, with some not trusting or passive towards professionals. Oakley (1974) said the sick role was for men because women were not given the same considerations within it.

In the 1960s, professionals were considered paternalistic towards their patients (Sokol, 2006). Oken (1961) found that 90% of doctors preferred not to inform patients when they had cancer, a disease that at that time had few treatments, feeling it could harm the patient or they were afraid of patients' reactions, or both. The study also indicated that influences of the doctors' burdensome emotions and assumptions were not likely to change their practice. He found their concerns for their patients, mixed with futile circumstances (when no treatment would change the outcome), led them not to tell patients their diagnoses (Oken, 1961). This study is used as a historical benchmark for truth-telling and patient involvement.

Glaser and Strauss (1965) also found that doctors relucted to tell patients they were dying. Nurses and other professionals were expected to follow the doctors' orders and required permission to discuss dying with patients. It was more than just avoiding the topic; they argued there was often a joint effort between the doctors and nurses to mislead the patient, even if the patient was suspicious, to think s/he would get well again.

Originally published in 1958, Saunders' (2006) article entitled: 'Should a patient know...?' argued for a compassionate, individualised approach to answering that question. Although she did not advocate initiating truth-telling as is common today, she stated that if a patient asked, one should tell the truth. She provided a compelling story for the time: truth can help

a dying patient with acceptance and peace (Clark, 2014). Later she wrote about engaging

patients in discussions about their 'total pain', her concept of suffering psychologically,

socially, spiritually and physically, representing the early days of a holistic approach to care

and signifying the importance of patient involvement (Mehta and Chan, 2008).

Saunders' vision resonated with the public that those dying deserved care, changing the

perception of curing or doing nothing (Richmond, 2005). Her pioneering approach still

influences practice many years later, with the first-ever National End of Life Care Strategy

quoting her work (DH, 2008).

In 1975, Illich said that within the patient and professional relationship, medicine does play a

role; however, he saw it differently from Parsons. Illich supported person autonomy and

control but explained it could result in 'industrial overproduction', the social engineering of

medicine into overproduction for profit, resulting in the smothering of health itself (p.78).

Between 1960-1980 a convergence of 'multiple currents' influenced and shifted society and

healthcare, including a 'Normative to question authority to a growing movement advocating

consumer rights and patient autonomy in health care' (Hinshaw, 2022, p.46). The shift was

'Compounded by several scandals in which human subjects were abused in clinical research',

resulting in 'Protections embodied in the principle of informed consent... which was extended

to patients in general' (p.46).

In 1976, Byrne and Long, known for mapping out what transpires during patient and doctor

consultations, found that often interactions spanned between doctor-centred and patient-

centred dialogue and patients preferred patient-centred. Patient-centredness was a new

concept for the time (Denness, 2013). In 1979, Novack et al. published a near replica study of

Oken's (1961) questions and found opposite results from the original study with 97% of the

267 participants would tell patients their cancer diagnosis. Societal changes and shifting

expectations continued to play a role in evolving approaches. From the 1980s to the 1990s,

with government's thrifty spending matched by increased demand, the public gave the NHS

low satisfaction rates, resulting in reforms (TKF, 1998). Soon after this time, the first Patient's

Charter (DH, 1991) was produced, which 'Raised individuals' expectations about the quality

of care and encouraged them to demand better services' (Greengross, Grand and Collini,

1999). From the 1990s to the present day, expectations have continued to change, with

policy supporting the transition towards including patients' involvement in their care and

truth-telling (Hinshaw, 2022). 'Good Medical Practice' (GMC, 1995) set out a duty of care to

include patients in discussions and the planning of treatment. Wagner, Austin and Von Korff

(1996) published 'Improving outcomes in chronic illness', explaining how the traditional

approach was a mismatch for those with a chronic illness and how it was 'failing' them (p.12).

People advocated change. World Health Organization (WHO) published 'Innovative care for

chronic conditions' (2002), supporting a 'paradigm shift' for a 'different kind of health care

system' where professionals 'must be re-oriented around the patient and family' (p.5).

Communication skills were key in the culture shift where professionals were required to

involve patients in decision-making (Kaba and Sooriakumaran, 2007).

DH published two influential reports in 2008. One was the 'End of life Care Strategy',

establishing 'A vision for giving people approaching the end of life more choice about where

they would like to live and die' (p.1). The strategy outlined a pathway, with the first step

being 'open, honest communication' and dedicates a chapter to the workforce to have

knowledge, skills, education and training, highlighting communication (p.49). The second

report was a command consultation reviewing patients' rights; 'High-quality Care for All: NHS

Next Stage Review', focusing on quality of care and patient experience (Darzi, 2008). The

report's recommendation to establish an NHS Constitution for England came to fruition in 2010, laying out expectations. Policy shifted further with the following reports: 'Mid Staffordshire NHS Foundation Trust Public Inquiry' (Francis, 2013) and 'More care, Less Pathway: A Review of the Liverpool Care Pathway' (2013). These reports highlighted how dishonesty, lack of transparency and inadequate communication have detrimentally impacted patients/families and made recommendations for education, training, maintained competencies and, for the second, more research in understanding the dying's experience highlighting communication. In the case of Montgomery vs Lanarkshire Health Board in 2015, Montgomery was not informed of the risks of giving birth due to her circumstances resulting in her son being born with cerebral palsy. The UK Supreme Court ruled that patients have the right to be informed of treatment and be involved in making decisions (Chan et al., 2017). These transitions put the focus on patient involvement and satisfaction with care.

Better outcomes occur when patients are involved in their care (Appleby and Robertson, 2015). Complaints about poor communication is a consistent theme in the NHS (NHS Digital, 2019; Parliamentary and Health Service Ombudsman, 2019). The 'Complaints about Acute Trusts 2014-15' report presented the need for healthcare professionals to improve their communication around end-of-life situations saying professionals should offer patients/families sensitive discussions about prognosis and care (PHSO, 2015). As the report was only to give acute trusts their complaint systems data, it does not set out training recommendations for achieving this. Due to repetitive complaints about end-of-life care, the PHSO published a short report with case examples named 'Dying with Dignity', highlighting the main problem, a lack of honest communication, and recommending training on difficult conversations (2015).

The government commissioned an independent review in the same year to learn how to improve end-of-life care (The Choice in End of Life Care Programme Board, 2015). Soon afterwards, the DH committed to the public to equalise quality care at the end-of-life across the health system by 2020 (DH, 2016a). The pledge had six commitments, all relying on effective communication. The first one read, 'Have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing so that you can live well until you die' (p.10). The other five included giving information for informed decision-making, having a personalised plan, involving other as needed and wanted and having a primary point of contact. Soon after, the government mandated Health Education England (HEE) to 'Deliver a national action plan to promote best practice in workforce education and training in end-of-life care' and to 'work with' medical and nursing advisory groups to improve education on 'patient choice in end-of-life care' (DH, 2016b, p.16). As a result, HEE's Skills for Care and Skills for Health (2017) produced a competency framework listing non-specialists, 'Core skills and knowledge…, against which local commissioners, services providers and clinical teams can benchmark their own standards, identify areas which need to be improved and take steps to address these' (p.4). This framework targets two of the three disciplines covered in this research: the nurses and physiotherapists.

Over the past 20+ years, there has been a transition with more focus on professionals, especially doctors, to have a proper 'bedside manner' and improve their communication skills with their patients (Barnett et al., 2007; Amiel et al., 2006). Communication skills are needed to ensure that professionals are not just directive but conversant in exchanging information and ideas with their patients, negotiating a plan and providing emotional support when needed (GMC, 2019). Evidence suggests 'Whole system approaches, such as clarifying roles

and responsibilities within the team to facilitate end-of-life communication' is needed (Walczak, 2016, p.13). Next, I consider the particular area of communication, conversations becoming difficult.

4. What are "difficult conversations"?

Initially, I set out to define the subject of difficult conversations to construct meaning (Hart, 2018, p.210), but a definitive definition was lacking in the literature I explored. Authors of the literature I explored may believe the definition is evident, a known factor, as most describe their topic as difficult. Due to a lack of material, my strategy shifted to look at the 'examples' and 'accounts of variation' to illustrate the range of conversations I considered might fit a characterisation of difficult based on my experience (Hart, 2018, p.210).

Many studies describe 'breaking bad news' as difficult, usually relating to doctors in acute settings, and either concentrated on patients' perspectives or a training evaluation. Breaking bad news also includes transiting patients away from active treatment for non-curable cancer (Pfeil et al., 2015) and informing patients or their families the dying phase is near (Griffiths et al., 2015).[2]

Another frequent example found in the literature was 'Advance Care Planning' (ACP), where a patient and a professional discuss future plans 'In case they lose capacity to make decisions or communicate their wishes in the future' (De Vleminck et al., 2014). Professionals consider ACP conversations difficult due to the disclosure of prognosis or what to expect with disease progression, which is a 'critical juncture upon which all else hangs' (Almack et al., 2012, p.2).

---

[2] The dying phase/actively dying is when an individual's body is shutting down. The time varies between weeks, days or hours.

Like ACP, an additional example was 'goals of care' discussions (a term commonly used in North America). These are about 'Communication and decision making… as a process that occurs between clinicians and a patient (or substitute decision-maker) to establish a plan of care in an institutionalised setting' (You et al., 2015, p.549). Piggott et al. (2019) used something similar, additionally stating that these conversations usually include decisions about life-sustaining therapies such as artificial nutrition and hydration [and] dialysis, as well as Cardiopulmonary Resuscitation (CPR) (p.2).

Recognising conversations can become difficult in other scenarios outside of deteriorating health, I include Bernhardt et al.'s (2010) qualitative study. They describe difficult conversations in their principal question to professionals enquiring after a 'particularly distressing… patient-care related encounter' professionals had had that 'kept them up at night' (p.290). It was not focused on conversations per se but situations and proposed that certain circumstances bring about these situations: differing values between the professional and the patient/family reflected in the decisions made by the patient/family. An example was patients not placing 'The same value on an empowered and equal place for women' where an assertive partner makes decisions creating internal conflict and distress for the professional (p.291). Other circumstances were around dying, lack of respect or adequate support, making an error, when the patient is 'demanding or unlikable', and when there is a sense of 'injustice/inhumanity' such as a lack of services or support for patient/family (Bernhardt et al., 2010, p.293).

Other studies alluded to a definition, such as when they speak of communicating with palliative care staff and dying patients as 'more difficult' and involving 'a complex mix of physical, psychological, social and spiritual issues in the context of impending death' (Slort et

al., 2011, p.167-168). With the topic of terminal cancer, Pfeil et al. (2015) similarly explain how communicating 'The transition from specific anticancer treatment to best supportive care often triggers ethical challenges around whether or how to address death explicitly and implies talking about valuable goals for the last weeks or months of life' (p.1). The authors add that these interactions require 'Dealing with patients' feelings of hopelessness and disappointment' (p.1). Best, Butow and Olver (2016) illustrate "difficult conversations" as subjects of intimacy, although with unnamed subjects. The research focused on how doctors talk about spirituality with patients with cancer, something they reported required themselves to be open, honest and intimate with a patient (p.522).

I sought other studies about professionals' perspectives on challenging communication, expanding my original view past deteriorating health or end-of-life. In the end, definitions were loose and varied in the literature, especially from professionals. However, various examples help give approximate understanding of what professionals consider difficult, suggesting exploring additional communication circumstances may be helpful. Not all studies in this review are about deteriorating health and end-of-life; however, they are examples of challenging conversations. This gap informs my research approach.

Although the research in this review does not explicitly define what constitutes a "difficult conversation", there are studies with varying contexts, and some defining subjects under investigation help narrow down my focus. Next, I will provide more context for the studies and explore two common themes determined by the frequency discussed: barriers and facilitators to difficult conversations.

5. Barriers

This section explores seven key themes from the literature regarding common barriers in conversations that cause them to be considered "difficult". First is emotions, specifically negative ones such as sadness and anger. The second is that professionals want to protect patients. The third is avoiding potential emotional reactions, and the fourth is uncertainties about a diagnosis and/or prognosis and/or treatment options. Fifth is the difficulty for professionals finding the right moment to have the conversation; sixth is a mismatch of expectations between professional and patient. The seventh common barrier is systematic issues within health care. Find the extensive literature signposted in Table 1.

Table 1 Common barriers in conversations

Theme	Authors
Emotions	Piggott et al., 2019; Fulmer et al., 2018; Chandar et al., 2017; Best, Butow and Olver, 2016; Berglund, Nassen, and Gillsjo, 2015; Griffiths et al., 2015; Pfeil et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014; Mellor et al., 2013; Slort et al., 2011; Bernhardt et al., 2010; Panagopoulou, 2008; Selman et al., 2007
Protecting patients	Fulmer et al., 2018; Lazenby et al., 2016; De Vleminck et al., 2014; Mellor et al., 2013; Almack et al., 2012
Avoiding potential reactions	Piggott et al., 2019; Lazenby et al., 2016; Ahluwalia et al., 2013; Almack et al., 2012; Selman et al., 2007
Uncertainties around diagnosis/prognosis/treatment options	Sellars et al., 2017; Lazenby et al., 2016; Griffith et al., 2015; Ahluwalia et al., 2013; Almack et al., 2012; Portnoy et al., 2011; Bernhardt et al., 2010; Selman et al., 2007
Finding the right moment for conversation	Fulmer et al., 2018; Griffith et al., 2015; De Vleminck et al., 2014; Almack et al., 2012
Mismatch of expectations	Pfeil et al., 2015; Prouty et al., 2014; Almack et al., 2012
Systematic issues in health and social care	Piggot et al., 2019; Fulmer et al., 2018; Chandar et al., 2017; Lazenby et al., 2016; Best, Butow and Olver, 2016; Pfeil et al., 2015; You et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014; Mellor et al., 2013; Slort et al., 2011; Brännström, Forssell, and Pettersson, 2011

5.1 Emotions and emotional responses

Difficulties associated with emotions and emotional responses, such as anger, guilt, fear, sadness, stress and embarrassment, stand out in the literature and are generally classified as

"negative emotions" and obstacles to communication. Most of the literature used for this

review mentioned emotions (Piggott et al., 2019; Fulmer et al., 2018; Chandar et al., 2017;

Best, Butow and Olver, 2016; Berglund, Nassen, and Gillsjo, 2015; Griffiths et al., 2015; Pfeil

et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014; Mellor et al., 2013; Slort et al.,

2011; Bernhardt et al., 2010; Panagopoulou, 2008; Selman et al., 2007). When studies did

not mention emotions, it was noticeable. For example, in a survey of acute care nurses and

doctors, You et al. (2015) provided a list of barriers, such as families accepting the patients'

prognoses, language, and limited time. Surprisingly none of the 21 barriers listed included

emotions. Not including emotions is surprising since the authors state, 'Effective

communication skills are needed to navigate these strong feelings, and yet clinicians often

report discomfort in responding to the emotional reactions of patients' (p.544). Although

there are many intervention examples and training, Walczak et al. (2016) suggest the need

for further research 'To better establish the efficacy of interventions and strengthen the

argument for implementation in standard practice' (p.13). Potentially these could be studied

within the HEE's Skills for Care and Skills for Health (2017) framework. Breaking down

emotions and emotional responses further, I found that professionals had two sides: their

views about patients' emotions and their own. Patient's/family's reactions (meaning

demonstrating emotions) or the fear of reactions impact how and if a professional engages

(Best, Butow and Olver, 2016; Griffiths et al., 2015), and professionals label patients/families

as barriers (Piggott et al., 2019; You et al., 2015; Prouty et al., 2014; Mellor et al., 2013; Slort

et al., 2011). For example, in a large qualitative study about cancer care, Prouty et al. (2014)

interpreted focus group discussions about emotions ('grief, fear, discomfort and feeling

overwhelmed') as barriers to communication between professional and patient.

Professionals' responses to these emotions are also 'complex' due to the different individual patient needs (p.1126).

A mixed-methods study with patients and GPs, some with specialised training in palliative care, highlights patients' fear and 'strong emotions' although they are not defined as challenging (Slort et al., 2011, p.171). This study about communication in community palliative care found 'strong demands' from relatives challenging (p.171). The authors do not clarify if this is due to emotional interaction or the expectations themselves. They state the GPs are 'Not able to handle pressure exerted by the patient or relatives' (p. 171). A potential influencing factor in this Netherlands study is euthanasia (purposely ending someone's life due to pain and suffering), which is legal there, with GPs more likely to discuss it than here in the UK. The study expounds on how participants feel they do not have a good understanding of euthanasia and often feel helpless and that they cannot help the patient more or are conflicted with their own beliefs or both (Slort et al., 2011). Working within euthanasia raises ethical challenges for professionals, which may compound conversations.

Best, Butow and Olver (2016) explain how sometimes patients can be 'distressed' in conversations and that some distress '…isn't necessarily bad' (p.524). This qualitative study with doctors talking with patients in the late stages of cancer about spirituality argues that professionals need to be able to deal with distress and not shy away from it.

Patients' anger was another reaction often mentioned, finding it taxing to deal with and seeking to avoid it (Griffith et al., 2015; Bernhardt et al., 2010; Selman et al., 2007). The large qualitative study solely focused on community nurses by Griffiths et al., (2015) highlights other challenging reactions to conversations with individuals near death. It used focus groups to explore nurses' points of view since they often support patients with deterioration and dying at home. The authors found that the participants believed informing the

patient/family when someone's life-limiting illness progresses towards actual death is one of the hardest tasks in providing care at the end-of-life because of the patient's/family's reaction, which they characterised as confusion, lacking awareness, and especially denial of the prognosis and anger (Griffith et al., 2015).

Demonstrating emotions during consultations is not just from the patient/family; professionals can also have emotions that can play a part. In some research, these emotions are mentioned but not explained. For example, two quantitative survey studies report how participants did not engage in ACP conversations due to discomfort; however, the discomfort is not explained further (Fulmer et al., 2018; Chandar et al., 2017). Chandar et al. (2017) reported that many participants (doctors, some nurses and a couple of administrative staff) found either patients or families were uncomfortable having conversations about ACP, and to a lesser degree, uncomfortable for themselves (p.426). However, the study followed a quality improvement scheme on process issues and, therefore, may reflect a 'discomfort' with the system or the process rather than the professionals' ability or comfort levels with the conversation.

The large Fulmer et al. (2018) study found that doctors view end-of-life and ACP conversations as 'important' (p.1203). The authors argue that these conversations are 'critical' and just over half of the participants responded that a barrier to engaging in ACP and end-of-life conversations was 'feeling that the conversation might be uncomfortable' for the patient (p.1204-5). However, the question's phrasing does not distinguish between discomfort for the patient, themselves or both (p.1202). If these doctors were asked about other conversations in practice, conversations they felt crucial, important and perhaps uncomfortable, could it be said that the study may have had differing outcomes?

When studies did explain emotions, they explored how these emotions influence professionals' interactions with patients. A randomised control study with 67 male medical students found that lying to a patient (actor used) to conceal her terminal brain tumour was less stressful than telling her the truth (Panagopoulou, 2008). They found that participants disclosing the information versus just knowing about the diagnosis significantly increased negative mood and anxiety. They attributed this to the participant feeling more in control when concealing the information.

Professionals are concerned about witnessing or thinking about patients' reactions, such as having tears or demonstrating anger, and are concerned that frightening, causing anxiety, or offending the patient can impact a conversation (De Vleminck et al., 2014; Mellor et al., 2013). Professionals also fear being seen as giving up hope or removing patients' hope (Chandar et al., 2017; Pfeil et al., 2015; De Vleminck et al., 2014; Almack et al., 2012; Bernhardt et al., 2010).

A small qualitative study by Pfeil et al. (2015) found that oncology doctors struggle not to let their emotions influence a decision and try to focus on the 'objective medical evidence' (p.2). Through interviews with hospital specialist doctors and nurses, the authors state that doctors find working in a team essential to aid them with 'emotional distance' decision making (p.4).

In some research, professionals voiced feeling frustratingly inadequate or powerless when there truly was little or nothing one could do to help a patient (Sellars et al., 2017; Berglund, Nassen and Gillsjo, 2015; Slort et al., 2011; Bernhardt et al., 2010). The feelings often occurred when there was uncertainty around prognosis or best treatment (Bernhardt et al., 2010). For example, Berglund, Nassen and Gillsjo (2015) aimed to understand caring for older residents living in a care home with chronic musculoskeletal pain. Through interviews, this small qualitative study found that community care professionals (physiotherapists,

nurses and occupational therapists) had 'feelings of frustration, inadequacy, and hopelessness' when other professionals failed to listen and recognise the needs of older adults by considering pain reasonable (p.4). However, the authors also found that participants felt this sense of powerlessness as a job requirement. The article implies that this feeling of commitment or duty of care enables professionals to continue doing their job, even with uncertainty and doubt. Participants described it as 'the essence' of the care, a fundamental element in supporting these patients (p.4). The authors argue that this work 'requires reflection and support' such as supervision and working in teams (p.7). These are not always provided or practised by community care professionals due to the work culture and time limitations due to the workload (Burton and Launer, 2003). I wonder if the sense of commitment/duty of care makes professionals engage with and stay in difficult conversations? If so, does it also generate guilt when a professional avoids a difficult conversation? Also, is there a tension between negative emotions influencing professionals' practice and duty of care? I explore these questions in my research study.

In another example, through phone interviews with doctors, nurses, and counsellors in genetics, Bernhardt et al. (2010) found that professionals were impacted by upsetting interactions with patients/families. The authors explain that when professionals experience distress, it can distract them from care, lead to burnout, a lack of job satisfaction and a sense of 'powerlessness and grief' (p.289).

According to Sellars et al.'s (2017) qualitative study about clinicians' perceptions of ACP in patients with chronic kidney disease, some professionals feel 'professional disempowerment'. The feelings were due to the system, policies and culture not supporting

the execution of ACP and the quandary of having to make decisions at times of uncertainty (p.321).

Mellor et al. (2013) explain how professionals' emotions could influence conversations. Participants of the large qualitative study about 'sexual wellbeing', feared patients' reactions and expressed uncertainty on 'how to deal' with the topic (p.5). Participants gave the rationale for protecting their patients. The next section explores this theme.

5.2 Protecting patients' feelings

In several studies, professionals were trying to protect patients by not engaging in conversations about end-of-life or advance care planning (Fulmer et al., 2018; Lazenby et al., 2016; De Vleminck et al., 2014; Almack et al., 2012) and sexual wellbeing for Mellor et al. (2013). Two qualitative studies found that professionals did not see engagement as their role, assumed patients would not like to discuss the difficult topic or both (Lazenby et al., 2016; Mellor et al., 2013). Both studies also found that participants (nurses and doctors and additionally, in Mellor et al. (2013), therapists, support coordinators and healthcare assistants) were concerned that bringing up the topic would harm patients.

Furthermore, Lazenby et al. (2016) found that even though professionals knew patients were already aware of their deterioration by attending their dialysis and seeing others worsen, they still thought it best for patients not to know about their prognosis. They believed patients would become depressed if they knew. The authors suggest that professionals believed they needed to protect patients' feelings.

 Safeguarding patients' hope by not disclosing is another form of protecting patients (Piggott et al., 2019; Fulmer et al., 2018; Pfeil et al., 2015; Prouty et al., 2014; Almack et al., 2012).

Many professionals struggle with the 'balance' between hope and reality (Prouty et al., 2014, p.1127).

Surveys used in the Fulmer et al. (2018) study asked participants if they discussed as a patient with their own doctor about their own end-of-life care wishes, even though they were not at the end-of-life. Forty-eight per cent had and were more likely to converse with their patients about end-of-life (p.1203).

To protect their patients' feelings, professionals often avoid difficult conversations, but they would also to avoid reactions, which will be shared next.

5.3 Avoiding potential emotional reactions

The anticipation of potential emotional reactions, their own just as much as the other person's in the conversation, influences the professional, so much so that s/he may not even mention the topic, hoping to avoid those potential reactions (Piggott et al., 2019; Lazenby et al., 2016; Pollock and Wilson, 2015; Ahluwalia et al., 2013; Almack et al., 2012; Selman et al., 2007).

Research explains that professionals today are often afraid of patients'/families' negative reactions, just as Oken (section 3.1) found in 1961 when doctors thought it best not to tell patients they had cancer (Mellor et al., 2013). Although the cancer diagnosis may now be disclosed, Pfeil et al. (2015) found oncology doctors would maintain patients' hope instead of engaging in conversations about future goals when encountering patients with 'unrealistic expectations' for their condition (p.2-3).

For patients with incurable end-stage renal disease requiring haemodialysis[3] to keep alive, Lazenby et al. (2016) found that end-of-life conversations were almost non-existent. However, some participants thought planning did take place but informally. These outcomes inspired me to explore avoidance further and ask professionals why they think it happens. I wondered if professionals see patients in the 'sick role' as Parsons (1991) described and see themselves in the role of an expert giving guidance.

Best, Butow and Olver (2016) explained that one doctor shared how avoidance is easier when one does not have time or feels stressed. Although all professionals are responsible for being honest and engaging with patients, studies shared examples of when responsibility was left for another professional to pick up but lacked coordination, leaving it unclear if and when a conversation would happen (Griffiths et al., 2015; Pollock and Wilson, 2015; Bernhardt et al., 2010). A type of "pass the parcel" ensues, but often where there is never an opening of the conversation or if there is, 'A lot of it is too little too late' (Lazenby et al., 2016, p.264).

In a large qualitative study analysing audio-recorded consultations between doctors and patients with heart failure, Ahluwalia et al. (2013) found doctors only hinted at ACP 15 times out of the 71 consultations, and only 11 brought up an actual component of ACP (p.201). The components included describing heart failure, asking about patient's wishes and documenting wishes. The diagnosis is significant as these patients have 'A highly uncertain and variable trajectory, marked by frequent exacerbations and increasingly complex treatment decision-making' (p.200). The authors argue that speaking with these patients about ACP is important but found participants missed opportunities to engage in them,

---

[3] Haemodialysis is a time-intensive process of purifying one's blood when their kidneys do not function correctly.

educate about low success rates and consequences of CPR. Researchers did not ask participants about their reasons; however, they reference other studies suggesting the barriers of uncertainty (discussed next), limited time, and a 'lack of skill and comfort with having the discussion' (p.203).

5.4 Uncertainty of diagnosis/prognosis/treatment options

Professionals' uncertainty or medical uncertainty is a common reason for avoiding difficult conversations (Sellars et al., 2017; Lazenby et al., 2016; Griffith et al., 2015; Pollock and Wilson, 2015; Ahluwalia et al., 2013; Almack et al., 2012; Portnoy et al., 2011; Bernhardt et al., 2010; Selman et al., 2007). Uncertainty was listed as a main barrier in a systematic review about ACP with chronic obstructive pulmonary disease, even though consensus across the studies was that ACP should be done (Meehan et al., 2020). In a systematic review, Oishi and Murtagh (2014) found that 'uncertain and unpredictable illness trajectory' impacts good quality care (p.1092). These could challenge conversations by causing professionals stress or making them feel 'inadequate' for not knowing or doing more (Bernhardt et al., 2010). The more uncertain the situation, the more likely one is to avoid the conversation (Selman et al., 2007).

Prognosis uncertainty impacts what one reveals to patients (Lazenby et al., 2016; Pollock and Wilson, 2015). Lazenby et al., (2016) explain that although the evidence is already available that only half of those on haemodialysis survive after three years of dialysis, professionals are not confident about individual prognosis. They often do not engage in conversations about prognoses or withdrawing treatment, leaving patients unaware of what to expect. Moreover, often patients end up, as participants described, '"Over-dialyzed" [with] prolonged,

potentially unnecessary, treatment… when they have very little quality of life and are no longer aware of their surroundings' (p.264-5).

It is unclear if the struggle with uncertainty is about the professional's ability to cope with it or their perception of patients' reactions to this uncertainty, or both. Using a scale to measure primary care doctors' perceptions of patients' 'Ambiguity Aversion', Portnoy et al. (2011) found that doctors 'Would disclose uncertainty based on their beliefs of patients' reactions (p.363). These reactions were disengagement, fear of the conversations, avoiding deciding on a plan of action, a lack of confidence in treatments and being upset. As a US study, primary care included internists and specialists, with those in general practice more open to sharing the uncertainty. Other influencing factors included gender, race, years of experience and the number of patients seen each week.

5.5 The right moment to have the conversation

Uncertainty is related to knowing when the right time is to engage in a difficult conversation, with some (Griffith et al. 2015; Pollock and Wilson, 2015; Almack et al. 2012) specifically naming prognosis uncertainty (Fulmer et al., 2018; De Vleminck et al., 2014). Fulmer et al. (2018) reported that 60% of the doctors surveyed said they find it challenging to know when the right moment is to engage patients in conversations that can become difficult because they fear they will remove the patient's hope (p.1204).

Community nurses struggled to find the right moment to break the news of impending death, even when all agreed it was much better to have conversations to help the person prepare. Participants voiced concerns about bringing it up too early, saying it could disrupt the feeling of normalcy for the patient and family. They also voiced concerns they may not be allowed back into the patient's home, which they had witnessed before (p.142).

De Vleminck et al. 's (2014) qualitative study used focus groups to explore GPs' perceptions about engaging in ACP conversations and found they did not know when to discuss ACP with dementia or heart failure patients. The authors illustrate GPs' gaps in knowledge about the two disease trajectories: not recognising these patients as end-of-life (p.4). If professionals are not clear that someone is at the end-of-life, they are unaware they should be finding the right moment. Interestingly, during the focus group, some participants questioned their responsibility in having ACP discussions with these patients. They stated it is much clearer for those with cancer because the public knows it is a terminal diagnosis without treatment and even sometimes with treatment making it easier for the professional. This raises the question for further exploration of whether these uncertainty concerns and patients giving up hope have more to do with professionals avoiding potential emotions, or could it again be seeing patients in the 'sick role'?

5.6 A mismatch between patients' and professionals' expectations

Patients'/families' expectations often do not match professionals' expectations (Pfeil et al., 2015; Prouty et al., 2014; Almack et al., 2012). From interviews, Almack et al. (2012) found a misalliance regarding who introduces future planning conversations. Patients in the study expected professionals would, if necessary, while the professionals would wait either for the patient to bring it up or until it was obvious the patient was actively dying. When patients brought up the topic, it was much easier for the professionals. Interestingly, the authors defined all the study's patients as being in their last year of life, yet only five out of 18 had conversations about their wishes and preferences for end-of-life care. The authors speculated that avoidance occurred due to uncertainty of the prognosis, patient or family not being willing to discuss it, the patient being unaware or in denial about progression, or

believing they would remove hope from the patient, which could depress the patient and cause harm.

Another example found that professionals appear to blame patients when communication fails (Prouty et al., 2014). This study held nine focus groups with mixed primary and secondary care professionals, predominately doctors and nurses, asking about communication failures. Participants shared that this mismatch often resulted from patients' expectations being at odds with reality or with what professionals can provide. The information patients share can often be mistaken or lacking as they did not want to displease or alienate the professional.

These studies produced more questions for me. Do other disciplines feel the same about the mismatch of expectations, and does it link these barriers to communication? Can there be a resolution concerning the mismatch between the patient and the professional by clarifying expectations?

5.7 Health care system issues

Many articles reviewed identified health care system issues that presented barriers for professionals to discuss deteriorating health and end-of-life care. Two main issues were professionals not having enough time and the lack of continuity of care due to poor coordination between professionals.

Earlier time was shown as a process: knowing when to engage in a conversation. Here we look at time as a resource. A systematic issue listed most frequently and a common thread amongst most of the literature was time; professionals lacked the time or had time pressures with patients or both, and often this was the reason given as to why one did not have a difficult conversation (Meehan et al., 2020; Piggot et al., 2019; Fulmer et al., 2018; Chandar

et al., 2017; Best, Butow and Olver, 2016; You et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014; Mellor et al., 2013; Brännström, Forssell and Pettersson, 2011; Slort et al., 2011). As one participant explained in the Prouty et al. (2014) study, 'You're on a gerbil wheel, and in order to make your salary you've got to see so many people… it isn't a matter of greed. It's a matter of how am I going to get through the day?' (p.1127).

Professionals face difficulty finding 'enough time' to deliver care for those with palliative needs (Slort et al., 2011, p.170). Due to the emotions involved in the conversations, professionals may need time to work through the information and support patients/families; however, time may be a luxury.

Prouty et al. (2014), Piggott et al. (2019) and Fulmer et al. (2018) identify financial implications for taking more time. Professionals recommend improving communication in cancer care by permitting more time for communication with patients and to 'compensate' for that time (Prouty et al., 2014, p.1128). Piggott et al. (2019) argue that although conversations about goals of care equate to lower costs and better quality of life for patients, they also found 'one of the more important' systematic barriers according to the participating doctors and nurses is the scarcity of time (p.5). Fulmer et al. (2018) found that although 99% of the doctors in a survey study valued ACP discussions, most do not have them due to the lack of time. Participants (95%) favoured the new payment opportunity for doctors to engage in these discussions, connecting the issue of time with payment. Interestingly, however, few in the study bill for these, even though most doctors agreed reimbursement should be made.

In the UK, similarly, GPs have argued for increased incentives to allow them more time with patients requiring these types of conversations. As of 2019-2020, the Quality and Outcomes

Framework (QOF), a voluntary incentive programme for GP surgeries, increased incentives significantly for demonstrating quality care for those patients facing life-limiting illnesses and end-of-life care, including time for discussions and planning (Primary Care Strategy and NHS Contracts Group, 2019; Royal College of General Practitioners and Marie Curie, 2019). The systematic problem of not having enough time may relate directly to costs or perhaps the commodity of care, where professionals need to be paid extra in exchange for the product of an ACP.

Other systematic issues emerged from the literature review that can be 'common and complex' (Prouty et al., 2014, p.1128), such as 'continuity of care' (Slort et al., 2011, p.170) and information exchange between professionals - often due to limited time (Prouty et al., 2014; Brännström, Forssell and Pettersson, 2011). The multi-professional approach to care lacks a formalised direction on responsibility, which can lead to ambiguity about which professional should take responsibility for giving sensitive information to patients (Meehan et al., 2020; Chandar et al., 2017; Lazenby et al., 2016; Pfeil et al., 2015; Pollock and Wilson, 2015; You et al., 2015). A study with 15 doctors specialising in heart failure there were different views on whether primary or secondary care should have overall patient responsibility (Brännström, Forssell and Pettersson, 2011). The differences related to doctors not knowing an individual's disease trajectory, when treatment should change to palliative care and reluctance to refer too early. Doctors recognised the need for improved communication and follow-up.

These issues develop into fragmented care (De Vlemick et al., 2014; Slort et al., 2011). A survey found acute nurses' responses stood out from doctors that having multiple doctors involved with patients was a barrier to difficult conversations (You et al., 2015).

Chandar et al.'s (2017) quantitative study found varying responses between specialist and primary care on who should have ACP with patients. Pairing this study with the De Vleminck et al. (2014) qualitative study on barriers to ACP discussions helps give a better understanding. They found that GP participants complained about a disconnect in the form of poor information exchange between hospital consultants and community professionals. GPs said that consultants, especially oncologists, were pursuing 'curative treatments' when it was clear the patient was getting worse (p.7). The findings match what Pfeil et al. (2015) found: that some oncologists take on 'a passive role' and do not take responsibility for speaking with patients about end-of-life (p.3).

Two studies explain how some professionals do not take ownership of ensuring the patient is aware and feel 'others' are responsible (Chandar et al., 2017; Lazenby et al., 2016, p.266). Chandar et al. (2017) found that professionals' disease specialism was a factor in their responsibility to engage patients in ACP conversations. As there is no set directive of responsibility for disclosure, 85% of the cardiologists in the study did not think they were responsible for having them; as opposed to most of the oncologists where over 80% did take on the responsibility. Primary care doctors felt a stronger responsibility for those with heart failure than cancer and thought the oncologist should have conversations with cancer patients. The position of primary care is important since, at end-of-life, more people prefer to die at home instead of in a hospital (Oishi and Murtagh, 2014).

A couple of participants from Pfeil et al.'s (2015) study believed their role was to cure patients; otherwise, as one participant stated, '"…When I have to tell the patient they will soon die… this is, in a way, already my closure of the relationship with this patient. From this moment on, the patient is basically already dead"' (p.3). However, the study also found that some participants took 'a proactive role' and prepared patients for end-of-life because they

believed it was a duty to have 'honest disclosure' to reduce 'unrealistic expectations' and 'empower patients' (p.3).

In the various trainings I provided for multi-professionals from both community and acute settings, I would ask learners, 'Who should be responsible for difficult conversations?' There was a commonality with professionals thinking it was someone else's role to have them. So, whose job, is it? This debate and the ambiguity of whose role it is to initiate these conversations is a common theme from the literature reinforcing my perception regarding professionals seeing other professionals as responsible. It surprises me that there is also a strong distinction in attitude between the same profession in acute and professional settings. A problem here is to assume the challenging conversation is just a one-off conversation with one person instead of the many conversations with various primary and secondary care professionals, as it is more of a journey for the patient (Sellars et al., 2017; Griffiths et al., 2015).

6. Facilitators to conversations

The literature also identified positives for conversation facilitators. For example, preparation and planning can help, including discussing the future sooner to plan more effectively (Lazenby et al., 2016; Griffiths et al., 2015; Almack et al., 2012; Selman et al., 2007). Other facilitators are listening well (Best, Butow and Olver, 2016; Slort et al., 2011) and demonstrating respect, dignity, empathy and honesty (Slort et al., 2011). The importance of trust and established relationships are prominent in the literature as they can help when difficult topics need to be discussed (Owens et al., 2017; Best, Butow and Olver, 2016; Berglund, Nassen and Gillsjo, 2015; Slort et al., 2011). There is a recognition that these characteristics fall short within education (Best, Butow and Olver, 2016). However, Pollock

and Wilson, (2015) found mixed results with some professionals thinking trusted relationships make conversations more challenging.

For example, Owens et al. (2017) interviewed and held discussions with mixed primary care professionals who help patients with Parkinson's disease or diabetes to help themselves. The authors claim their research is the only study to have investigated defining success in self-management; interestingly, they did not seek patients' definitions. The study looks at professionals' perspectives, and although the focus does not exactly fit my definition of difficult conversations, it raises issues about what others may consider difficult and helps expand my starting definition. The findings emphasise building trusting relationships and identified themes for successful relationships to be engaged from both patient and professional, with professionals being accessible and facilitating openness to other professionals, and ongoing support by being there when needed (Owens et al., 2017).

In another example within Western healthcare Berglund, Nassen and Gillsjo (2015) emphasised professionals struggle to focus on more than the disease or problem at hand and consider the patient holistically. The authors explain that achieving this occurs with a sense of dedication to deliver good care, done by developing respectful relationships with patients through trust and having the 'courage' to stick with the issues at hand, even if one is faced with mixed emotions, feeling uncertain and powerless (p.6). Almack et al. (2012) found that when ACP conversations went well, the relationship was the main component that helped lead to open and ongoing conversations.

Studies also made recommendations. Best, Butow and Olver (2016) advocate creating safety for sharing and paying attention to body language. Slort et al. (2011) suggest that professionals anticipate patients' needs, speak without medical jargon, be willing to start

conversations, provide reassurances to patients/families and develop a relationship with the patient. Prouty et al. (2014) suggest using enquiry to learn patient expectations and understand what the patient knows and wants to know.

There were also system-wide recommendations, such as increasing time with the patient (Prouty et al., 2014; Slort et al., 2011). However, the benefit may be only for the patient; as the Fulmer et al. (2018) study shared, participants felt having end-of-life discussions were more difficult 'than rewarding' (p.1204). Fulmer et al.'s (2018) recommend supportive systems, training for professionals and payment for having these difficult conversations (p.1205). Unfortunately, the study did not compare other studies or provide supporting evidence that would have made a more persuasive argument.

Other recommendations to facilitate conversations included continuity of care and interdisciplinary working (Best, Butow and Olver, 2016; Prouty et al., 2014; Slort et al., 2011), making home visits more accessible (Slort et al., 2011), establishing a care pathway, interprofessional training (Selman et al., 2007) and obtaining and learning from feedback (Prouty et al., 2014). Berglund, Nassen and Gillsjo (2015) proposed that having courage is not just helpful but is required for professionals to 'remain in the encounter despite feelings of insecurity and uncertainty' (p.1).

Understanding how professionals perceive and experience difficult conversations and what helps make them easier may support job satisfaction, build resilience and help improve recommendations for approaches and effective interventions. Knowing if the same approaches apply across professional disciplines would be useful.

7. Summary

For this review, I looked to the literature to test my definition and interpretation of difficult conversations, challenge my assumptions and give me a broader perspective on the issues that may impact conversations, making them difficult. This chapter provided a literature review on professionals' recognitions and perspectives to help explain what is known about why conversations can be difficult and what can facilitate them, which helped confirm yet also expand my understanding.

However, there are gaps in the literature about the professional's perspective, including the types of conversations they consider difficult, their feelings and understandings of them, and how they perceive difficulties emerging in practice around deteriorating health and end-of-life. As one study put it, 'Probably because this is a difficult issue to research, there has been little evidence about this crucial aspect of practice' (Almack et al., 2012, p.2).

Reviewing this literature helped me refine my research objectives to explore **how professionals (community nurses, GPS and physiotherapists, hereafter 'professionals') define and characterise conversations as difficult around deteriorating health and end-of-life; and their (professionals') perceptions of what makes conversations difficult, including how they interact with patients/families during these conversations; and any differences between the professional groups**. Although I started with deteriorating health and end-of-life, the literature review revealed other circumstances where professionals see communication as difficult. This learning expanded the research to include questions to professionals about what circumstances for them proved challenging. The review also identified and related the question of how conversations occur from professionals' perceptions of how they interact

with patients during a difficult conversation and **any differences between different**

disciplines.

The following chapter explains how I will answer these questions, using qualitative methods grounded in interpretivism. It discusses the methodological approach, the research design, and the methods used for data collection, data analysis and ethics.

Chapter 3: Methodology

1. Introduction

In the previous chapter, I reviewed the literature on how professionals view conversations that become difficult and what influences their practice in having them. The review enabled me to refine my research focus.

 In this chapter, I explain the epistemological and theoretical approach used for the research. The first part of this chapter comprises interpretivism's methodological approach. Next, it details the grounded theory approach used for data collection and analysis, and the grounded theory methods employed. Then the chapter covers how I used reflexivity and ends with the ethical considerations.

2. Methodological approach

Initially, when I began this research journey as an insider researcher, I had aimed to evaluate the experiential, multi-professional education training titled Difficult Conversations and its impact on professional practice. I was interested in not just knowing the effectiveness of the training but how it was working, and what made a difference or not in its effectiveness (Robson, 2011). By understanding, I could then look to improve the training. However, I came to realise that the types of questions bubbling to the surface were about 'how' and 'why', which required a different approach (Ormston et al., 2014, p.3). Questions such as 'How do professionals categorise a conversation as difficult?' or 'Why are certain conversations so challenging?' and 'How are emotions involved?' were grounded in a desire to understand individuals' perspectives and actions. A more iterative approach was needed

which would allow me to constantly reorient the research as a I progressed, more in line with a grounded theory methodological approach (Polkinghorne, 2005).

This process was itself iterative. A great deal has been written about emotions, especially patients' emotions, which motivated my initial research and influenced these questions of how they fit into the process of these conversations. This eventually suggested a more exploratory approach, more suited to grounded theory (Corbin and Strauss 2015; 1990), rather than the evaluative aim I had initially imagined. I changed the study to address these questions, to more deeply explore professionals' perspectives and thus evaluate how the workshops influenced their practice.

The working definition of "difficult conversations" I employed was talks or discussions where participants feel it to be hard, usually uncomfortable and challenging, needing extra effort and skill to navigate through them. In other words, it is when a conversation is about a topic that is tough to bring up or engage in based on the emotional content. I used this definition for context in the Information Sheet (Appendix C).

While conducting the research, I recognised a struggle between exploring and evaluating, and I kept reminding myself to stay in an explorative frame of mind. With eyes wide open, I wanted to step back, explore how and why professionals do what they do in real-life practice, and understand more about where they are coming from, what helps them and what gets in their way. In doing this, I made a point to tell participants at the start that although the study context was deteriorating health and end-of-life, I wanted to hear what they considered difficult, whatever that may be in practice.

After all the initial set of interviews were complete with the analysis continuing, I discussed with my supervisor the tension between explorative and evaluative and decided to focus on

the emergent themes, which were explorative and thus required a more iterative

methodological approach, such as grounded theory (Polkinghorne, 2005), and to leave out

the evaluative piece of the research initially planned for this thesis.

Learning perceptions and understandings drew me to an in-depth approach using qualitative

research because it emphasises how people make meaning of the world (Robson, 2011). It

does not mean I did not have my hunches and assumptions about these questions, especially

as an insider researcher. My practice of 'noticing' gave me insight whilst running

communication workshops for professionals (Mason, 2002). For example, I had observed

that professionals often considered difficult conversations with a patient/family in the

patient's last days of life uncomfortable. I also expected professionals to deflect

responsibility for having these conversations because the guidance is not clear on when and

how to engage in conversations about deteriorating health and end-of-life and professionals

often do not get enough training to do them well (Fulmer et al., 2018). I also found

professionals genuinely thought it was someone else's role because when it is everyone's

responsibility to engage in these conversations, often no-one then takes responsibility. I did

not let these assumptions cloud my judgment and managed them using reflexivity, which is

discussed further in this chapter. I also chose qualitative research for its flexibility with the

design; it encourages exploration and recognises the role research can play (Schwartz-Shea

and Yanow, 2012, p.26). As an insider researcher who worked in the organisation providing

the training (organised and taught), this last point was important to consider because insider

knowledge can be beneficial in understanding, but it comes with bias that must be addressed

and interrogated (Mason, 2002). This qualitative research uses the epistemology approach

of interpretivism. There is not just one reality, and the world around us can be best

explained by those living in it (Ormston et al., 2014, p.5).

2.1 Interpretivism

An interpretive view is a well-suited approach for my research as it sheds light on individuals and their experiences. It gives those living in the phenomenon, in this case, both the participants and me as the researcher, a voice and influence, because the data collected informs the design (Schwartz-Shea and Yanow, 2012; Ormston et al., 2014). I will look at insider bias and insights gained from reflexivity.

The interpretivist view recognises 'there are multiple truths' (Evans and Hardy, 2010, p.26), and it stresses the importance of 'entering research participants' worlds' (Charmaz, 2006, p.19). By entering their worlds, one is listening and observing, but also engaging and questioning, trying to understand. Ormston et al. (2014) explained how Max Weber suggested that individuals have their own interpretation of the world around them (p.12-13). As each person is unique, so are her/his views, experiences and perceptions, which define her/his truths. Weber also believed that understanding these interpretations can come from observing and/or explaining (p.12-13). To interpret what is happening to these individuals, the key is to respect everyone's uniqueness (Charmaz, 2006). As Charmaz states:

> We demonstrate our respect by making concerted efforts to learn about their views and actions and to try to understand their lives from their perspectives. This approach means we must test our assumptions about the worlds we study, not unwittingly reproduce these assumptions (2006, p.19).

Although there are individual interpretations, there are commonalities within the uniqueness, making it important to balance the two. Pulling these unique experiences together makes up 'multiple realities' (Charmaz, 2006, p.126). I am interested in exploring these multiple realities and understanding individual perspectives, beliefs and actions in

practice. With understanding comes ideas for recommendations and support for others, future training and potentially tools or techniques to use in practice, all with the belief that difficult conversations should be had in practice and not avoided. The current healthcare culture in the United Kingdom believes that people have a right to know the truth if they want to know it and be partners in their care to decide what they will or will not receive. Interpretivism shaped my research design; the step-by-step procedure for carrying out the study helped ensure meaningful outcomes and tie back to the original research aims and objectives (Yin, 2018; Lewis and McNaughton, 2014). I used the interpretive methodology to understand the various realities of professionals.

As a result of this process during the initial stages of the research, I used a grounded theory approach as a strategy, with Corbin and Strauss's (2015; 1990; Charmaz, 2006) interpretation. Grounded theory allowed me to use my creativity as well as my 'tacit knowledge' which was useful since my initial exploration showed me that there was more to the issue of difficult conversations, but I wasn't sure what (Cutcliffe, 2000). I therefore needed to allow themes to emerge freely rather than make assumptions that were then tested.

It was the most appropriate approach because the process of grounded theory supports the examination of 'topics and related behaviours from many different angles-thus developing comprehensive explanations' and with new theories developed, offers 'a strong foundation for further studies using qualitative measures' (Corbin and Strauss, 2015, p.11). In addition, it offers clear procedures to follow that are systematic yet flexible which was helpful for me as a novice researcher (Robson, 2011).

2.2 My research design and approach

This research's question was to explore the individual realities of how professionals define and characterise conversations as difficult around deteriorating health and end-of-life. Objectives draw out more specifically what is being 'examined within the scope of the study' (Yin, 2018, p.27). In seeking to answer this question, the study's objectives were to:

- Explore the individual realities of how professionals define and characterise conversations as difficult;

- Explore their (professionals) perceptions of what makes conversations difficult;

- Examine professionals' perceptions of how they interact with patients during these difficult conversations; and

- Explore any differences between the professional groups in having difficult conversations.

My sample strategy at first was purposive and then moved into grounded theory's school of thought around theoretical sampling, which uses data to help drive what and where to collect next, having the emerging theory be the guide (Cutcliffe, 2000; Glasser and Strauss, 1967, p.45). So as I collected the data and analysed it, I produced 'concepts', that then 'generate questions', which led me to sample further for 'more data collection', which developed the concepts further (Corbin and Strauss, 2015, p.135). This iterative process continued on with the aim to develop concepts until the point of theoretical saturation – when there is nothing new to learn about those concepts (Corbin and Strauss, 2015).

Participants in this study were all community healthcare professionals (hereafter: professionals) sharing similar experiences of needing to have (as part of the professional role) and having had themselves, conversations with patients/families around deteriorating health

and end-of-life (Lewis and McNaughton, 2014). Selecting such professionals was intentional with the focus on front-line generalists in primary care who do not have specialist training and experience in conducting end-of-life conversations.

There were limitations due to the small size and restrictions on who and from where I could recruit. Due to the limit of access and time, I did as Corbin and Strauss (2015) recommended; I took a practical approach and looked to those accessible and near me.

Over seventeen months, I recruited participants by convenience upon attendance to already running half-day, multiprofessional, experiential workshops/training titled Difficult Conversations that I helped run. The workshops were aimed at community healthcare professionals to improve communication around deteriorating health and end-of-life. The general attendance for these workshops was 10-25 people from different work environments. If individuals registered in advance, they received an email from the administrator informing them that I was recruiting volunteers for this research with an attached information sheet (see Appendix C). Participants were approached at registration on the workshop day and asked to participate in the research. Workshop facilitators also verbally promoted the research before starting the session. My role was as the researcher. I did not teach these workshops, nor did I stay to observe them. All participants were most likely already thinking about this topic and may have had some interest in it. Volunteering to participate in the research allowed them to share their stories, thoughts and experiences around this topic. I recruited thirteen professionals, five General Practitioners (GPs), four physiotherapists and four nurses, from different work settings in London, except for the physiotherapists, who all worked in the same environment. All but one of the participants were female.

Participants had varying experience levels, and they all agreed they had had challenging conversations with the people they provide care for and/or their families. Participants permitted using their pre-and post-surveys, the same ones used internally by the social enterprise for evaluation given to all workshop attendees by the facilitator and to partake in interviews.

A major drawback of qualitative research is that generalisability is limited, and researchers have different views about even the ability to generalise. Some say one cannot statistically generalise when the numbers are too small to be statistically significant or have any statistical importance; however, qualitative research is not meant to be representative of, or generalisable to, a population (Corbin and Strauss, 2015). As Schwartz-Shea and Yanow (2012) wrote, 'interpretive research focuses on context-specific meanings, rather than seeking generalised meaning abstracted from particular contexts' (p.23). Like most researchers, I do want to generalise in some way. Robson explains how researchers can generalise:

> In the form of a theoretical conceptualisation of what they have found… Or in realist terms, that they have evidence for mechanisms operating in certain contexts. Or, in very general terms, that the findings from the study somehow 'speak' to what might be happening in other settings or cases (Robson, 2011, p.152).

For example, the outcomes of this research can be relevant to other professionals who have similar conversations; therefore, as Robson (2011) explains, I can use an analogy to generalise. Reliability such as having the study replicated with the same results is another drawback of qualitative research; detailed notes, or what Robson (2011) calls an 'audit trail', gave me the ability to demonstrate results and how I came upon them (p.159). Although

repetition may not be exact, detailed design documentation, in principle, can aid in replication attempts (Yin, 2018).

3. Data collection methods

Choosing to use a grounded theory approach encouraged the focus to be on gathering detailed data that could 'shape and reshape' the data collection (Charmaz, 2006, p.15). The gathering approach was semi-structured, which entailed both theoretical assumptions and emerging knowledge. I collected rich information from numerous viewpoints of different professionals with the aim to investigate multiple perspectives through multiple sources and with multiple methods for collecting data (Lewis and McNaughton, 2014, p.66). These sources and methods facilitated the collection of in-depth and valuable information.

The primary data collection methods were interviews (at two different points in time with the same individuals to establish trust between interviewer and participant and encourage, then share, further reflections to learn new concepts), my research diary and field notes; however, I also collected surveys. I found the process of recruitment challenged by the surveys. Participants were more likely to engage in the research once they could meet me and briefly discuss the study; however, participants often joined and gave consent to the study after completing the survey. I also experienced attendees consenting to the research but not scheduling an interview.

After collecting four surveys, two with interviews and two without, I discussed the issue with my supervisor. Since I expanded on many of the survey questions in the interview, I agreed that the survey data added little to the data gathered. I removed the two participants who did not agree to an interview date and focused less on obtaining consent before completing

the survey. The survey collection continued to see if there were differences, but in the end, only verbal interviews were used in this thesis.

With the interviewees' permission, the interviews were digitally recorded and then transcribed for analysis. I also took field notes by hand as a backup. I wrote down what I was hearing, such as how one spoke with the tone of voice and pauses, my interpretations of what was said, and my thoughts, ideas, experiences, perceptions and reactions to the data. Coinciding with these notes, I wrote my reflections - including my use of reflexivity in practice, emotions and initial indexing ideas in my digital research diary throughout the research process. They were captured as further data and used to examine how I may have influenced the findings and analysis.

Other methods were considered, such as observing participants during a difficult conversation and interviewing patients/families who experienced a difficult conversation. These conversations are often hard to predict for community professionals, coordination at multiple sites and gaining consent from both patient and professional would have been challenging. The sensitive nature of these conversations also posed an ethical issue of intruding into these conversations. I looked at other ways to investigate and decided on interviews as the least intrusive.

3.1 Individual interviews

I chose interviews because they provide a wealth of information (Robson, 2011) by exploring the 'how' and 'why' which supports the iterative process (Polkinghorne, 2005). Interviews are a 'core' and 'effective' method of data collection because they offer windows into participants' worlds and provide a platform for them to share their understanding of their world (Lewis and McNaughton, 2014, p.55; Charmaz, 2006, p.25). Yin (2018) described

interviews as being helpful 'By suggesting explanations (i.e., the 'how's' and the 'why's') of key events, as well as the insights reflecting participants' relativist perspectives' (p.118). Interviews aim to get the interviewee talking. The interviewer's role is 'to listen, to observe with sensitivity, and to encourage the person to respond' (Charmaz, 2006, p.25-26). Additionally, interviews provide ease of use, making them practical.

To achieve the extensive depth qualitative research strives for, I used semi-structured (partly formatted, partly open-ended) interviews. They were 'Open-ended yet directed, shaped yet emergent and paced yet unrestricted' (Charmaz, 2006, p.28). I provided some structure by designing a 'set of questions asked sequentially' to help prompt, guide and keep on topic; however, these questions were open-ended and flexible, 'Designed to explore the views of the interviewee in detail' (Seale, 2004, p.165). Both my insider knowledge and existing literature informed the topics. For example, since existing literature referred to conversations as difficult and gave examples but no explicit definitions, I made sure to ask participants about what "difficult conversations" meant to them.

Another example is barriers and how the review and my experience have informed me that emotions play a large role. Therefore, I asked participants to tell me about difficult conversations they have had in practice, first to see if emotions come up on their own, and then I probed, asking about emotions they may elicit. For all topics covered, see Appendix D. However, being aware that my preconceived beliefs and ideas would influence me, I wanted to have an open mind. After crafting the initial interview schedule, I consulted with expert colleagues and my supervisor. They suggested I add more probing questions within questions, such as asking for types and characteristics of conversations. They also suggested

I ask for examples to help participants think more deeply and to improve the flow. I adapted the schedule based on their feedback.

Participants were interviewed at two different points in time, with the second point continuing the first conversation so to gain more detailed information, driving the discovering of new concepts for theoretical sampling. I considered the interview incomplete until after the second interview point occurred, which informed my sampling. The initial interviews were 1 to 7 days after an education workshop about difficult conversations that highlighted conversations around the deterioration of health and end-of-life (June 2016 and July 2017). Recognising the topic's sensitive nature, I used the initial interviews to learn more about participants' thoughts and impressions about conversations they characterise as difficult in practice (definition, approach, struggles) and to develop a trusting relationship. During the second interview point conducted three months after the first (September 2017 to October 2017) with the same participants, I built on the trust and encouraged participants to think more concretely to help gain a shared understanding. The timing of when I could recruit new participants again was after the completion of the second interviews, but the concepts became themes with depth and clarity, reaching saturation (Corbin and Strauss, 2015). Knowing these professionals were busy, I was concerned about having enough time with them, so I enquired with colleagues (GPs and nurses) about what they would prefer if it were them. They said it would be easier to give two separate interviews than one long one. The purpose of the two interview points was not to compare and contrast; however, I noticed differences between some people/groups, so occasionally one of my findings will be about these differences. I took advantage of engaging with them at the second point to ask about other topics that came up from other participants and to have the individual expand on

topics from their first interview. For example, I followed a pattern from the first interview about personal fear, leading me to pose a question about how participants handled "frightening" conversations in the second interview.

I left the option open to each participant to have the interviews in person or over the phone, knowing each has pros and cons. Trying to be flexible, I offered to go to the participant's preferred location. The face-to-face option was often a deterrent, and I found individuals giving reasons why they could not participate. Many stated it was too complicated to arrange a quiet meeting space and did not want to travel to meet elsewhere. In the end, all preferred the phone option. The pros to having the interviews over the phone were convenience, requiring less time from the professional and travel for myself. I was less likely to influence the interview as the participant could not see my face and body language (Robson, 2011). The disadvantages of the phone interviews were the inability to witness the participant's body language and/or cues, and the interviews tended to be shorter as participants often ended them sooner than those conducted in person (Seale, 2004).

I used a grounded theory approach to collect and analyse the data (see section 4 of this chapter). In line with the approach, I analysed data alongside interviewing and adapted interview questions and subsequent interviews in response to emerging themes as the study progressed. For example, I discovered in one interview that an individual hinted at how patients with poor care complaints can be more challenging. I wondered if this might be the case for other professionals, and could this be a barrier for engagement in these conversations? I considered the limits of maintaining confidentially for participants if they shared information that raised regulatory issues and recognised my ethical obligation. In subsequent interviews, I enquired if conversations with patients with complaints about poor

care differed from other types of difficult conversations. On reflection, I found this process challenging and discussed approaches to interviewing with my supervisor.

Pre-written questions gave me the feeling of safety but left me with more unasked and unanswered questions and disappointment with the interview. I reflected, questioned the quality of the information I received and re-evaluated my strategy (Robson, 2011, p.154). Once I received feedback on this interview, it was as if I was permitted to go off the prescribed route. The subsequent interviews were much richer and more interesting. A reflection documented after making the change:

> My biggest learning from today is that the interviews seem to be going longer now. I think this has to do with the improvement of the interview schedule, as there are more probing questions that have gotten participants to think through more. I think it is also due to the fact that I am getting better [at interviewing]. With that feedback [from my supervisor], I feel I have been given permission to explore more with someone if they bring up a point that is of interest to me. Before I was trying to stick to the script and let them speak, it didn't allow me to probe as much as I could have, and I don't think it was as rich of an interview. No one has complained about the length so far (Diary, 17.5.2017).

One of the advantages of the qualitative approach is that it allowed me the flexibility to adapt and change the questions I was asking. Next, I will clarify how I applied a grounded theory approach to the analysis.

4. Data Analysis

Grounded theory recognises that the researcher plays a part in research. Pre-existent theories were not tested; the data produced new understandings and theories. However, I was not starting from zero because there is no zero. As an insider researcher, I bring my thoughts and experiences which guide me, but I also recognise they influence the research. As Charmaz (2006) states, 'No researcher is neutral because language confers form and meaning on observed realities' (p.46-47).

Data analysis using a grounded theory approach allows analysis to begin as data is collected and is ongoing throughout the study, enabling constant comparisons (Corbin and Strauss, 2015). The process is not about having preconceived answers but being open-minded, learning from the experience and collecting data. I was keen to learn from experience and adopt a practical approach. Evans and Hardy (2010) wrote, 'Knowledge is not waiting to be discovered but created through experience' (p.27). Although the encouragement is for researchers to be open-minded, there is still the need to be sensible and practical; 'There is a difference between an open mind and empty head' (Dey, 1993, p.65). As for being practical, Ormston et al. (2014) explained how William James and George Herbert Mead, 'argue for pragmatism – choosing the approach that best fits the specific research question' (p.20). Others agree that a pragmatic approach is more realistic to implement and more manageable to conduct (Corbin and Strauss, 2015; Charmaz, 2006; Seale, 2004).

Comparisons begin when data collection begins. It continues throughout the study with a constant endeavour between the here and now, concentrating on what is happening while collecting data and comparing with other data (Corbin and Strauss, 1990). Almost naturally, the mind continually verifies information, questions verbal cues or tone of voice, compares

what one knows or feels and makes judgments and/or choices and decisions. During the semi-structured interview, this endeavour occurred for me, giving great importance to capturing as much as possible in my research diary. These comparisons influenced the interview's progression, were written in my research diary and were reflected on afterwards to be clear on how this process influenced the study, helping to keep my biases and preconceived ideas in check. Other times comparing data occurs more formally after the interaction. Again, sometimes the process is natural and obvious, but the process often requires much thought which can be strenuous. In the end, the consistency is this back-and-forth movement. Strauss and Corbin (1998) said it best when they appeal to researchers:

> To question, to be able to easily move from what they see and hear and to raise that to the level of the abstract, and then to turn around again and move back to the data level. We want them to learn to think comparatively and in terms of properties and dimensions so that they can easily see what is the same and what is different (p.8).

Additionally to these levels of abstract and data, one must be 'systematic' yet also 'creative' (p.13). As one is about following the order and being methodical, the other is about following the imagination and being inventive, and these binary opposites are the essence of a grounded theory approach.

As I gathered data throughout this study questions were asked and comparisons were made (Strauss and Corbin, 1998). It was an ongoing process, not the type of study that waited until the end of data collection to maintain order and control (Edwards and Talbot, 1999, p.120). Just as Corbin and Strauss (1990) recommended analysing 'the first bits of data for cues', I analysed the first recruitment interaction and interview (p.6). I repeated this with each encounter and interview with participants. I adapted my approach for subsequent

interviews; for example, I allowed myself to ask questions that came to mind during the interview, rewarding me with richer answers and dialogue. Through coding, comparisons were made, which often sparked curiosity and led in those curious directions as the research took place and created concepts and, thus, categories (Corbin and Strauss, 1990, p.7). The immediate analysis was complicated, and the time requirement was extensive for the coding process due to multiple interviews so close to each other. Once data stopped providing much additional value to the categories, it suggested the sample was saturated, and no more data was collected (Seale, 2004, p.242). Although the basis of analysis uses grounded theory principles of coding and categorising, the approach was practical and feasible, using 'proformas' per research participant (Edwards and Talbot 1999, p.125). Reflexive notes were also analysed throughout the research by categorising and sorting.

The analysis also included looking at literature as 'Undoubtedly the academic literature may prove one of the most useful sources of analytic strategy' (Dey, 1993, p.69). Reading what others have discovered, explained or even discredited planted new ideas and curiosities to explore in my data. Also, other researchers conducted their studies provided examples to consider to, 'identify some questions or even some hypotheses which can be explored through our analysis' (Dey, 1993, p.70).

The steps involved in the coding process started with the recorded interviews themselves. During the interviews I took notes, and then after the interview I wrote reflective notes in my research diary. Before transcribing the interviews, a quick data comparison took place, which influenced the next interview. The recorded interviews were transcribed and then listened to again while reading the written words, correcting errors, and becoming more familiar with the data. The notes taken were also added to the transcription document using comments through the Track Changes feature of the software. Next, I reviewed the transcript, field

notes and research diary, made comparisons, highlighted text and added comments (memos) throughout the margins. I tagged some as a theme; others were thoughts, comments or descriptions of what was said. As Gibbs (2007) suggested, I searched for the words 'never' and 'always' to take notice of what was indeed being said (p.51). I then went through the transcript again, reading line by line, looking for anything I might have missed, but I did not code each line as it seemed repetitive and sometimes unimportant. As I went I re-looked at the memos written. If no code was tagged, I produced one that described the text. I saved this new version again, tracking each time as I went. Once I completed this process, I made a spreadsheet and copied the selected texts, placing each under the appropriate code for further comparison and scrutiny. Data that did not fit into any category was left out but saved to return as needed for re-examination. Through comparison and scrutiny codes were merged and often themes developed. At times, the number of codes forced me to compare again and scrutinise, and categorisation began. This lengthy process became easier once there were categories clarifying where coded data belonged. However, this process made comparisons again, producing altered or additional categories. Once all coded data were categorised, themes and sub-themes became clear.

Using grounded theory approach, I was wearing my 'researcher's analytic lens' throughout the research process, which made it essential to have reflective practice due to the 'type of filter covers that lens and from which angle' I viewed 'the phenomenon' (Saldana, 2016, p.7-8). I will go into more detail on reflexivity next.

5. Reflexivity

As Glaser and Strauss (1967) recommended that the researcher not squash one's own experiences but nurture them, I used my insider experience and knowledge to guide my

approach, interactions, analysis and judgements (p.252). I did not ignore that bias plays a role in insider research. Instead, I opened myself to probe more deeply, challenging perceptions and assumptions and, simultaneously, used my insight as an advantage. I did this reflectively, which allowed me to think critically over my actions, decisions and thought processes, to consult and deliberate my 'own sense-making' (Schwartz-Shea and Yanow, 2012, p.100). For example, I am aware that I approached this research and recruited and interacted with participants with defined ideas based on my education, experience, culture and beliefs. I had to unravel these to actively analyse my understanding. Ongoing reflexivity strengthened my 'Personal responsibility for the research and its outcomes' (Schwartz-Shea and Yanow, 2012, p.101).

Before this learning experience I had different roles where I found myself involved in evaluation and research and was keenly aware I was learning as I went. I had mentorship and support but felt the need and interest in more formal education. When I moved to the United Kingdom, I discovered I could straddle the fence between health and social care but found I identified more with healthcare. I have worked in learning and development, including communication skills, programme/project development and management. I came to this research topic as an insider to teaching communication training around deteriorating health and end-of-life. Instead of assuming why participants characterised these conversations as difficult, I wanted to investigate the "why" and the "how".

In using interpretivism, it was important to get the participants to do most of the talking and explaining, to peer into how they construct their world. I knew my identity and bias could immensely influence my role as a researcher since I helped design the workshop where I recruited participants. I tried to distance myself from the workshop by not getting involved with the preparation, registration or teaching and by presenting myself as a researcher.

However, some participants were aware of my affiliation with the workshops. It was equally important to caution myself against making 'Assumptions about what the research findings might look like before the data are collected and analysed' (Kelly, 2004, p.131). Therefore, I used the research diary to capture reflections regularly and as recommended by Evans and Hardy (2010), to be as explicit and transparent as possible. Through reflexive practice, I consistently asked myself, 'How am I influencing this?' For example, two participants mentioned having unhappy patients when they had to rearrange appointments or had long wait times. In my research diary at the time, I had a question asking if these were *really* difficult conversations as they did not seem so to me. At first, I discounted these examples, noting in them my research diary as "challenging?!" I thought perhaps it was due more to the participant's role or discipline; however, I later realised it was more complicated and needed to consider my possible bias. I recognised participants influenced my working definition, which required further reflexivity.

I was keen not to hear what I wanted but to challenge any assumptions I had. All researchers are biased; it is inevitable. However, it was clear that this research was not to be used to 'substantiate a preconceived position' (Yin, 2018, p.86). For example, I noted down in my research diary my assumptions were being challenged during the recruitment process:

> I had this notion that GPs would be challenging to recruit and then engage with the research. After working with them, my experience and what they are constantly saying is that they don't have time for anything… I am surprised each time a GP consents to be part of the research! (Diary, 19.5.2017).

Before each interview, I took the opportunity to type any thoughts or concerns about the upcoming interview. The subjects of these reflections ranged from recruitment and

84

scheduling to engaging this participant. It was especially important before the second interviews where I reviewed the previous interview transcription and coding and had new thoughts and reflections to capture. The process aided me in the preparation of the follow-up interview. In addition, I mentally reminded myself of my role as a researcher. It was challenging at times to remain neutral and not challenge or engage more with an individual, so reflecting afterwards was useful to think through these challenges and how I could have influenced the findings.

An example of using my research diary for reflexivity to keep myself in check was when one participant was emotional in both interviews. In my field notes, after the second interview point, I wrote, 'She is burning out and can see it, but does not see her boundary issues; if I could only help point them out!' The participant asked me for help as she knew my connection to teaching workshops, and I felt conflicted. After the interview, I gave her some resources; however, I declined to tutor her as requested. Later I sent a follow-up e-mail checking in on her with some resources as I felt obligated to help where I could. I reflected long on this struggle as an insider researcher in my diary.

She was not the only participant that demonstrated emotions. On reflection, I noted similarities between my experience and participants' descriptions of how they felt talking with the patients/families who demonstrated emotions. Just as they struggled with the situation, I, too, struggled. Some participants sounded vulnerable, and others cried, challenging me as an insider researcher to remain in my role as a researcher. It was especially true when the interview ended with this sadness, and I felt responsible for their current state and wanted to bring the person back to some happier thoughts. A diary aided my reflexivity by allowing me to process, assess by questioning, and question how I might

influence the participant, the data collected and the data analysis. Through reflection, I

noted 'changes in self during the progression' (Corbin and Strauss, 2015, p.37). My research

diary was part of the data collection, coding and analysis.

Practising reflexivity helped me recognise my bias. This impacted my study's transition from

evaluative to evaluative and explorative, and then to just explorative. For example, I asked

participants questions about their previous training, as well as questions about the Difficult

Conversations workshop. Having done basic evaluations of the workshops in the past (pre-

and post-assessment surveys), I realised I was not as interested in their answers. I recognised

my lack of interest could impact the quality of data collected, and I could have missed

opportunities to prompt further. Although I coded and analysed these answers, I found the

more explorative approach much richer through reflexivity. Therefore, I decided on an

explorative focus for this thesis.

6. Ethics

All research must have ethical considerations to protect subjects from harm by reducing

potential risks. It forces researchers to think through and answer any possible ethical issues

before starting. It also focuses one to commit to maintaining standards throughout the

research. It is especially true when research 'blurs the line between researcher and

participant' (Corbin and Strauss, 2015, p.13) in practitioner research. Through ethics, I

thought through the design and then carried through implementation, analysis and reporting.

This study went through a full review and later a change in action, receiving favourable

decisions through the Royal Holloway University Ethics Review. The change in action

extended the end date and opened the pool of recruits to include secondary care due to

recruitment barriers and delays. In the end, I had no changes and could recruit participants up to theoretical saturation.

Although I could not guarantee that no harm would come to participants, the risk of them suffering negative consequences in this study is low. However, there were risks. For example, identifiability could occur due to participants giving ample personal examples. If identities were exposed, participants could suffer embarrassment, stress, negative attention and/or distrust if they conveyed any perceived weakness or inability to have difficult conversations. Also, there was a risk in not managing clear expectations as participants could think I could sort problems relating to the topic (as per the previous section example). Another potential risk concerned the emotional content of the interviews and participants' relationship with the topic. As I could not predict if the questions would cause distress (Seale, 2004, p.185), I knew that the subject matter could be challenging for some people.

As an insider researcher, there were other ethical implications to be considered. For example, I thought through how being connected to the workshops from which participants were recruited could result in individuals wanting advice. I had to consider encountering dangerous/damaging practices in advance, and I used reflexivity to help address ethical implications and considerations.

It is also good to point out potential positive consequences in looking at potential negative consequences. Participants could have benefited from the process of reflecting and sharing their practice and experience since these topics are often not discussed with others. Professionals have difficult conversations in clinical practice, but in isolation with little opportunity to share how it went and how they were feeling with others. As individuals

thought back over their experiences, feelings and outcomes and articulated these to another person, they were processing what could have given them insight, leading to new understandings.

6.1 Minimising risk

I implemented the following steps to minimise risks of harm to participants by reducing the potential exposure. Each participant received full disclosure of the research process through written consent and an information sheet (see Appendix C), which highlighted voluntary participation, the potentially sensitive subject and the treatment of information shared as confidential. During the recruitment process, individuals were given the opportunity to ask questions and reminded that they could withdraw from the study for any reason. I carefully reviewed the consent form with each participant verbally and asked if there were any questions. Each participant gave consent by signing a consent form. Before beginning each interview, I reminded participants about the study and confidentiality.

I considered all information and data collected to be confidential and, once transcribed, they were anonymised. Of course, there are limits to confidentiality when safeguarding and professional transgressions are involved. Although none were revealed, I considered the possibility. If an issue arose, I would have reported on to the proper authorities. Participants were asked their names and job roles for the study. Other personal identifiable information, such as phone numbers and e-mail addresses, was held for coordinating interviews. No written findings contain any personal identifiable information, and although I name roles, I ensured nothing could be traced back to the individual to protect participants' anonymity. As there is only one male, all participants are referred to as female to protect his identity.

Contact details were held separately from outcome data. Hard copy notes are in a secure

location. I kept electronic files containing notes and audio files on a secure, restricted drive.

Only I have access to these files on my private password-protected Google.drive.

For managing expectations, I emphasised my role as a researcher and reminded the

participant of this when necessary. Recognising the interview questions could elicit

emotions, initially, participants were made aware this could occur, and they could stop and

take a break or terminate the interview at any point if they did not wish to continue. While

conducting interviews, I was careful to 'avoid undue intrusion' by respecting participants'

wish to not go further about a particular example or subject, and when there were noticeable

emotions, time was given through pauses or silence and then checking in to make sure s/he

was okay to continue (Webster, Lewis and Brown, 2014, p.85).

At the end of each interview, with noticeable emotions demonstrated, I checked with the

individual to ask if she was 'okay', attempting to leave the person in a good state of mind.

Through reflection, I realised that I could have an interviewee be not 'okay'. As a result, I

decided that if that happened, I would offer to speak longer to the person until s/he was

feeling better and/or suggest the individual speak with a friend, colleague or occupational

health. This was not needed in the end.

6.2 Transparency

As Stanley and Wise (1993), as cited by Ali et al. (2004), suggest, researchers should not

remove themself to reduce bias and influence the outcomes but recognise the entanglement

(p.25). As the researcher and the one who wrote the curriculum and coordinated these

workshops, I recognise the entanglement. There were some biases, and to reduce the bias, I

did not facilitate any of the workshops affiliated with this research because I wanted

participants to see me in the role of researcher. Nor did I stay for workshops after recruiting

participants. I did not want the participants to think they were being observed or evaluated as this was not the purpose of the study.

I practised reflexivity to be aware of and understand the insider-researcher influence on the study. Evans and Hardy (2010) expressed that it 'Is key, with researchers explicitly acknowledging the roles that their own subjective values and beliefs play in the research process' (p.79). The practice of reflecting and reflexivity took place throughout the research process.

7. Summary

I began this chapter by defining interpretivism epistemology and how I applied the position of trying to understand professionals' experiences. It described the research design, rationale, theoretical approaches, and methodology. Then the chapter reviewed the methods used and went into detail about data collection. It then described the grounded theory approach used for data analysis through coding and categorising and concluded with reflexivity and ethical considerations.

Over the next three chapters, I present and discuss the key findings of applying the epistemological and theoretical approaches to the research question: how professionals characterise conversations with patients/families around deteriorating health and end-of-life issues. The next chapter, Chapter 4, explores how professionals categorise conversations as difficult in practice.

Chapter 4: Findings and discussions on characteristics and definitions

1. Introduction

The previous chapter explained the methodological approach, and now the focus shifts to the research findings, analysis and discussions of this study. The findings constantly compare the participants and the three disciplines, emphasising distinctions. As there is only one male participant in the study, all pronouns are female to protect identity. As Yin (2018) recommends, I use direct quotes to help provide evidence and explanation, with 'cross-case analysis' for ease of reading (p.227-8). Chapters 4 to 6 discuss the findings, explaining how they match or mismatch with the literature review; however, additional literature was sought, considered and included as new findings and ideas emerged.

This chapter covers the research objective, define and characterised how professionals conversations as difficult. It covers professionals' knowledge of, their conceptualisation and thinking about difficult conversations. It also includes the objective of exploring differences between participants' disciplines; however, the differences between them were few. I present the findings in terms of the different dimensions people spoke about concerning the themes, but occasionally when there were notable divergent views and where there were differences between professional groups, I highlight them and break them down with numbers for context in the account of the findings.

Recognising there are different ways of understanding professional knowledge, I present how professionals define difficult conversations in two different manners in this next section. The first presents the professionals' words and their struggle to define why certain conversations are difficult. The second presents the examples they used to describe their thinking. I will

then explain the differences between the disciplines in the examples given. Following the findings is a discussion focusing on these main themes.

2. Categorising conversations as difficult

Categorising a conversation as difficult was quick and easy for participants. However, a definition was often delayed or never given, and when given, it usually was done with uncertainty and as an example. Through the development of participants' explanations, they applied further meaning. Some gave an example and, when pressed, would say that example was difficult, not providing further explanation. I came into this research with the term 'difficult conversations' as if conversations either are or are not difficult; however, participants did not see them as a binary yes or no. Instead, they gave gradations or 'levels' (GP4) and 'degrees' (GP2) of difficulty making up the intricacy of these conversations. Throughout the interviews, I noticed that participants often gave examples of conversations with a comparison of intensities to help them express their discomfort or difficulties with situations or topics, naming some more challenging than others. For example, two participants said some conversations could be a lower difficulty level because the conversations are 'not as emotionally charged if you like' (GP2).

These "levels" reflected the intensity of the conversation for an individual; however, there were similarities between the participants. Participants gave examples of higher difficulty levels such as terminal conditions and resuscitation discussions and patients wanting an intervention that is not recommended or funded by the NHS, such as an MRI, surgery or medication. One participant said she thought the difficulty level comes down to 'a strong, personal, emotional reaction, so where the situation is really bleak, whether it be an untreatable cancer or a severe, intractable pain that you just can't get on top of… It would be

the worst, most difficult' (GP4). This same participant spoke a lot about difficulty levels with examples. One was when patients had firm and different beliefs, such as religious or cultural, or 'a disconnect' (GP4). Another example was 'Where you feel that there's a gap in your professional knowledge or you're not particularly proficient at' whatever is being discussed (GP4).

Two participants said that conversations with those suffering from chronic pain are the hardest. One explained, 'I can't do anything for that patient, so the patient has exhausted all options... and there's nothing else that I can do for them' (Physiotherapist4). Another explained why she thought these conversations were so challenging and said, 'I guess because of the transference of the patient's distress and misery, which leaves you feeling pretty sad yourself at the end of their consultation' (GP4). She continued that it, 'makes you feel slightly helpless and that challenges your professional mindset that we all like to have, that we can always do something' which causes 'damage to professional pride' (GP4).

Knowing the patient/family well influenced the conversation to be a higher level of difficulty for three participants. However, two other participants found that knowing the individual made it easier.

Sometimes participants saw difficult conversations differently from my working definition, not seeing them as a single event but as a process of a patient's overall care. The participant often shared an accumulation of experiences with a patient over time and possibly with various professionals involved. When this happened, participants commented on circumstances and conversation(s) (examples presented in section 3). To note, how participants characterised and explained these conversations might relate directly to their identity as primary care practitioners and their education and training or lack thereof.

Although "difficult conversations" is common in palliative and end-of-life care, it was not seen in the same way by community care professionals.

When asked about training, only two participants had some advanced communication skills training, and another two had some general communications training, but not around sensitive subjects. That leaves nine participants with no communications skills training, with one adamantly stating, 'I did not ever at any stage get any communication skills training' (GP1).

Overall, participants described difficult conversations as complex with three main sub-themes which crossed over each other: "sensitive", negative feelings/emotions and conflicting expectations.

All participants but two nurses described 'conflict about expectations' between patient/family and professional (Physiotherapist4). Of these responders, five spoke about both expectations and emotions. One said, 'It's difficult when, I suppose, there's emotional conflict' (GP3). Additionally, three participants said difficult conversations can be 'life-changing conversations, really, aren't they?' (Nurse1). One nurse said they were about death. One GP said they occur when the other individual is not working with you, and another nurse said they are when she felt the visit outcome was poor.

2.1 Sensitive subjects

With further prompting about categorising conversations as difficult, five participants said they were 'something that is going to be sensitive... whatever the topic might be' i.e., content, for patients/families or professionals (Nurse2). For these individuals, the subject matter determined a conversation to be "sensitive", explained as something 'some people

don't like to talk about' (Nurse1) or 'A subject that could be a bit awkward that one might find difficult to broach' (Physiotherpist1). Some participants described it using the word 'sensitive' (Nurses1, 2 and 4 and Physiotherapist3).

Participants gave examples that fit into three key areas. One subject was the patient's health, with topics like no cure, deteriorating health, a new diagnosis of a life-limiting condition and end-of-life. The second was patient's expectations being at odds with the participant's or patient's demands for certain treatments, such as a scan or an injection when the participant did not think it was needed. The third was not so much about the subject but the negative response, for example, a tearful patient or the dynamics between a patient and family yelling at each other. I created the following diagram to show three key areas linked directly to other influencers: negative feelings/emotions and conflicting expectations, which I will expand on next.

Diagram 1 Three key influencing subjects
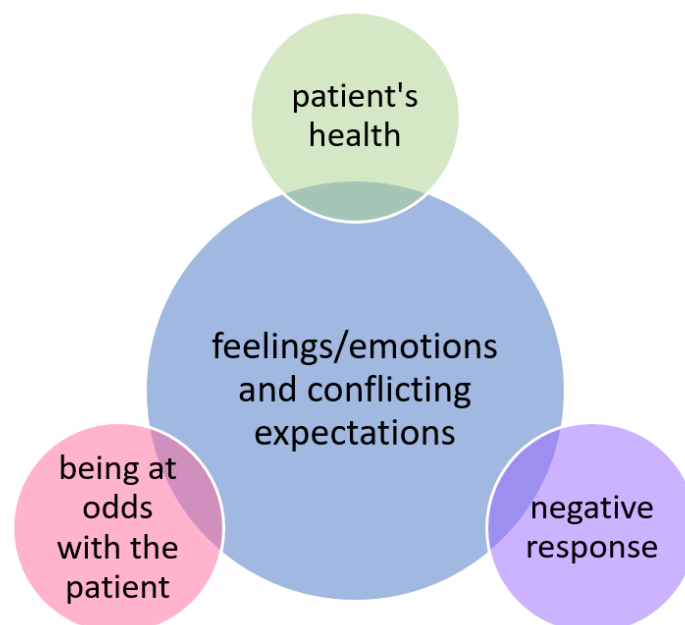
2.2 Negative feelings and emotions

Participants characterised conversations as encompassing negative feelings and emotions. 'There's usually excessive emotion happening... usually negative emotions, I would say' (GP3). All but three participants spoke of negative emotions as a source of difficult conversations, with negative feelings and emotions such as sadness, anger, fear and distress, for either the professional or the patient/family and often for both. The numbers in the chart below represent the number of participants who spoke about that feeling/emotion.

Chart 1 Number of participants verbalising negative feelings and emotions

■ anger 11	■ fear 11	■ distress/upset/unsettling 10
■ sadness 9	■ anxiety/nervous 8	■ frustration 8
■ emotional 8	■ shocked/surprise 6	■ discomfort 6
■ apprehension/worry/dread 5	■ annoyance/exacerbated 5	■ stressed 4
■ feels useless/at a loss 3	■ guilt/regret 3	■ judged/defensive 2
■ abandonment/rejected 1	■ misunderstood 1	■ strange 1
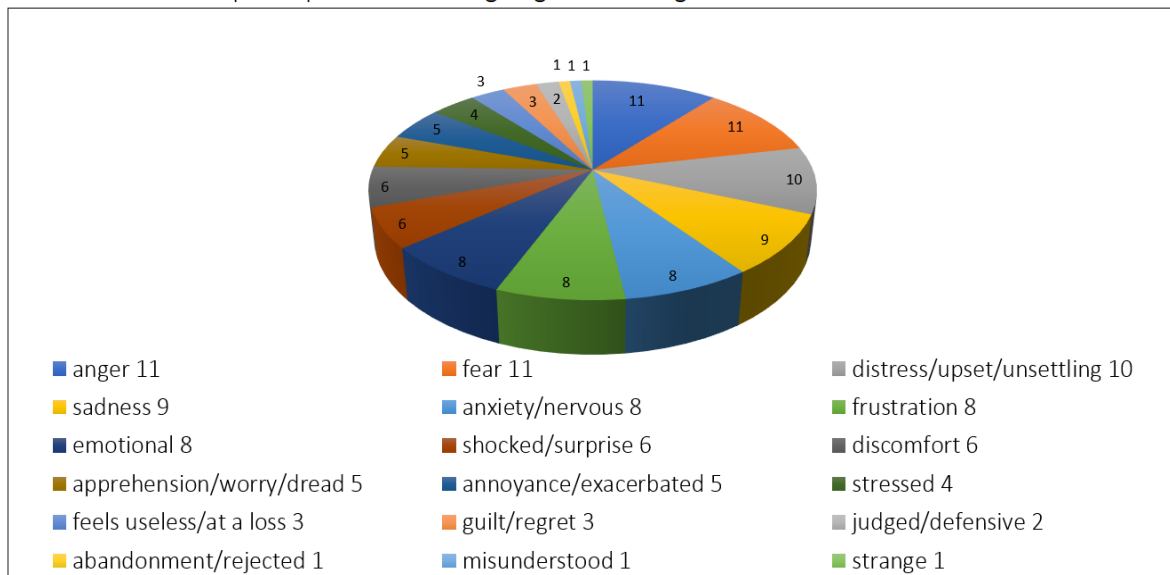
As one participant put it, there are 'so many emotions that can cause difficulty' (Nurse2). See Table 2 for a breakdown by discipline group.

Table 2 Negative feelings and emotions by discipline

	GPs	Physiotherapists	Nurses	Total
Anger	3	4	4	11
Fear	5	3	3	11
Distress/upset/unsettling	2	4	4	10
Sadness	4	2	3	9
Anxiety/nervous	3	3	2	8
Frustration	2	3	3	8
Shocked/surprise	1	2	3	6
Discomfort	3	1	2	6
Apprehension/worry/dread	3	2	0	5
Annoyance/exacerbation	0	2	3	5
Stressed	1	2	1	4
Feels useless/at a loss	2	0	1	3
Guilt/regret	1	1	1	3
Judged/defensive	2	0	0	2
Abandonment/rejection	1	0	0	1
Misunderstood	1	0	0	1

Participants explained that these feelings and emotions were often displayed within a reaction: crying, raised voices, yelling, disengagement in the conversation, wanting to leave, not making eye contact or looking shocked. Participants said that these emotional reactions from patients/families could trigger a conversation to be difficult, leaving them to struggle. They said this was especially true if the other person becomes angry, confrontational, sad or 'over-emotional' (Nurse2).

Participants shared how their own feelings also contributed to the difficulties. As one participant put it, 'I think difficult conversations quite often have more to do with how the professional… is feeling as opposed to how the patient is feeling' (GP1). When participants actively thought back over an experience of being in a difficult conversation, most remembered how uncomfortable they felt, often with a 'strong internal emotional response' (GP5) due to the individual's reaction or even anticipating one. These feelings and emotions intensified as they were left unsure what to say or do.

Another feeling described was lacking confidence which occurred when participants did not know much about the subject matter or the circumstances. One described the feeling as 'a strong emotional or stress response in you, in having an anxiety about having it' (GP4). Two participants spoke of being surprised in a conversation and not having information or being unknowledgeable of the topic, leaving them feeling 'caught off guard' or unprepared (GP1).

Eight participants said feelings or emotions cause conversations to become difficult. Whilst others laboured to answer or gave examples, one participant was sure of her answer. It could be because she was transitioning into a palliative care role, so she may have already formalised her thinking to help her practice. She said difficult conversations mean 'a reflection of our apprehensions' (GP1). She described how conversations become difficult when professionals struggle with their own feelings/emotions and, therefore, a 'reflection of professionals' emotions about the subject' (GP1). This participant named one of the main findings in this research at the very start of the research; I just did not know it at the time.

According to participants, the difference between a conversation and a difficult conversation was the negative feelings and emotions; however, for most participants, the patient's/family's reaction was not the defining factor, but it was their own response to the reaction that classified it as such (covered more in Chapter 6).

2.3 Conflicting expectations

Participants perceived that often patients/families had expectations that conflicted with their own, and all but three used it as a definition, with five saying it in combination with negative emotions. Frequently conflicting expectations were explained as being about 'a change in direction' or a challenge with the current expectations of the conversation (Physiotherapist1). Participants spoke about expectations of what one presumed would

happen (or not) in the conversation, the disease, treatment and/or care. As one participant explained, 'Maybe [they] don't have the insight into what you're challenging them on' (GP3). Patients/families often thought the treatment would work and were surprised or shocked when it did not. It is a 'discrepancy' (GP4) or 'a big mismatch' (GP2). As one participant put it, this mismatch is 'between what they [patient/family] think we can achieve and what we can actually do' (GP4). She explained that doctors are 'programmed' to provide a 'quick fix'; however, 'that isn't available or possible for the vast majority of things that we encounter' (GP4). She said, 'I guess that's a key tension that leads to a difficult conversation' (GP4). These expectations rubbed together, and negative emotions incited them. A participant explained that difficult conversations occur when a professional goes against a patient's hope or is not living up to the patient's expectations. It can happen too when challenging someone's expectations by giving the patient/family bad news (explained further in section 3.2.1).

Five of the participants spoke about how the process of a conversation was what made it difficult, not the outcome of the conversation, meaning that going through the experience itself was what made it challenging. One had conflicting feelings saying, 'it's always around conflict of thoughts about what's going to happen in that session, what things need to be done' (Physiotherapist4). She spoke about a negative outcome, saying, 'I've learnt over time to not be affected by them or see it as a negative thing, and just go with it' (Physiotherapist4). Three other participants in opposition classified conversations as difficult if the conversation had a 'bad outcome' (Nurse4) or the outcome did not meet expectations. They considered the outcome good if there was a plan or an agreement. However, they considered it a difficult conversation when there was no resolution/agreement.

One participant explained she felt the most challenging conversations, although they happened less frequently, were the ones where the situation was made worse by the conversation and ended poorly (Nurse4). She believed that if the patient felt 'helped', it was a positive conversation and not difficult. When she felt she could not help the patient, she equated this to a negative outcome and a difficult conversation. Another participant said that if the patient does not want to talk about the sensitive topic, she sees this as a poor outcome, taking responsibility for not moving the conversation forward.

Thus far, I have presented the findings on how participants tried to describe difficult conversations in conceptual terms and the troubles many had in doing so, which could be due to the term itself, "difficult conversations", not being helpful. Community care professionals may view the term as a palliative and end-of-life care term or may not identify with it. Next, I will share the findings on the examples given instead and how participants explained that conversations are multilevel.

3. Examples participants used to describe their thinking

I now want to give a richer sense of how participants understood difficult conversations by presenting the situations and activities participants gave for a more embodied definition.

3.1 Emotional reactions

Emotional reactions from either party in the conversation were a common theme in the examples given by participants. For example, participants reported that patients'/families' responses were often shock, fear, sadness or anger. For the professional, the sentiment was that one would be 'caught on the hop', even stunned or afraid of the conversation's direction (GP2), leaving participants feeling uncomfortable, shocked, afraid, anxious and unsure of how

to proceed. Work experience can influence these reactions, described more in Chapter 6, section 3.1. They said the reactions were a result of three factors. One factor was discussing a sensitive topic. A second was unexpected conversations, and the third was an emotional reaction resulting from the other person's initial emotional reaction or the anticipation of one.

One participant encapsulated many participants' underlying anxiety concerning uncertainty that one never really knows how the patient/family will react because things 'happen out of the blue' (Nurse3). She gave an example, 'You didn't know they had a relative, and the relative suddenly is there commanding who you are or why you're there and all sorts of things'.

A few participants elaborated on how unexpected emotional reactions affect them during a difficult conversation. One said, 'You are sort of shocked, and you just stare at her, and you just don't know how to help her, how to manage their feelings, manage her' (Nurse4). For participants, this experience feeds into fears of future conversations, not wanting it to happen again. Many participants talked about being fearful of the unpredictability, saying they think, 'How will this person react?', leading them to avoid difficult conversations.

Seven participants gave their emotional reactions as examples when trying to explain difficult conversations. They found it challenging when patients/families had emotional reactions as they often provoked emotional reactions in turn for themselves. All thirteen participants also said of emotional reactions cause conversations to become difficult (see Chapter 5). These emotional reactions often occurred when there were conflicting expectations which I will explain next.

3.2 Conflicting expectations

Participants said conflicting expectations were examples of difficult conversations which occurred when they perceived the individuals in a conversation had different expectations about what would happen or be said. It often occurred within a conversation, but participants explained it could also be in the context of the patient's health and progression of a disease going in a different direction than expected. In section 2.3, participants used "conflicting expectations" to define difficult conversations. This section focuses on the findings where participants gave examples of conflicting expectations between professionals and patients/families, focusing on breaking bad news.

Breaking bad news was a common example participants gave to help explain conflicting expectations. It is the act of telling a patient/family something unexpected or unwanted. Traditionally in health care, when people speak of breaking bad news, they tell a patient about a poor prognosis or that s/he is dying. However, one participant explained that bad news is 'not necessarily life-threatening' but can be about 'a serious life-long condition', which can still be 'hugely life-changing' (GP4). Another example was pain, although the individual did not use the words "breaking bad news". The participant said:

> If I can't change it… and they've come back to me because they don't feel any better
> with the treatment that they've got, then it is sometimes you just have to say to the
> patient, 'Well, I think this is as far as we can go, and you have to live with your pain.'
> Those ones I don't like (Physiotherapist4).

Six participants said an example of a difficult conversation was when they had to give a patient bad news and always spoke about negative emotions. It was either their own or the other individual's emotions in the conversation. Two participants spoke about it being hard

to accept, as a professional, that one cannot change what is happening to a patient (GP2, GP4). Another said she felt like 'you suck all of the hope out of the family' in delivering bad news (GP5). There was also a consciousness of 'the lasting impact it [the bad news] has…afterwards' (GP5). Two participants were concerned about balancing out the negative; as one said, 'Be as positive as you can about what can be done, what can be offered, rather than what can't be done' (GP1).

A nurse also explained how her title 'Dementia Nurse' alone initiated bad news delivery, so she often presents herself as a 'Memory Nurse' instead (Nurse2). She explained how patients and sometimes family members are often unaware of or have forgotten the diagnosis of dementia. She found it easier to ease into the bad news.

Breaking bad news 'is not always so much a difficult conversation when the patient is expecting [it] because sometimes they're actually relieved to know the reality of what's happening, so it's not always the bad news per se' (GP2). Two participants stated they did not necessarily consider delivering bad news difficult, with one stating it is 'just a statement of fact' and 'part of the job' (GP1). Next, I will present the main differences between the three disciplines in their examples.

3.3 Differences between disciplines

All participants gave multiple and diverse examples of difficult conversations. Although there were some commonalities between participants, the three different disciplines differentiated between the comprehensive examples.

Nurses tended to have the most variety of examples ranging from mental health issues relating to 'trying to get them to comply with treatment' (Nurse3), dealing with chronic

disease, and 'expecting the end-of-life or dying' (Nurse4), and dealing with the family's anxieties around end-of-life. A noticeable difference from the other disciplines was that although some spoke of levels, all the nurses mentioned difficulty levels.

Nurses' and GPs' examples in this study overlapped the most. Except for one GP, both disciplines discussed breaking bad news. GPs ranged from 'a diagnosis of a chronic condition, even diabetes or COPD or anything' (GP1) to discussing resuscitation. Four of the five GPs gave resuscitation discussions as an example of a difficult conversation, whereas physiotherapists and nurses did not mention them. These participants were concerned about patient's/family's perceptions. One explained, 'That's always a difficult conversation, how to explain that a not-for-resuscitation decision does not mean no care' (GP4), which participants said is the main concern for patients/families who often see it as letting the patient die. They also voiced concern about the quality of care the patient would receive after signing it. One was particularly concerned about the quality of care and questioned, 'You think, so if I put this [Do Not Attempt Cardio-Pulmonary Resuscitation - DNACPR], is the patient going to have good care in the community?' (GP5).

Physiotherapists often gave examples about going against the patient's expectations, such as 'giving out results or withholding treatment' (Physiotherapist1), and when patients were not 'reaching goals' (Physiotherapist3). Physiotherapists tended to explain that patients often received miscommunication about what physiotherapists can do. A commonality for all four physiotherapists was that they gave examples of patients experiencing pain. Although two GPs mentioned patients with pain, for the physiotherapists, the examples were more about how the patients expected them to fix it and often quickly. Another commonality for the physiotherapists in the study is that they understood breaking bad news as something the

104

doctor or other professionals do because they considered this term to mean explaining a diagnosis or prognosis, which they saw was not in their role. Participants said that when patients deteriorate, they no longer see a physiotherapist. Therefore, physiotherapists are not involved when patients receive bad news. However, all four physiotherapist participants gave examples of difficult conversations that I perceived as breaking bad news. They gave examples such as telling patients they are denying certain treatment such as an injection or an MRI or explaining to a patient s/he is no longer progressing with mobility. When I asked about these examples in the context of breaking bad news, they explained they were about confirming or going against patients' expectations.

All the nurses voiced difficulty talking with someone they thought was 'in denial,' whether the patient or a family member. Participants explain this as someone not wanting to acknowledge the facts or accept what is happening. One explained, 'When they're in denial and they're angry, they're frustrated, and they're not ready to accept their diagnosis, then obviously that makes it a lot more difficult' (Nurse1). An example given was a patient receiving chemotherapy for cancer, 'thinking that it will give a cure. [However] you can see the signs and symptoms that he is deteriorating. You're trying to explain that no matter what the procedure is there - nothing can be done' (Nurse1).

All three disciplines in this study experienced difficult conversations. There were differences in what they saw as difficult and the intensity of difficulty they attributed to conversations between participants and disciplines. However, there were also notable similarities within each discipline.

Next is a discussion about the findings thus far, focusing on possible explanations for why professionals struggled to define difficult conversations and the examples they provided instead. The discussion draws on the literature from the review and additional readings.

4. Discussion

The first part of my research question was to explore how professionals characterised and defined conversations as difficult in practice. I wanted to see if I could break down the similarities and differences, to explore individual views to see what triggers these conversations. I found it interesting and myself surprised when most struggled to classify and characterise a difficult conversation, not have reasons or explanations, even after being pressed, but had examples at the ready instead. On reflection, I realised I had expectations of what I thought I would hear. Hence the 'probing and pushing' I balanced with 'knowing when to stop'; ethics in motion requiring decisions to be made in practice and reflecting on these decisions afterwards to bring forward my assumptions (Evans and Hardy, 2017, p.955). All are challenges of qualitative research. Although participants struggled to define and explain why they found them challenging, almost all answered, and could talk through, give examples, and describe how they saw these conversations as varying levels of difficulty. This discussion provides possible explanations for why participants struggled, the commonalities that emerged and themes within the examples participants provided. The discussion looks at how these conversations are not an either/or concept for participants.

4.1 Why it may be hard for professionals to define difficult conversations

Searching to understand why most participants struggled to define a difficult conversation, I looked at Luntley's (2009, 2011a, 2011b) work about knowledge and expertise, particularly

his 'expert knowledge' theory. Luntley (2011a) disagrees with other theorists that depict 'expert knowledge' as 'know-how' and believes this 'Is either a label for mere behavioural skills or a short-hand for something that, if it is to justify performance, needs to be rendered as propositional know-that' (p.26). He argues that propositions are 'not just things that fill books', but they 'fill the forms of our actual real engagements with the physical, social, emotional and ethical environments that we manage' (2011b, p.28). Propositional knowledge, he argues, is, therefore, a concept that one can express or demonstrate. He states that not only 'good old-fashioned propositional knowledge will do', but 'It is the only type of knowledge fit for the purpose of making sense of the idea that it is knowledge that makes practice wise' (2011b, p.27-28). In my research, I asked participants to define a difficult conversation, i.e., what knowledge they have that makes their practice wise. Luntley (2011a) may argue that 'the building blocks of thought', or the concept of a difficult conversation, is an 'activity-dependent concept' that cannot be articulated in words, whether orally or in written form (p.24). He argues that activity-dependent concepts 'require subtle activities of perception and manipulation' to understand them (2011b, p.33). So, if professionals perform an activity-dependent concept of having a difficult conversation in practice, s/he will argue we should not expect them to articulate what they do. Instead, we should expect them to demonstrate it or give examples. We should expect them to say, 'like this' (2011b, p.32-34) or just as participants did in this study, 'oh, you know' (GPs 2, 3 and 5, Physiotherapist2, Nurses 1 and 2).

Luntley (2011b) believes that experts may be able to explain their experiences and talk about their knowledge; however, 'We should not assume that what it is like is the same as what they report in the moment' (p.34). One may argue that a difficult conversation is unlike his example of a nurse changing a bandage and that it is language-based; you must speak to

converse. One may not classify it as an activity-dependent concept; however, a difficult conversation does require the 'need to see and handle things' to develop good communication skills (p.33).

Luntley (2011b) would argue that one requires more than a mode of communication to organise or categorise it for oneself or others to learn any activity-dependent concept. He would say one must perform the activity in the environment to provide the specific context required to demonstrate knowledge (p.35). Conversations about deteriorating health and end-of-life, the types of difficult conversations foregrounded in this research, have a specific context involving negative feelings and emotions and often conflicting expectations. The environment has a finality to it and for the professionals this type of conversation does not happen every day. As Luntley says, engaging in the environment by actively participating, watching, doing and practising is to gain professional knowledge and embed it into practice. It may explain why participants struggled to use language as I expected them to use it. I was frustrated as I asked them for a different sort of answer in articulating the idea embedded in the activity. Instead, they told me how they understood difficult conversations by describing situations where I would recognise the idea embedded in that activity. It could be that the answers participants gave were not indications of lacking professional knowledge but more about the wrong question or asked outside of the environmental context. When they gave vivid examples and explanations, it demonstrated professional knowledge. A strength of qualitative research is its 'openness to the possibility of surprises', recognising and challenging researcher knowledge and embracing the challenges giving shape to the findings and learning (Schwartz-Shea and Yanow, 2012, p.33). Having not anticipated the inarticulacy, Luntley helped me understand participants' responses.

Next, I will explore another possible explanation or a link to Luntley's ideas about why participants find it challenging to provide classifications.

4.2 Emotions may affect the ability to define difficult conversations

Looking further to understand why participants struggled to define difficult conversations, I looked at Burkitt's (2014) work on emotions. Burkitt says our ability to develop 'language, perceptions, feelings and thoughts and images become semiotic in that they are meaningful signs that we can *name*' that changes 'through the meaning attached to the word' (p.70). He believes the words then permeate 'our perception and change not only what we see but also what we think' (p.70). One can verbally state what emotion s/he feels, but how it is said helps give some context. He believes that language only goes so far and that one must experience it to have an accurate understanding (p.71). Experience can be real or imagined. This is similar to what Luntley (2011a, 2011b) says about an activity-based concept, with the similarity of language limitations.

Burkitt states that language 'is always something of an abstraction from the situations in which we live and in which experience is formed' (p.59). He states three fundamental intertwining elements. Firstly, is that words become feelings; they 'shape, form and restructure feelings and other perceptions as these are linguistically articulated' (p.71). Secondly, we have emotional responses to situations in the form of a 'stream of consciousness' and talking to ourselves or, as he calls it, 'inner speech' (p.71). Thirdly, feelings, emotions and language relate to our past and imagined experiences (p.71). The present circumstances are not just stimulating our current feelings and thoughts, but our feelings and thoughts about 'possible outcome[s] of those circumstances' (p.55). What I think and believe about what I see are shaped by my emotions (Barbalet, 1999, p.261).

Burkitt believes emotions are involved with everything we think and process; we cannot separate them. He may argue that thinking about difficult conversations can conjure habits already developed for professionals and mixed with the individual's values and current feelings and emotions that emerged while reflecting, making it hard for people to identify the actions within them. In other words, it is plausible that thinking about difficult conversations comes with the feelings and emotions involved from the past and images of the future, which can impact the ability of professionals to explain. These feelings and emotions may make it difficult to specify and articulate a difficult conversation. These themes occur again and are expanded on in Chapter 5.

I explored two possible reasons why professionals struggled to conceptualise how difficult conversations occur in practice. I asked professionals to put words to propositional knowledge, to put language to an embedded skill (Luntley) with the complexity of strong feelings and emotions associated with difficult conversations (past, present and imagined), creating a complexity that was challenging to work through (Burkitt). I did not find evidence to suggest one is a better or worse explanation and recommend it for future research. Language can only go so far: experience (imagined or real) is needed to understand. The next section considers the findings from examples providing context and explaining further the varying types of conversations professionals face.

4.3 Adverse reactions

Patients' adverse reactions, such as distress, anger, sadness and unacceptance, are not just common examples found in the literature; they are also reported to cause conversations to become difficult (Piggott et al., 2019; Chandar et al., 2017; Griffiths et al., 2015; Pfeil et al., 2015; You et al., 2015; Slort et al., 2011). It was not surprising to see these emotions

frequently mentioned in this study, but it provides relevance to my work. These reactions are also associated with grief and loss (Dunne, 2004), so it is not surprising that these were common within the dominant context of deteriorating health and end-of-life.

Literature suggests that when patients receive unexpected information, it produces unpredictable emotions due to these conflicting expectations (Griffiths et al., 2015; De Vleminck et al., 2014; Bernhardt et al., 2010). Piggott et al. (2019) point out that professionals not engaging patients in conversations about their disease process, including their goals, creates a disconnect between the healthcare system and the patient. Add on professionals' lack of time for conversations about deteriorating health, and 'patients may not have the same ability to recognise their hospitalisation as a worsening of their prognosis' (Piggott et al., 2019, p.5). "Disconnect" leaves patients with different expectations. Existing literature focuses on professionals' perspectives that patients/families either deny or lack awareness of their condition or deterioration, causing unpredictable reactions (Chandar et al., 2017; Griffiths et al., 2015; De Vleminck et al., 2014). Griffiths et al. (2015) additionally found those with denial to be 'more complex to manage' (p.141). Bernhardt et al. (2010) found how the patients' reactions made professionals feel 'somewhat inadequate and helpless' and troubled for 'inflicting harm on the patient' by disclosing the bad news (p.292). Professionals from this study also said emotional reactions were common when a sensitive topic is unexpected. Examples of unexpected topics varied from a new diagnosis to disease progression and, as in the literature, are often due to those in acute settings not telling patients about their deteriorating health/diagnosis (Piggott et al., 2019; Lazenby et al., 2016; Pfeil et al., 2015). Nurses and physiotherapists in this study said the same about non-acute diagnosticians, the GPs. The challenge may be is less about the unexpected and more about

the unwanted, and maybe the fear of, adverse reactions. This suggests a lack of training on coping with the unexpected and the shock and fear of having these conversations.

This study expands on the knowledge that when professionals think about potential reactions from a patient/family, the thoughts produce interpersonal emotions such as anxiety, fear and/or the need to brace oneself (see Chapter 6). The difference between the literature and this study's findings may be due to differences in study designs. Existing literature focuses on specific diseases or contexts such as end-of-life or Advance Care Planning (ACP), where professionals were asked about barriers and attitudes towards those topics. In this study, participants were asked broader questions about difficult conversations in general, with the participants providing the context of what they considered the most challenging scenarios.

4.4 Conflicting expectations

Examples from existing literature could be interpreted as conflicting expectations, although they are not presented as such. These include studies explaining how patients/families are either not aware of or denying the reality of their condition/situation (Piggott et al., 2019; Griffiths et al., 2015; Prouty et al., 2014; De Vleminck et al., 2014; Bernhardt et al., 2010; Selman et al., 2007). Specifically, breaking bad news is a common concern (Griffiths et al., 2015; Bernhardt et al., 2010). Griffiths et al. (2015) suggest community nurses deliver bad news within their role; but most studies about breaking bad news are from an acute setting and mainly about doctors, as opposed to this research, conducted with community professionals.

The setting practice and the discipline are significant and may help explain how the results from this study are different. In acute settings, patients require urgent or emergency treatment and care, whereas in community care patients are usually more stable. Perhaps

urgency in an acute setting drive the differences between disciplines. Two acute studies found that although nurses and doctors said it would be appropriate for non-doctor professionals to engage in goals of care discussions with patients, most saw the role ultimately with doctors (Piggott et al., 2019; You et al., 2015). Alternatively, there is a disconnect with community doctors perceiving the hospital doctors as unrealistic in pushing futile treatment (De Vleminck et al., 2014).

In this study six participants gave breaking bad news as an example of a difficult conversation about a life-limited diagnosis or a poor prognosis, even though some gave examples in different contexts. At first, I was surprised that more participants did not mention the term in this research. However, after consideration, breaking bad news for most of them means telling a patient/family about a life-limiting diagnosis or a poor prognosis. One participant pointed out that she did not feel difficult conversations are about breaking bad news because she feels professionals, specifically doctors, must give bad news all the time.

Although most physiotherapists and nurses in this study gave examples of breaking bad news, they did not identify with the term perhaps because the phrase is primarily used by hospital doctors (Griffiths et al., 2015). It could also be that participants saw breaking bad news as a one-off occurrence: often, participants were not giving the bad news but picking up the pieces after it was delivered and supporting the individual to cope, especially when the news had been poorly given. They reported often answering many questions, clarifying news, or sometimes re-breaking the bad news because the patient did not understand. For those I interviewed, breaking bad news, such as a new diagnosis or giving a prognosis, was not a predominant occurrence since it happened more often elsewhere. On reflection, in the workshops I taught, acute and community professionals often said they were not the ones to

deliver bad news, nor did they see themselves as the ones who should. Physiotherapists and some nurses from the workshops I taught and those in this study reported they are less or not likely to break bad news as it was done by another professional. This could be due to how professionals see their roles. Physiotherapist may see her job ending when a patient is no longer progressing. However, nurses and physiotherapists often help patients adapt to news, such as deteriorating mobility.

4.5 Planning for the future

Previous studies present ACP and discussions around care goals as examples of challenging conversations (Piggott et al., 2019; Lazenby et al., 2016; Pollock and Wilson, 2015; You et al., 2015; De Vleminck et al., 2014; Ahluwalia et al., 2013; Almack et al., 2012). ACP is a discussion to develop a plan (usually in writing) that incorporates the patient's preferences and wishes about future care, often including life-sustaining treatments and DNACPR. Care goals discussions are like ACP; however, they are less formally documented. Generally, doctors initiate care goals discussions, while doctors or nurses initiate ACP discussions, and a patient also start ACP. Traditionally, these conversations occur in acute settings or outpatient oncology clinics when it is clear the patient's prognosis is poor; however, most doctors from both primary and secondary care believe ACP is important (Fulmer et al., 2018). Various recommendations and forms have been available, but there was no universal guideline for ACP until March 2022 (NHS England and NHS Improvement et al., 2022). The 'Universal Principles for Advance Care Planning (ACP)' (2022) speak to the benefits of ACP and set out discussion principles, which include for them to be person-centred, focusing on future needs in the context of 'what matters to them and their needs', agreed and 'sharable' (p.4). Having discussions with patients ahead of any potential decline has been touted as the

gold standard of care; however, many professionals do not actually have them (Fulmer et al., 2018; Chandar et al., 2017; Lazenby et al., 2016; Pollock and Wilson, 2015; De Vleminck et al., 2014; Ahluwalia et al., 2013; Almack et al., 2012).

The findings in this study were different, with two out of the three professions (nurses and GPs) in the position to have these types of discussions; however, participants did not provide them as an example. One exception is resuscitation decisions given by GPs as a principal example of a challenging conversation; however, they did not include other aspects of planning for future care. It could be that they did not see future planning discussions as difficult or assumed ACP/goals of care discussions were included within the label of DNACPR. However, the literature explains that clinicians often have DNACPR conversations in isolation, without ACP/goals of care discussions (Hall et al., 2019). Alternatively, it could be because I did not specifically ask about these aspects, or it could be, as the literature suggests, that these types of conversations are not often done in practice (Fulmer et al., 2018; Chandar et al., 2017; Lazenby et al., 2016; Pollock and Wilson, 2015; De Vleminck et al., 2014; Ahluwalia et al., 2013; Almack et al., 2012).

4.6 Nature of professional/patient relationships

There may be several possible explanations for what constitutes a difficult conversation and its difficulty levels. The NHS system expects patients/families to play an active role in their care (DH, 2013), which could also ask patients to divert from their 'sick role' (Parsons, 1991). Going outside these roles may have caused conflict and tension in the relationship of power and hierarchy. This diversion from the social system may challenge the social control that professionals hold because patients rely on professionals to tell them what is wrong (Parsons,

1991). Therefore, these professionals may struggle to share the expert role. There are different but shifting expectations, with everyone caught between them.

Parsons (1991) provides an understanding of the nature of the professional/patient relationship. An example is when a participant saw a patient she had not seen before who wanted a letter justifying a request for a second opinion outside the NHS. She explained that the patient 'had an agenda', and she told the patient, ''I'm really sorry, but I've never met you before, and no, I haven't had time to read through all your entire records'' (GP3). She explained appointment time limitations and added, '…he was obviously the sort of person who's never satisfied with his treatment, always wanting something different.' She concluded, 'That was a bit difficult, but at the end of the day, I'm not going to lose sleep over it, because as far as I can see, he's the one with the problem' (GP3). It could be that this individual was never going to be satisfied. Alternatively, drawing on the theoretical perspective of Parsons (1991), this scenario may represent a patient not conforming or not following the expected role as a 'good patient' (p.195). Pushing, questioning or challenging, may have annoyed the professional by being 'deviant' from his role (Parsons, 1991, p.195). The patient may not have fulfilled his end of the relationship by not respecting her expertise. He may have left the professional to feel justified as she was no longer required to devote her emotional and mental support to him (Parsons, 1991, p.217).

It could be that Parsons' (1991) sick role no longer provides an account of the patient and professional relationship. As patients are considered to no longer acquiesce but instead be active partners in their care, the relationship may have shifted. Maybe the relationship does not play as much of a role in these conversations. Maybe the relationship between professional and patient/family has changed. Perhaps future research can look more closely at these changes. For example, in this study some participants said the more they knew a

patient/family, the harder it was for them to have sensitive conversations, whilst others said

that the relationship helped. Future research could uncover their differences.

The literature from the review does not focus on difficulty levels for professionals within

conversations. Most likely this is due to the literature studying specific scenarios and finding

barriers and facilitators, whilst this study focused on conversations as a binary of difficult/not

difficult. To note, there are differences between the disciplines' roles and tasks in this study

which can impact conversations. For example, maybe all three would discuss mobility;

however, a physiotherapist may focus on strength and endurance, whilst a GP may

concentrate on a disease impacting mobility, and a nurse may emphasise care needs to help

with the lack of mobility. However, this study does suggest that experiences and examples of

conversations considered to be difficult have some overlap and similarities between

professionals and different disciplines.

Additionally, this study suggests that none of the three disciplines view difficult conversations

as an either/or concept, and they agree that there are levels or graduations of difficulty.

These levels can also complicate one's ability to define a difficult conversation. However, the

defining factor of what makes a conversation more challenging than another is individualised;

what is extremely difficult for one may be much less difficult for another. These findings

suggest a need for more formalised training so those struggling can be supported and

upskilled.

5. Summary

How professionals characterise conversations as difficult in practice is complex. I described

participants' professional knowledge of concepts and discussed the difficulties and possible

explanations of why participants struggled to define difficult conversations. Then I explored

professionals' definitions using examples, followed by a discussion on how they help us understand what a difficult conversation means.

Through discussion, reflection and examples, participants could paint a picture of what "difficult" conversations meant to them. All three disciplines preferred to provide context and description, and the main three categories of conversations categorised as difficult are:

- sensitive subjects,

- negative feelings and emotions, and

- conflicting expectations.

The next chapter presents the findings on participants perceptions of what makes conversations difficult conversations.

Chapter 5: Findings and discussions on what makes conversations difficult

1. Introduction

In contrast to the previous chapter that explored the individual realities of *how* professionals define and characterise conversations as difficult, this chapter covers the professionals' perceptions of *what* makes conversations difficult. I explain the findings concerning the aspects of the themes individuals spoke about and, when notable, the differences between disciplines. It starts with the two key findings, patient/family reactions and differing expectations. Then I explain other important themes that emerged: time restraints, participants' thoughts about their mortality and how the uncertainty of a patient's diagnosis or prognosis can influence conversations. The chapter then follows with a discussion using the literature from the review and additional literature as new findings and ideas developed.

2. Patients'/families' reactions

For many participants, the response of the patient/family is what characterised a conversation as difficult, not the content of the conversation. One participant explained these reactions occur because 'people are people, and we all have issues and baggage and respond to things differently' (GP1). The numerous, varied reactions demonstrated 'lots of different emotions', and most often, participants considered them negative, excessive and often dominating in the conversation (Physiotherapist4). However, six participants also spoke of positive emotions patients/families demonstrated, such as empowerment, gratefulness and relief. The other typologies were acceptance or non-acceptance of the

situation and unpredictability of the patient's/family's reaction. I now explain further the types of patient/family reactions.

2.1 Patients'/families' negative emotions

Study participants spoke of a disparate range of emotions and what brings them together is that the participants considered them negative. Chapter 4 explained that negative emotions, 'like sadness, or anger, anxiety, distress, anything that might cause someone some distress or discomfort' (Nurse3), defined difficult conversations. It expands on and redefines my working definition by putting more emphasis on negative emotions. Here, I go beyond the classification of negative emotions and look deeper, to understand in what ways and to what extent negative emotions make conversations difficult. Participants also said negative emotions could cause conversations to become difficult. As one participant explained, 'You're just seeing them [patient/family] at a really vulnerable time' (GP1). Participants also acknowledged that these emotions came not only from the other person in the conversation but also from within themselves, which I address in Chapter 6.

Negative emotions were a prevalent theme and often crossed over into other themes, making it challenging to separate them. Participants reported that these emotions took time to address and respond to; however, time restraints and pressures added to the burden (more in sections 4-6). I recognised the following trends of participants' perceptions of patient's/family's negative emotional reactions: anger, sadness and frustration.

Anger was a trend, with five participants saying having a conversation with an angry patient is one of the most challenging situations. When someone was angry, demonstrated by, for example, a 'face of thunder' (Physiotherapist4), professionals felt it 'changes the dynamic of the conversation very, very much' (GP2). Professionals reported feeling they could be the

aim of that anger and felt threatened or defensive, especially if the individual demonstrated aggression. Personal space was also sometimes a concern, with participants feeling trapped and fear of the individual lashing out. One participant explained how she had a patient yelling at her in her face and responded 'a bit like a red flag to the bull' by becoming angry and 'losing it' as a professional (GP3). She gave another example with a 'psychotic patient' saying, 'I understood where he was coming from… but I also understood he was a dangerous patient who I would, at all costs, want to calm him down and help him to help himself' (GP3). However, another participant recognised that anger:

> Is a normal part of grief, and it is a normal part of reaction to bad news or not having your expectations met… it's part of the normal emotional repertoire of reactions to those situations. So, it is something all healthcare professionals experience (GP2).

Sadness was another emotion participants referred to as challenging, with many examples about crying; 'they just burst into tears, or they ball their head off' (GP3). Participants struggled to know how to respond, unsure how to best provide support or avoid upsetting the individual more. One participant explained sadness mixed with anger and how patients/families can express 'sadness to the point that they would cry. Sometimes they are angry, and their anger sometimes is towards you, so sometimes you are at a loss of what to say and how to support them' (Nurse4).

Participants also named another common emotional reaction: frustration – an irritation with the circumstances. It was often explained with sadness and/or anger. Compared to the other disciplines, frustration was the emotion physiotherapists saw the most from patients. As one said, 'Frustration, a lot of them are quite upset, quite tearful, either just… and disbelief in some cases, and, yes, some anger but mainly frustration I'd say' (Physiotherapist3).

Some participants sought to explain or give a good reason why patients became emotional. For example, one participant said, 'because they're suffering from pain or whatever else is going on' (Physiotherapist2). Another explained why she thought patients become frustrated by saying:

> Because they can't do the things they used to, they're not going to be able to live out the things they thought they were going to be able to live out, so perhaps a sense of great sort of loss is very prominent in those conversations too (GP2).

While a participant was tearful during an interview, she said, 'I think probably that the patient feels like they've been let down possibly, sometimes abandoned... They probably feel this is all doom and gloom' (GP5).

When asked why emotions make conversations difficult, one participant said emotions influence thinking and behaviour negatively. She said an individual may 'not [be] thinking in a very logical way' (Nurse2) and went on to explain,

> Emotions can affect the way people see things, and obviously can affect their attitudes towards what's happened to them, and so they can actually perhaps verbalise in quite an extreme way in contrast to perhaps when they've had time to quieten down and see things in a slightly more calm way, then they may behave very differently (Nurse2).

Although negative emotions were indicative of difficult conversations for participants, positive emotions were sometimes present, mostly with a patient/family expressing gratitude or relief to know what was happening or what to expect. Three participants said that although difficult, those conversation outcomes were sometimes the most rewarding due to the patient's/family's positive response. One explained: 'Sometimes the patient can be quite

grateful that you've had that honesty immediately, that they're not led on'

(Physiotherapist3). Another participant said, 'It's amazing what patients can do when they

know what they're up against' (GP1). In awe, she later added, 'it's amazing how – what

resilience they have' and said patients have 'inexplicable courage'. One said that even after a

challenging conversation, 'it's really nice to be able to get the patient to where they need to

be' (Physiotherapist4).

Two examples stood out from other participants because I would not have classified them as

positive reactions. Two participants considered, 'stoicism', resignation, and emotions under

control as positive reactions. They said they were the most common and did not find them

as challenging as other reactions (GP3, GP4).

One participant spoke of patients'/families' reactions as positive, whereas other participants

considered them negative. She said the negative emotional reactions were normal and that

professionals should expect patients to express them because patients are processing what is

happening. However, to note here, she referred to these types of difficult conversations as

ones well led by the professional (GP1).

Next, I will explain when patients/families accept or deny the circumstances and how it can

affect their reactions.

2.2 Unpredictable patient/family reactions

Participants often explained that they struggled with the unpredictability of

patients'/families' reactions. One participant encapsulated this general view by saying she

was always nervous engaging with challenging situations because you 'don't quite know' how

it was 'going to go' (Nurse2). She said, 'You don't know how the people are going to react'

(Nurse2). She said there could be other issues that could come out that she was unaware of,

such as 'personal issues and relationship issues, family history issues' that she was not expecting (Nurse2). Two participants spoke about often wanting to 'rewind' or restart conversations whilst having them so they could go slower 'so that you will have to feel what will be the response of the [person]' (Nurse4).

Several reported that preparation — reading notes and letters before the visit — helped them anticipate potential questions. However, one participant explained the limitations of preparation. She said, 'Even if you've prepared yourself… you don't know what somebody's reaction will be until you're in the moment and you're having to think, and you're having to adjust as you go; it makes it all feel very uncomfortable' (GP2).

The key concern for participants was how they would respond to a patient's emotional reaction:

> What am I going to have to cope with? Is she going to break down in tears? Is she going to get angry? Is she going to go into denial? Is she going to stop seeing me again because she's going to become annoyed and upset that I've said that thing to her? All these unknowns. It's much easier to stick to your safe and previously carved-out relationship! (GP3).

Underpinning this concern was fear. Memories from past experiences came into play. For example, 'you remember the patient's face. I sometimes remember their name as well, and just think, gosh, that really scared me' (Physiotherapist4). Fear is discussed more in Chapter 6.

One of the main categories of difficult conversations described by participants was negative feelings and emotions (the others were sensitive subjects and conflicting expectations). This

section focused on patients'/families' expressions of negative emotions, making conversations difficult. However, another factor involved was differing expectations which I will explain next.

3. Differing expectations

Another predominant theme under the perception of what makes conversations difficult in practice was different expectations or a 'mismatch going on' (Physiotherapist1). Chapter 4 explained conflicting expectations as one of the characteristics of a difficult conversation. Here I explain how participants went further, deeper, to explain how these expectations can make conversations difficult. This dimension presented in different ways. One was when the patient/family had expected something different than the participant or the course of his/her condition. Another presented as conflict between the patient/family and the participant. Another was interpersonal feelings for an individual. I will go through these now and then explain the differences between the professional groups.

3.1 Participants confronting patients'/families' expectations

Although expectations could also be for the professional, participants often described differing expectations occurring when a patient/family was unexpectedly faced with the prospect of what will happen or should happen. As one participant described it: 'a direction change' (Physiotherapist1). Two participants said confronting patients'/families' expectations was the main source of difficult conversations. One explained:

> If you go in with what you think's going to happen and that doesn't happen, that feels
>
> uncomfortable. Then, if someone's telling you something that you don't feel is what
>
> you're expecting, that's when that conflict happens… It's when one party has a

different outlook or approach to another with a different expectation then I think that

causes a problem (Physiotherapist4).

Often participants expected difficult conversations based on the topic or situation; however,

some explained that:

They might come up in the middle of a consultation because perhaps I have a

different agenda to the patient or vice versa... Or I'm unable to meet a patient's

expectations, or I... [did] not follow down the pathway that they'd hoped to follow

down during the consultation, so it can then come up out of the blue (GP2).

Another participant explained differing expectations as 'a clash of either opinions' or 'a block

[for the patient]' (Physiotherapist2). For example, patients will often have an 'expectation of

the outcome of their treatment or the goals they want to achieve, and then they're not

always possible or realistic', which leaves the professional to clarify (Physiotherapist3). At

other times, the individual is not progressing as both had anticipated.

One participant said she would change the patient's/family's understanding of the

circumstances if she could. She explained why:

I think the more people understand then the less frightened and the less likely they

are to become upset. It is still very emotive; it is still upsetting, but they can at least

understand the situation, so you don't get as much conflict as you probably do with

some difficult conversations because of people's lack of understanding (Nurse2).

She found differing expectations to be a norm. Several participants mentioned how

important it is to clarify, explain or even try to turn patients' expectations around, suggesting

the need for a difficult conversation. Participants were able to explain and provide

understanding to patients/families and often found the differing expectations resulted from

miscommunication within the health care system. One participant expressed empathy for these circumstances and said, 'They've got to be pretty frustrated with the system, and I would say probably quite disappointed that things aren't going their way' (Physiotherapist1). She reflected how patients' expectations shifted over time, expecting more now than when she started working 19 years ago. She finds they are 'empowered' but also 'more demanding' (Physiotherapist1). One participant explained, 'If someone's got maybe insight to their issues; then they'll be more willing to have discussions with you' (Nurse3). Three participants spoke specifically about end-of-life and how sometimes the patient is not shocked or surprised. One participant explained, 'They've usually got much more understanding of the situation than we fear, I think' (GP4). Another participant verbalised how when a conversation about end-of-life care occurs, 'it is named' (GP1), which confirms the patient's insight and can help normalise it. However, one participant did not agree with the others and did not engage in end-of-life conversations - due to her fear of introducing thoughts of dying to the patient. She waited until it was clear the patient was resigned to it happening. She said, 'Maybe they accept that they are at the other end, but I in no way [give] assistance until this happens' (GP5). Acceptance can overlap with awareness, but participants described it as being open to talking and having an 'accepting attitude or behaviour' (Nurse4). When this was the case, 'if a patient's very accepting and open to talking about things, that can make the conversation not easy, but it can make it easier' (Nurse1).

3.2 Conflict between patient/family and participant and interpersonal conflict

A higher intensity conversation involved confrontation, a clash of opinions or expectations, which caused greater and sometimes extreme emotional reactions (section 2) and conflict. A

participant explained why conflict makes a conversation difficult, 'I guess nobody really likes confrontation. People like their lives to run smoothly, everybody to be nice, and things to go the way they want. When it doesn't, that does become difficult' (Physiotherapist4).

Conflict often occurs when the patient/family finds the information shocking or surprising, that is, a conflict from what they expected their reality to be. It also occurred when a patient did not understand the medical implications and expected to get better, but the professional did understand and knew the patient would deteriorate. Seven participants said that when the person was not accepting or 'in denial', it made the conversation more difficult. Participants noted how patients/families could adapt and normalise their circumstances by either accepting what was happening or living day-to-day and not seeing the bigger picture.

Three participants said that patients are often more aware of their deterioration than their families. They believed patients often protected their families, 'might minimise their problem' (Nurse3) and not share how they felt. Also, participants said that the family wants what is best for the patient, but often without an agreement on what is best, which is often due to it not being discussed, resulting in more complicated conversations with the family.

Participants described 'denial' as the person not wanting to believe what was happening or 'not ready to accept their diagnosis' (Nurse2) or 'won't accept maybe… that we're recommending treatment for them' (Nurse3). One participant said 'denial' mixed with grief can impact an individual; and sometimes only have a narrow focus on a problem or issue and could not see, let alone speak about, what was happening (Nurse1). She felt that if the patient/family were 'in denial', then the outcome (this could be the overall care and not just the conversation) would be poor.

Interestingly, two nurses linked denial to the outcome of visits/conversations. They described not having a plan in place or a patient not wanting to engage in a conversation as one not accepting the situation, resulting in a poor outcome for the nurses. One participant shared how patients' lack of information about their disease or condition, or maybe progression and prognosis, can cause a conversation to be difficult (Physiotherapist3). Participants said this often happens when another professional, such as a consultant from the hospital, had not disclosed information earlier or when they avoided disclosing information.

Another example was when participants felt a patient/family did not agree or trust the professional's opinion or the healthcare system. Sometimes this manifested into an 'us and them' scenario where patients believed the professionals were barriers or a hurdle and, therefore, against them. As one physiotherapist explained,

> I really struggled to get them onside or to get them to understand what my reasoning was and my capacity as a physiotherapist. I think they were very frustrated from the whole system, and I think I was the next person in line to see them, but they weren't necessarily listening to what I had to say (Physiotherapist3).

Sometimes conflict stems from the values and belief systems, cultural differences or, more fundamental than that, an inability to relate to the other person or understand her/his point of view. One participant had a conversation where she felt 'a disconnect' between her 'own beliefs and views, whether socially or religiously and medically' and the patient's (GP4).

Another form of conflict was from within or interpersonal and psychological. It came from wanting to remedy the problem or help patients, knowing there were no fixes or treatments

to cure. A participant explained the duality of confronting patients'/families' expectations and dealing with their interpersonal conflict. She said:

> Fundamentally we all want to be fully on the patient's side, and we fundamentally want to fix things; and therefore, conversations where we're not in that role, are always going to be more difficult. I think any sort of situation where there is conflict is always going to be difficult, so where one cannot provide what the patient wants (GP2).

She expanded on this later by saying:

> There's a conflict between our wish to make people better and the fact that we can't make people better, and that creates situation conflict. In these particular situations, there's a conflict between the patient's wish to, say, be completely independent and the fact that their health has failed and then they were no longer able to be [independent] (GP2).

Participants' desire to make a positive difference for patients conflicted with the reality of being unable to cure or help the person (explored more in Chapter 6).

3.3 Differences between professional groups

The theme, differing expectations, had dissimilarities between the disciplines in this study. Of the nurses, two out of four named differing expectations, but they did not expand much. For the GPs and physiotherapists it predominated, often with differing expectations about their role. One explained:

Essentially... there's a discrepancy between expectations of the patient of what a GP

can achieve and how much influence we have over things like housing and social care

and benefits; a discrepancy between what they think we can achieve and what we

can actually do (GP4).

All four physiotherapists expanded on differing expectations saying they happened around

three topics: patients' condition/progress, the physiotherapist's role, the times/types of

services available and sometimes a combination of the three. For example, patients may

attend their first appointment expecting 'scans or injections', but as one participant said,

'actually, that's not something that we would provide at physiotherapy straightaway'

(Physiotherapist3). They also spoke about the importance of establishing expectations at the

start and managing them throughout. Physiotherapist participants said patients'

expectations often differ from reality, causing friction when confronted. Sometimes they

believed this was due to a lack of understanding of their role, process, or to other healthcare

professionals giving incorrect information or patients misunderstanding it. In the end,

participants reported how dealing with these different expectations often turned into a

difficult conversation. One participant said, 'So you can kind of tell when somebody comes in

and says, "I'm here for my scan. I'm here for my injection," already my heart sinks. Then it's

like, oh no, here we go' (Physiotherapist1).

Next, I present how participants perceived time, mortality and uncertainty influenced difficult

conversations.

4. Time

The theme of 'time' in both restraint and pressures emerged early on by participants

stressing that 'time is a big factor' impacting conversations by not having enough of it (GP2,

Physiotherapist4). I asked participants how they worked around time pressures, and for those who said it was a barrier, I asked how they would use it if they had enough time.

The disciplines have different roles and convergent views on time constraints, with all five GPs, two physiotherapists and two nurses seeing them as barriers. One expressed how 'the time pressure' creates anxiety and worry and a conflict between 'wanting to spend more time on it' and the reality of not having the time to do so (GP4).

Many participants shared how they try to be supportive and listen during a sensitive conversation; however, there is not enough time to do this well. One said:

> There's a twist almost that happens really quite a lot, which is somebody comes in with something minor... you think you've dealt with all that it was about, and then the real, the real comes out, sort of already three-quarters in the way into the consultation when there's not much time left (GP2).

She also said, 'When things don't go well, it's often because of a time issue' (GP2). Having more time helps, especially if something unexpected occurs. Many participants verbalised the importance of developing trust and relationships with patients/families, which also takes time.

When I asked participants what they would like to change if they could, many said to have more time or more staff so then more time would be available to support patients/families. One participant said due to lengthy assessments she sometimes feels there is insufficient time to listen to the patients thoroughly and if she had time, she would spend it listening (Physiotherapist3). Participants said that when the time was limited, what helped was being prepared and having a structure.

All three disciplines identified time pressures; however, the nurses often voiced an ability to work around the problem due to their job structure. They would frequently visit patients, allowing conversations to be more ongoing and allowing them to continue conversations in following visits. However, one nurse also said that when pressed for time, she works extended hours. She was not the only one; other participants also responded to time pressures by working longer hours unpaid. The reason participants gave for the lack of time was the number of patients they needed to see in a day and to spend the extra time needed with the patient/family they must 'manufacture time' (GP2) later.

A difference within this theme amongst the disciplines was that all five GPs consistently raised the point that time was not always related to a difficult conversation, and that there was not enough time for regular consultations either. One participant explained how she ran late due to the 'very elderly' patients she saw who 'often need more time to get into the room or undress if you need to examine them' (GP2). Another said she ran late for all her consultations and reviewed and reflected on her issue with time. She found importance in the emotional side of providing care and added more time into her consultations to address it, regardless of whether they were difficult.

5. Participant's mortality

Early in the study, one participant spoke concerning how she thought about the impermanence of her existence. It occurred to her when caring for patients at end-of-life or with a life-threatening diagnosis. I wondered if this was similar for others and thus applied grounded theory (see Chapter 3 section 3.1) and added a question about mortality to subsequent interviews. GP1, GP2 and GP3 did not receive the additional question due to when their interviews took place. Nine of the thirteen participants said they often thought of

their mortality or the mortality of a close loved one when difficult conversations arose around deteriorating health and/or end-of-life.

For example, one said, 'if it's someone who's fairly close to you personally in age, demographic background or something, then it does resonate more with you' (GP4). One participant said the more personal the conversation was, such as with a patient you knew very well, the more one was to think about one's mortality (Physiotherapist1).

Sometimes participants reported being aware whilst it happened and could name it. One said, 'You think, oh my goodness, that could have been me' (Nurse1). She recognised the need to separate work and her personal life by stating, 'I have to continually remind myself that this isn't going to happen to yourself necessarily, just because you see it every day at work' (Nurse1). Another explained that you could have 'a very visceral response in yourself if you're giving a diagnosis to someone very similar to yourself, where you can imagine being on the receiving end of the diagnosis yourself' (GP4). She spoke of 'the raw emotional response that you might get because of fear of this happening to you, or memories that it evokes' (GP4). She expanded by saying:

> Well, at the most profound level... it makes you think about your own mortality and makes you think about the time when inevitably you will be diagnosed with some hideous condition yourself! So, it brings fear, I suppose, in you. There's the fear that this might happen to you one day... there's sometimes a little internal battle that goes on in your head [debating lack of professionalism by being distracted and] part of your humanity and how you understand them and empathise' (GP4).

One participant had a different line of thinking regarding her mortality, saying she had a 'settled mind' when thinking about her death but was concerned for others close to her and

said, 'sometimes, you are thinking this could be my parents' (Nurse4). Others also explained how their families affected their actions, such as 'you have to give more care because this always could be my parents' (GP5).

As a result of thinking about a loved one or oneself, participants reported 'that's where the emotion comes into it' (Nurse1). Moreover, conversations became more demanding as they invoked negative emotions such as sadness, fear, anxiety, guilt and a sense of added responsibility.

Four participants said they thought about their mortality before a conversation or after, on reflection, processing a visit, but not during one. Two commented on how it helped them in their approach and the delivery by asking themselves, 'How you would want to know about it, or how you would like [to be] treated in a sensitive way' (Nurse3).

6. Uncertainty of a diagnosis/prognosis or treatment options

When there was ambiguity regarding a patient's diagnosis, prognosis or treatment options, two of the thirteen professionals said they felt at a loss about what to say, making the conversation difficult. Specifically, they struggled with confidence in how much information to disclose, as they reported they did not want to scare the patient/family unnecessarily. When a diagnosis is uncertain, one tended to feel the patient was less accepting of what she was recommending, resulting in poorer outcomes for the patient (Physiotherapist4). The other participant explained how she had dealt with discussing the uncertainty of a prognosis with a patient:

So, I think I'm talking science, but I'm not giving anything the patient would really like to know. I'm communicating on a different sphere. I talk medical jargon about population. Patient wants to know about individual disease trajectory (GP5).

The uncertainty also pertained to herself. Whilst talking with her, she fluctuated back and forth between what she should or should not have said. She felt pressure from the patient/family and herself, leaving her doubting herself for not knowing the answers. The patient's/family's demonstration of negative emotions exacerbated it leaving her concerned about leaving 'emotional scars' on the patient/family (GP5).

Thus far, I have provided participants' perceptions on what makes conversations difficult in practice. Now I will move into the discussion of these themes.

7. Discussion

According to participants, most difficult conversations refer to actual situations, subjects or the anticipation of them for the patient/family or the professional. However, sometimes, the conversations do not give rise to difficult situations. This discussion analyses the indicators that emerged on what participants perceived makes conversations difficult in practice. It covers patients'/families' reactions and differing expectations, professionals' time pressures, their thoughts about mortality, the uncertainty of a patient's condition and differences between the professional groups. In this discussion, I will use Burkitt's (2014) theories on emotions and Parsons' (1991) social action theory and literature from the review to understand these results.

7.1 Patient/family reaction

A large body of research suggests that professionals find talking with patients/families challenging at times due to the patients'/families' 'emotions' or 'emotional reactions', predominantly anger, embarrassment, discomfort, sadness, distress and anxiety which is in accordance with my experience (Piggott et al., 2019; Fulmer et al., 2018; Chandar et al., 2017; Best, Butow and Olver, 2016; Berglund, Nassen and Gillsjo, 2015; Griffiths et al., 2015; Pfeil et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014; Mellor et al., 2013; Slort et al., 2011; Selman et al., 2007). I interrogated this literature for validation and to see if there was more to what I knew. Selman et al. (2007) named frustration which I also found. In a few studies, patients'/families' reactions or professionals' thinking of potential reactions impacted how professionals engaged and continued conversations (Griffiths et al., 2015; De Vleminck et al., 2014; Mellor et al., 2013). For Mellor et al. (2013), what compounded this was professionals anticipating potentially angry reactions, leaving them worried about being equipped to handle the responses. Specifically for patients with dementia, De Vleminck et al. (2014) found that GPs feared they would cause patients to be anxious or depressed. Negative emotions are common with grief (Dunne, 2004), which brings into question the need for more awareness and integration of emotional support and grief counselling in the process. Due to this thesis' word limitation, I did not explore this further, but more research in this area could be helpful.

This study's main findings support these studies that professionals' perceptions of patients'/families' negative emotional reactions challenge professionals and for all disciplines in this study, unpredictable reactions played a significant role. This study extends the evidence on perceived patient/family frustration as this was a strong emotion named by the

physiotherapists. My study augments the literature by finding that although these reactions were difficult for professionals, most likely due to a lack of training, the difficulty was more due to the professionals' fear (covered more in Chapter 6) about how patients/families would respond.   Next, I will discuss how professionals' and patients'/families' different expectations influence patients'/families' reactions.

7.2 Differing expectations

Existing literature speaks of a mismatch between parties, often with patients' expectations or understandings differing from professionals, including their opposition to a topic (Piggott et al., 2019; Pfeil et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014; Almack et al., 2012). Two studies found that professionals think the mismatch can also be due to patients' unrealistic expectations (Pfeil et al., 2015; Prouty et al., 2014). When patients/families are aware of or accept the circumstances, conversations become easier (Pfeil et al., 2015; De Vleminck et al., 2014). Bernhardt et al. (2010) found that professionals experienced interpersonal conflict when their values differed. My study supports these outcomes, suggesting that professionals could benefit from conflict resolution and coping skills. My study also supports previous studies in that communication can be difficult when there is a mismatch of expectations between professional and patient/family; a lack of insight or understanding can also cause conflict between the professional and patient/family. My study highlights that an unexpected mismatch during a conversation can trigger an emotional response in the professional, making the conversation more challenging, thus linking to my previous point (7.1) on professionals' emotional responses. I discuss this further in Chapter 6. A possible explanation of these findings and patients'/families' reactions could be the deviation from what Parsons (1991) called 'social control' (p.258) and what Brown (2008)

says is a change in society and culture seeing healthcare as a commodity. To explain this

further: Parsons (1991) would say that patients/families display negative emotions and

differing expectations, especially to the point of conflict, by not living up to the expected

patient role. The sick have 'relative legitimacy' if they play the correct role, upholding their

obligations within the social system (p.211). In the 'sick role', it is socially acceptable to

depend on others for care; the patient is excused from regular responsibilities as long as s/he

seeks help, cooperates with a professional and tries to recover (p.294). The person burdened

with the illness or injury receives some leeway due to '"natural" reactions to the frustration

of expectations' (p.202). In this study, this theory would suggest the professional should

tolerate the patient (which I also extended to include the family) demonstrating frustration

and having different expectations, but only to an acceptable limit, to maintain social control

and retain her/his position.

Over forty years, social values have shifted to 'self-responsibility, individualism and consumer

power' and view healthcare as 'another commodity in a marketised society' (Brown, 2008,

p.273). There are also societal changes that challenge the traditional professional and

patient/family relationship. Examples are patients/families having access to more

information through internet advances and an increase in litigation in healthcare, with most

cases being due to poor communication (Brown, 2008; Kaba and Sooriakumaran, 2007).

Over time, as patients became more autonomous, some professionals found value in having

the patient/family be more involved in consultations since 'patients are experts in their own

field' (Kennedy 2003, p.1276). These factors influenced policy, training and practice, focusing

on communication skills. The NHS now embraces and expects professionals to follow this

concept with 'The NHS Constitution for England' (2021), stating care must focus on the

patient's experience and goes further by pledging a partnership in care. However, it has

been a slow transition for some as communication continues to be a top complaint in the

NHS (PHSO, 2015; Brown, 2008). This culture shift may explain what professionals from this

study perceived as differing expectations. Patients/families may feel entitled to more from

professionals, even if the professionals may see it as unreasonable or implausible. There

could also be tension between social control. An expectation that patients should be passive

could be clashing with the expectation for patients to be an expert in their own

experiences/illnesses and know how to navigate the expression of this expertise, causing a

double-blind patient role. Continuing to use these ideas in the next section, I focus on

denying information or circumstances.

7.3 Patients/families 'in denial' and professionals' views of poor outcomes

Existing literature found that some difficult conversations were due to a lack of awareness or

understanding of the disease/progression/circumstances or were due to 'denial' or non-

acceptance of the information or circumstances; all linked to negative emotional reactions

(Piggott et al., 2019; Griffiths et al., 2015; Pfeil et al., 2015; You et al., 2015; De Vleminck et

al., 2014; Prouty et al., 2014; Mellor et al., 2013). One study considered this common, and

how patients/families coped with their circumstances (Griffiths et al., 2015). Some studies

found families more challenging than patients (Griffiths et al., 2015; You et al., 2015).

My study's findings have mixed results in comparison to these studies. Although half of the

participants in this study spoke about patients/families not accepting the information or

circumstances as challenging, a few recognised patients as more aware than their families.

This perceived awareness has developed with possible reasons to help explain the dynamics

of more challenging conversations with families.

As one participant said, denial can be a normal part of coping; however, professionals can also consider it a resistance to their expertise. In applying Parsons' (1991) idea of the 'sick role', perhaps professionals labelled patients/families as being in 'denial' because the patient/family was not abiding by his/her role in the patient-professional relationship. Professionals may view the individual as being in denial for not conforming, demonstrated by not trusting and believing the professional. This expected conformity relates to Burkitt's (2014) belief that all social relations involve power 'in some form or to some degree', leading to all emotions being 'interwoven into power relations, both shaping and being shaped by them' (p.150).

Due to increased litigations, distrust has become common between professionals and patients/families (Brown, 2008; Kaba and Sooriakumaran, 2007). Distrust could explain how professionals labelled patients/families as deniers since they were not guided with what the professional was saying. I was surprised that only one participant saw denial as a way for patients/families to cope or process what was happening, which adds to Griffiths et al.'s (2015) findings, albeit just one. Most did not see it as a possible lack of communication as it could be that professionals are not explaining treatments well or giving the whole story about disease progression. Why should patients be expected to know the severity and ramifications of a diagnosis if they are not told?

The finding that two participants who perceived a patient's/family's non-engagement with a conversation as a poor outcome could be because they focused on fulfilling their professional agenda and not necessarily the patient's agenda. As Parsons (1991) would argue, professionals may perceive this lack of engagement as patients not upholding their relationship's social requirements. The professionals adhering to this belief expect that patients are obliged to want to '"get well"', get help and 'cooperate' with them (p.437).

Therefore, when patients do not engage in the conversation or the plan, it is proof that they are not living up to societal expectations (Parsons, 1991). This can result in the professional feeling responsible for what they called a poor outcome or passing on the responsibility to the patient/family for not engaging.

Perhaps there is tension between what some professionals expect of the patient. According to Parsons (1991), society considers the professional the expert, and someone of 'authority, which is anchored in the values of the social system', knowing what is best and the patient accepting the expected 'obligation to "do his part"' by listening and doing as the professionals say (p.314, p.438). So, when a patient/family challenges or denies the information or circumstances, for the professional, it may be a denial of their authority and place in the social system.

7.4 Time pressures and uncertainty of a diagnosis/prognosis

Previous studies found that professionals consider time pressures as a barrier to communicating with patients/families, with their main complaint being that these types of conversations take more time than the system allows (Piggot et al., 2019; Fulmer et al., 2018; Chandar et al., 2017; Slort et al., 2017; Best, Butow and Olver, 2016; You et al., 2015; De Vleminck et al., 2014; Prouty et al., 2014). Most of these studies were with acute setting professionals, or a mix, with some GPs, mostly with doctors, and some with nurses. My study's findings support these findings. All three disciplines said that the lack of time creates pressure and stresses the professional. Because these conversations often have conflicting expectations and bring up negative emotions, time is needed to sift through them. Lack of time may not always cause a difficult conversation; however, when it is limited, professionals can feel compelled to compact information and support. Most likely intensifying the problem

is societal and system expectations of having patients participate more in their care, requiring more time (DH, 2013). The Queen's Nursing Institute and TKF reported that this is compounded for the GPs and nurses with an increased workload in quantity and complexity without increasing funding support, leading to staff shortages (Swift and Punshon, 2019; Baird et al., 2016). I could not find any supporting evidence on this point for physiotherapists. Training could include time management; however, due to the increased workloads and demands, having budgets supporting more time for professionals to spend with patients/families could have a much bigger impact.

A theme in the literature related to time is that professionals are often not sure when is a good time to initiate difficult conversations (Fulmer et al., 2018; Griffiths et al., 2015; Pfeil et al., 2015; De Vleminck et al., 2014; Almack et al., 2012; Bernhardt et al., 2010). My study does not support this since it was not a theme. It could be because I did not enquire about it, or maybe the context of the interview itself was not about a specific topic such as ACP. However, the timing of a difficult conversation is related to professionals' uncertainty of a diagnosis/prognosis in the literature and was a theme for two participants in this study (De Vleminck et al., 2014; Almack et al., 2012). Next, I will discuss uncertainty further.

Many studies in the literature review found uncertainty about a patient's diagnosis or prognosis as another layer of complexity that made conversations difficult (Piggott et al., 2019; Sellars et al., 2017; Lazenby et al., 2016; De Vleminck et al., 2014; Almack et al., 2012; Bernhardt et al., 2010; Selman et al., 2007). Some studies say the uncertainty of prognosis often leads professionals to avoid the sensitive topic (Lazenby et al., 2016; Almack et al., 2012; Portnoy et al., 2011; Selman et al., 2007), with Sellars et al. (2017) focusing on how uncertain prognoses can lead to medical futility. One study suggests professionals' uneasiness around medical uncertainty and disclosure of the uncertainty is linked to their

perceptions of how they think patients will react (Portnoy et al., 2011). My findings support

this, although with only two participants; professionals' perceptions of patients' reaction to

uncertainty influence the amount of disclosure. Uncertainty being common in the literature,

with sample sizes ranging from 12-53 and one with 1,500, I was surprised to find that only

two participants in this study mentioned it. However, in interpreting this, we must bear in

mind that this study is a small sample size.

7.5 Participant's mortality

Another strand of complexity illustrates that hidden under the surface of a conversation

about deterioration or end-of-life, the professional's mortality or the mortality of a loved one

may be influencing their response. Researchers have suggested that people's past

experiences and subconscious have a significant impact on them (Best, Butow and Olver,

2016; Bernhardt et al., 2010). This links to psychoanalytic and psychodynamic approaches

that emphasise the importance of examining feelings and developing an awareness of their

impact (Gibson and Gibson, 2016, p.19). As this is not a psychological study, I will not discuss

other links to these approaches.

Investigating spirituality at end-of-life, Best, Butow and Olver (2016) suggest that

professionals need to 'be comfortable with one's mortality' to discuss this sensitive topic with

dying patients (p.519). Fulmer et al. (2018) hinted at this topic, finding that doctors who

conversed with their own provider about their own end-of-life were more likely to ask their

patients about end-of-life wishes. This study also explored mortality and extending learning

by finding that professionals often think about their own or that of a loved one, and when

doing so, it impacts their emotions and often makes conversations more difficult. The

findings suggest that thinking about one's mortality can often help professionals have

empathy, prepare and learn. This finding generated more questions for me. What long-term impact does this have on professionals, and does it impact their balance of personal and professional work satisfaction, resiliency and possibly burnout? Is it, as Best, Butow and Olver (2016) suggested, that sitting with these thoughts and working through them is what builds resiliency and helps professionals, or does it hinder them? These would make interesting future research questions.

7.6 Differences between professional groups

Most themes, patient/family reactions, differing expectations, time, participant mortality, and uncertainty crossed the three professional groups. The differing expectations theme was more pronounced for the physiotherapists and GPs than for the nurses. For physiotherapists, this could be due to, as they suggested, the referrals they receive from other professionals misrepresenting their service or the reason for referral. As one physiotherapist said, there is often a systematic issue with a lack of good communication from those referring, impacting patients' expectations. However, it could also be the differences in the roles themselves, with the settings in which each profession works being the influencing factor on the professional's expectations: the nurses are more likely to work in the patient's home, a more intimate and personal setting, while the GPs and Physiotherapists are more likely to encounter patients in clinical settings. This is acknowledged but time and resources precluded exploration of this within this study; it would be worth exploring further in future. The difference in expectations for GPs could be due to their role in diagnosing and prognosticating, making them the first to counter patients'/families' expectations. Being less pronounced for nurses may have to do with their role whilst interacting with the patient/family since they provide care in the patients'/families' homes, in his/her natural

habitat, which may also make a difference. Physiotherapists see patients in an outpatient clinic, and GPs typically in a surgery, occasionally in their homes. Although the nurses in this study did not suggest it, it could be that the intimacy of being in someone else's home can impact interactions.

For patients'/families' acceptance aided through having difficult conversations, there was a notable difference in my study regarding the physiotherapists as it did not come up as it did with the other disciplines. It may be due to the type of discussions physiotherapists have with patients/families with GPs and nurses more likely to discuss deterioration. For example, when a patient is not progressing, s/he may not continue with physiotherapy appointments but would continue with GPs' and nurses' appointments.

8. Summary

This chapter covered some of the complexities of how professionals from this study perceived what makes conversations difficult in practice. It revealed how participants characterised their working world by detailing why they consider some conversations difficult. Reactions of patients/families and conflicting expectations were predominant factors. Conversations could be easier or mitigated if professionals had training on dealing with grief and emotions, including anger and conflict. The themes, time pressures, thinking about mortality, and uncertainty of a diagnosis or prognosis often cross-influenced with other complexities tangled in.

Another indicator of what makes conversations difficult is that many professionals personally react to negative emotions or conflicting expectations. This is discussed more in the next chapter.

Chapter 6: Findings and discussion on perceptions of interactions

1. Introduction

The last chapter presented participants' perceptions of what makes conversations difficult, focusing patients'/families' emotional reactions and perceptions of conflicting expectations and other influencers. However, the patient/family were not the only ones to have reactions; participants' feelings, experiences, and expectations influenced difficult conversations. This chapter will provide the research findings and analysis of how the participants perceived themselves interacting with patients/families during difficult conversations. The main themes are participants' feelings and emotions, and other influencers which aided them: having experience, a sense of duty, and the desire to feel helpful. The chapter also identifies differences between disciplines regarding these findings.

2. Professionals' feelings and emotions

Participants' perception of feelings and emotions, mostly negative ones, was a dominant influencer in considering conversations difficult for patients/families (see Chapter 5) and themselves, the focus here. One participant explained how others influence her feelings when there is conflict; saying, 'I tend to become more aroused; I tend to go red, my face goes red, my pulse is going faster, I've got some kind of pounding sensation in my head, that kind of thing' (GP3). Initially participants spoke in general terms about what emotions difficult conversations elicited. I had anticipated short and broad responses, which is why I had decided upon doing follow-up interviews in the design. The time between was helpful as participants gave more specifics within examples during the continuation of the interview.

This section presents participants' feelings and emotions, expands on one, fear, and explains how these emotions influence participants to avoid difficult conversations. Afterwards, I will explain participants' management of their emotions and how difficult conversations left them feeling afterwards.

Two feelings and emotions identified as 'positive', sympathy and empathy. Eight participants mentioned feeling sympathetic, meaning feeling sorry for someone and/or an understanding for another's experience or feeling empathetic, meaning 'putting yourself in their shoes' (Physiotherapist3). For example, one participant felt 'just raw sympathy for a patient' during a difficult conversation with a patient she knew well (GP4). One exception to seeing sympathy as a positive was when a participant said she sometimes feels forced to be (or maybe act) sympathetic even when a patient was yelling at her (Physiotherapist1).

Participants demonstrated empathy as a tool during difficult conversations. One participant said, 'I try and reason round it and see it from their point of view as much as possible' (Physiotherapist3). Another said, 'I always try and engage with the families' with 'kindness and compassion because I can't imagine what they're going through. It's obviously very hard, and I always try and be compassionate of their feelings' (Nurse1). One professional said it can be difficult to use this tool as it can conflict with maintaining professional boundaries. She said:

> Personally, I have a lot of empathy, maybe too much sometimes and I can get inside
> their situation. I can really understand their feelings, which makes it hard for me as a
> healthcare professional to try and, not put up a wall but just, you know, you can't sort
> of get too attached to all these patients in the scenarios because other [wise] you
> wouldn't be able to function, really, as a professional (Nurse1).

One participant thought patients want empathy from professionals saying it can be demonstrated by caring. She said, 'No-one cares how much you know when they know how much you care' (GP1).

Next, I will discuss the types of negative feelings and emotions.

Difficult conversations could be 'quite emotionally straining… quite hard going' (Nurse2). Participants shared many negative feelings and emotions during or after difficult conversations such as stress, fear, anxiety, sadness, frustration, anger, guilt, helplessness, distress, discomfort, exhaustion and unsettledness. The individualised feelings and emotions experienced fell into three categories. One category was the participants' feelings towards the patient/family or the circumstances. The second was related to their perception of the patient's/family's emotional response (or the expected response). Often these two categories overlapped. The third category was the participants' comfort level and experience of the circumstances.

Established rapport and trust influenced participants' emotions towards the patient/family or circumstances and exacerbated feelings if the participant had a close relationship with them. For example, one participant shared that she could get self-conscious and anxious,

> that sort of pit of the stomach feeling of, where to start, am I going to get the tone or the wording wrong… So, moving to the concept of helping people, not necessarily in the way of prolonging life, but making people comfortable is still a very difficult emotional thing to process (GP4).

Similarly, for another participant, a patient wanted treatment because he was expecting to get well, but the participant knew the treatment would not help. She said, 'I'm aware that I

am just planting a bomb in front of the patient, and I think it's like I am leaving [him] with explosives… It almost feels harrowing' (GP5).

Negative emotions seemed to intertwine between patient/family and professional. Participants shared examples of this second category of how these displays of emotions by patients/families influenced them, triggering their own internal emotions. As one participant said:

> I feel that I feed off that person's emotions, and so, therefore, I can probably create a more difficult situation than it needs to be because I don't like feeling uncomfortable. I don't like feeling that the patient is unhappy, and so that makes me anxious (Physiotherapist4).

One participant suggested that professionals should not take patients'/families' reactions personally because, 'the vast majority of the time, it has nothing to do with you… it's what they brought in with them' (GP1). Unfortunately, according to the participant, the professional often has an emotional response triggered by the negative emotions witnessed in the room. She also suggested that the professional's response is often not related to the circumstances but to the professional's feelings and can be due to 'something going on in our own lives' (GP1). Another explained how the patient's display of negative emotions impacted her:

> It sort of will start a depression building, the emotion, and I don't know how to handle it. When I am face to face with a person, and when this person will show his emotions, like he becomes upset and he become[s], he start[s] to cry, I don't know how to handle this. So, it's a little bit scary for me, but sometimes if you try to appease them, they would get angry at you, and then you're – you don't know what

to do. You will be there staring at them, and then you don't know what to say

anymore (Nurse4).

These emotional reactions or the thought of them produced fear for the participant. As fear

stood out in the findings, I will share more about this theme in the next section.

2.1 Fear

The theme 'fear' / 'fear, you know, the fear factor' (GP3) came up in the initial interviews and

was a predominant negative emotion expressed as being experienced during difficult

conversations for participants. Participants explained that fear means being afraid or

'daunted of what's going to happen' (Physiotherapist3). The sources of fear varied among

participants, from perceived patient/family reactions, causing harm, receiving a complaint,

and participants fearing their own reaction. One participant said some patients reminded her

of her mortality, which frightened her.

Eight participants said, 'being afraid of the unknown, being afraid of not knowing how your

patient will react' (GP3). As presented in Chapter 5 participants' perceptions of a

patient's/family's unpredictable emotional reaction involve imagining what could happen

often reminding them of similar situations from their past, afraid the reactions could happen

again.

Four participants feared they might cause more harm than good, especially for one

participant who was afraid she caused a patient's deterioration by informing the patient that

she was dying. She said the patient 'gave up' and quickly deteriorated (GP5). She mentioned

another patient saying, 'I reduced her life quality for probably the next four months because

all she was thinking about is that she has cancer' (GP5), shouldering responsibility for a

patient's decline. This fear impacted her still as she was afraid she may cause others to give up on living.

Five participants spoke either about complaints or fear of receiving one. One shared, 'There's the fear professionally of getting it all horribly wrong and that patient forevermore thinking of you as a really heartless, uncaring doctor, or putting in a complaint about you' (GP4). None of the nurses mentioned complaints which could mean a divergence for this professional group.

Fear produced delay and dread for participants and it left them unsure of what to say or do. One participant listed different reasons for fear: being 'afraid to tell people bad news', 'people's reactions', and how 'sometimes it can initially be an easier option not to face the difficult topics', but also said 'it can build up and then it just makes it a lot worse' (Physiotherapist3). This theme of avoidance is explained more next.

2.2 Avoidance

A theme that emerged early in the research tied to fear was 'avoidance'. As one participant said, fear can create a barrier and inhibit one from initiating the needed conversation. She said:

> It's so easy to hide behind tests and not really get to grips with what needs to be discussed... It's one of these coping things that a lot of doctors do... so you do a test, they've got to come back for a result. So, if the results are normal, then it's really good, so you can say, 'Look, it's all fine, everything is absolutely fine, this is brilliant, your kidneys are brilliant, everything is brilliant'. So, if everyone goes out feeling brilliant and then you haven't really dealt with what's really wrong! (GP3).

Even when treatment was not working, participants said there were times they would avoid telling the patient. Some explained it as putting the patient off, choosing their battles and/or being a 'cop-out' by referring to another professional (Physiotherapist4). One participant gave an example of what she would say, 'I would just stop right there and would just explain to them that perhaps it's better to continue the conversation some other day' (Nurse4). Participants shared how this can often happen when they have an insistent, angry and/or usually demanding patient.

Over half of the participants spoke about avoiding difficult conversations. The main reason was that 'people are afraid of people's reactions' (Physiotherapist3) and used avoidance as a strategy to manage emotions. This participant continued by saying:

> I think sometimes it can initially be an easier option not to face the difficult topics like goal[s]. I think people are afraid of upsetting the setting and things like that until it absolutely becomes essential, and then it becomes a lot more difficult (Physiotherapist3).

Another reason four participants gave was a desire to please the patient, with two wanting to make the patient happy to circumvent a complaint, and another two worried about how patients/families think of them. Participants also mentioned the lack of time as an influencer for avoidance (Chapter 5, section 4). One participant saw engaging with emotions or complex information as prolonging conversations. She said:

> If I feel like the conversation is about to have to go into something complex or difficult, or that's going to take a long time, and I'm already running very late, I might kick the can down the road, suggest another blood test that suddenly pops into my

mind or, 'Oh let's talk about this next time'. Prevaricating, deferring. I'm certainly

aware that I do that from time to time (GP4).

There were differences in how certain participants tended to talk about avoidance compared

to the whole group. For example, the physiotherapists tended to talk more about referring

patients to specialists and/or for scans and imaging, sometimes to appease the patient and

avoid conflict. At other times they refer so the patient can hear from another professional,

often a doctor who has oversight and responsibility of care, when they think the patient will

listen to and believe more. One shared that she believed that sometimes going against what

is medically known and referring on can help a patient come to terms with something and

move past the thought of a possible error. She said, 'they just cannot mentally move on'

without hearing a second opinion (Physiotherapist1).

Participants also see other professionals (usually from an acute setting but also in the context

of multi-disciplinary working) avoid conversations and how this impacts their work. When no

one discusses the patient's potential outcomes or prognosis, the patient is often left in the

dark, and the pressure builds for the other professionals involved. A participant explained

how often the conversations are too late or other professionals should have had it sooner. In

speaking about end-of-life circumstances, she stated, 'nobody ever discusses the end.

Everybody discusses the treatment. Everybody shies away from discussing the end unless it's

glaringly obvious that the patient is going to die in maybe one or two weeks' (GP5).

Although participants knew they avoided these conversations, five shared that they thought

they should not. When one participant was reflecting, she said, 'I've kind of reasoned it in my

head that way, but I know I should be able to, in my job, I should be able to tell them'

(Physiotherapist4). Sometimes participants recognised it in hindsight, but sometimes they

knew the conflict existed and rationalised it away. One said she could see the need for the

confrontation; however, she struggled and was conflicted about what to do. She wished she

had confidence and concluded, 'I don't think I am at that stage, so it will take a bit of work'

(GP3).

Next, I will present participants' views on how they struggle to manage their feelings and

emotions in these conversations.

2.3 Managing feelings and emotions

Many participants struggled with managing feelings and emotions during difficult

conversations. Participants were coping with three things: the emotions/feelings they

perceived others in the conversation demonstrated (discussed in Chapter 5), how others

influenced their feelings and emotions, and internal feelings and emotions. These last two

are often intertwined.

The emotions showed by the patient/family sometimes left participants doubting themselves.

As one said, 'Have I presented the information in the right way? Have I given enough

support?' (GP2). She continued, 'If a patient is really struggling, you then think, should I be

doing this differently? Have I done it right and so on?' (GP2). When I asked one participant if

she could change anything during a difficult conversation, what would she change, she

answered, 'Well, I would stop myself being fed by people's emotions. I think that would help

me personally' (Physiotherapist4).

Participants said they had 'to be strong' (Nurse4) to cope. Being strong meant they must

'just hide it up' (Nurse4) or keep their feelings and emotions under control to stay focused

and help the patient/family. One participant spoke in the third person about how the

reaction of the patient/family is 'a reflection' of the professional's ability to have the difficult

conversation without showing their own emotions (GP1). She said, 'somebody who builds themselves up and presents in a calm, trained manner that gives them all the information about what things are available' (GP1). Participants gave a range of reasons for wanting to keep their emotions under control. For one, it was about 'thinking clearly' (Nurse4). Another participant explained how she does not 'get too involved', by remembering her role and not letting her own 'personal opinions in any way show' (Nurse2).

Five participants struggled with keeping their feelings and emotions at bay during and after a difficult conversation because they often 'pick up the emotions of the person' in the conversation (GP2). One participant explained, 'so, you do sort of absorb some of those feelings, and you have to sort of go away and process them and put them down again [laughs]' (GP2). Another participant explained how she 'feeds' off the patient's emotions:

> I tend to react to that person, so if the patient is angry and defensive, I can feel myself becoming angry and defensive of my profession in my thoughts. If a patient gets very upset, I then think, oh my goodness me, I have to try and help the patient. This patient is at the end of their tether. Emotionally quite exhausting sometimes because you feel that you want to take on all their angst and all their upset so that they feel better when they walk out, and you feel completely drained at the end of it (Physiotherapist4).

One participant explained her struggle saying, 't's sort of internally… I can feel my heart rate going and, but then obviously you're trying to keep calm on the outside, trying not to show emotions' (Nurse3). To manage the emotions, participants described how they create a barrier to staying in the conversation and not letting their emotions take over, such as inserting another subject in the conversation as a distraction.

156

A participant dealt with her emotions by rationalising the situation. She said, 'When they're older, you can say that [they've] already have had their life... So, in order not to be very emotional, that's part of it' (Nurse4). Moreover, as mentioned before, participants often avoid sensitive subjects altogether. If discussed, some participants reported avoiding the emotions. For example, actively avoiding family members during a conversation, by not making eye contact or not engaging them. The reason was to save time or help keep the emotions contained for themselves or the patient/family. One participant shared that she avoids emotions in these conversations, but sometimes she is not successful saying, 'I'm not very good at dealing with negative emotion, and one of my ways of coping with that is to try to keep the emotion out of it if that makes sense, but you can't always work' (GP3).

2.4 Emotions after a difficult conversation

Participants reported having a mixture of emotions after difficult conversations. Some shared how adversity produced confidence and satisfaction even with challenging conversations, especially with a plan or the next steps agreed. One participant shared feeling at odds with a sense of accomplishment with a sad topic. Another explained how she did not allow these conversations to influence her, saying, 'I can't let every conversation, or every palliative patient bring you down because otherwise you'll be depressed in this room all day' (Nurse1).

Five participants shared how difficult conversations left them upset and sad. One said, 'you're left feeling miserable and deflated, partly because she's so miserable and deflated, but also because professionally you haven't got a magic cure for it' (GP4). These feelings, absorbing the patient's emotions and being aware of medicine's limits, were combined with feeling incompetent and powerless. She explained, 'your gut response is that feels like a

failure… You've failed as a doctor to make her better, to cure her' (GP4). She recognised these as embedded thoughts from her professional training; however, she struggled to see it differently. She said, 'It's about thinking about success in that situation in a different way, in perhaps helping the patients see their illness in a different way' (GP4).

Some participants described how past difficult conversations left an impression, an emotional footprint of sorts on some participants, making it hard to forget or let go of them. It was common to hear, 'that was some years ago now, but it's stuck in my mind' (GP4). One participant kept repeating, 'I remember them, I remember them' when recalling conversations that had influenced her (Physiotherapist4). She said, 'I remember how I felt in that time…, which is weird. I've got some horrible psychological connections to that situation' (Physiotherapist4). These experiences left a psychological mark, and for some, 'they haunt' them (Physiotherapist4). This haunting was often due to what the participant considered a poor outcome and worsened when she did not know how things turned out. This experience, in turn, left her with doubt about future cases.

Four participants were noticeably emotional during the interviews in describing their experiences. Two, for instance, cried. One participant shared, 'I mean yesterday having this discussion about this particular patient who is possibly terminally ill, I wanted to cry and, to be honest, I have been crying, like feeling tearful on and off since that conversation yesterday' (GP3). Another found the interview particularly taxing, saying, 'I think I'm drained!' after we were done (Nurse4).

This section focused on the themes related to participants' feelings and emotions. The next section will present other influencers of difficult conversations.

3. Other influencers to difficult conversations

Outside of feelings/emotions, three other themes emerged. These themes were about professionals' experience level, duty of care, and desire to feel helpful to the patient/family.

3.1 Work experience

Nine participants spoke about their work experience, lack thereof, or gave an example of how it influenced difficult conversations. Participants' years of experience varied. Two nurses and one physiotherapist had had four years or less in their role; one with a recent role change with an increase in having difficult conversations. Three GPs and one physiotherapist had over fifteen years of experience. The remaining six had between five and thirteen years of experience. Although the study looked at training and participants agreed training helped, due to the focus on professionals' perspectives and the lack of word space for this thesis, presenting more detail will not occur here. The following explains the theme further.

The impact of work experience had three main commonalities. Firstly, having it helped participants when having difficult conversations. A participant shared how she used to find difficult conversations 'emotionally challenging', but she thought that maybe because of experience, she now can 'put… [her] own personal emotions to the side and focus more on the patient, where they're at and how I can support them' (Nurse1). A GP participant said doctors have 'no training at all, none, nothing. You just come out of medical school having been taught anatomy' (GP1). She stressed the importance of learning communication skills. Two participants said their experience prepared them by exposing them to different patients and giving them practice and confidence in having difficult conversations (GP3, Nurse1).

Secondly was having experience related to specific issue knowledge, such as a disease or a situation around a diagnosis. Two participants shared that sometimes, they found a conversation more challenging when they lacked expertise with the topic or issue.

Thirdly was that several participants said they still found conversations challenging and uncomfortable even with experience. One participant said, 'I think it's an important skill-set, and it is something I have to use quite often, but I am still conscious that one can still feel quite uncomfortable' (GP2). Another said, 'It's really hard because I can really muck it up sometimes' (GP1).

However, three participants stood out. Two admitted they avoid these types of conversations. One shared that she did not have enough work experience with difficult conversations, so she attended the workshop. She was tearful at times, explaining how challenging she found them. However, when I spoke to her in the second interview, she explained that she felt more able to engage in difficult conversations following training. She explained that the work experience had helped her become less afraid of them. With over ten years of experience, the third participant shared her ongoing struggles with these conversations, became tearful whilst explaining the multiple barriers with them.

Next, I will present participants' duty of care regarding engaging in difficult conversations.

3.2 Duty of care

When participants did engage in difficult conversations, ten reported feeling a sense of responsibility, something required or a duty of care. One participant described it as 'something that is part and parcel of what we [do]' (GP1). Another described communication

skills as 'the base stone of our work. If you can't communicate effectively with people, then

you can have all the medicine in the world, and you're still going to be struggling' (GP2).

Five participants said having difficult conversations was something they should do; however,

sometimes struggled with them. As one said, 'You have a role to certainly bring certain

things to their attention so that they are informed of their situation' (Nurse2). Furthermore,

in doing so, participants 'might tolerate more negative things with a patient' (GP3). Several

spoke of professional responsibility, 'it's just got to be done' (Physiotherapist1), that they

wished sometimes they did not carry. One said, 'You wish you wouldn't have to give this

news' (GP5).

Nevertheless, being 'professional' for these participants required relaying and dealing with

patients/families responding to the information. Professionalism entailed engaging with

things they did not want to listen to or act on. Even if the other person is verbally attacking

you:

> You have to kind of listen, of course, you have to listen, and it's very difficult having
>
> somebody ranting at you, and you're, at the same time, trying to be very sympathetic.
>
> Of course, it's the right thing to do, but I think instinctively if somebody ranted at you
>
> like that in the street, you'd walk off. You wouldn't give them the time of day, really,
>
> but actually, it's a professional thing, that you have to kind of sit there and listen to
>
> that' (Physiotherapist1).

For many participants dealing with the patient's/family's reactions was an obligation, and

with this obligation came strain. One painted a picture of professionals carrying a heavy

burden in their role: 'I think it's the duty of the doctor to make the patient aware [of] what's

161

in front of them, and they're usually plodding along happily. They don't really expect it, so it's unexpected and serious'(GP5).

The participant assumed that addressing the sensitive subject would worsen the patient by just having the conversation. There was a sense of ambivalent professional responsibility to tell patients versus to make them better. Another participant said:

> You don't really want to feel like you're making somebody worse, like making somebody feel maybe a lot worse, you have to have this conversation but then also you don't really want to upset anybody, make anybody more distressed, that sort of thing (Nurse3).

Some participants spoke about how they must allow patients'/families' reactions whether they like it or not (GP3, Physiotherapist1, Nurse1, Nurse2), and maintain their professionalism, such as 'I have to be very careful that I keep my professional face on, as it were' (Nurse2). However, it did not mean it was not challenging for them. As one said, 'I felt a bit, let's say, scared that she was going to shout at me [laughter]. That sounds a bit daft, really, but it's very difficult listening to somebody [shouting at you]' (Physiotherapist1). Recalling examples, she shared how it did impact her emotionally, 'it didn't leave me feeling great afterwards, but you just have to accept that' (Physiotherapist1).

It was part of the job, but also something more. The reactions were something several participants recognised as a response to expect as the patient/family processed the information or situation and participants allowed them space even when patients/families lashed out. Professionals recognised a pull within themselves and said they resisted the automatic physical instinct and emotional response of fight, flight or freeze.

Three participants shared how they felt they should know all and have all the answers (GP4, GP5, Phsyiotherapist4). This expectation put pressure on them. Although they acknowledged they could get support, they were reluctant to ask for it.

Participants also expressed a desire to feel helpful to patients/families, which is presented next.

3.3 Participants wishing to feel helpful

Twelve participants said they 'fundamentally want to help patients' (GP2). This theme had two sides to it; being to assist or support and problem-solving such as removing the barrier, finding the diagnosis, 'sort things out,' or curing the patient. Some participants spoke of both. For the first point, one participant explained, 'well, I think as a health professional, you probably just want to help, try and help' (Nurse3). She explained the second side of helping, saying, 'People come to you because there is maybe a problem… Because they're not well, as well, or they've got issues that they want help with' (Nurse3). Often, professionals want 'to fix' (GP2, GP4) what is wrong with the patient, solve problems, or restore a sense of balance, such as giving the patient something or finding a solution when the patient receives bad news. Professionals explained it made them feel useful and demonstrated something tangible that they did in their job.

GPs tended to talk more about problem-solving than the other disciplines. Interestingly, one GP moved into palliative care by the second conversation, did not speak of 'fixing', and emphasised that one can still help the patient/family even when there is no treatment (GP1). One participant explained how being honest, developing trust, and going at the individual's pace can help patients/families, but said it is important not to give false hope. Here she explains why she thinks it is essential to have difficult conversations saying:

I think if you do it and you do it well, I think that can help also with - sort of have an impact on their future, how they might engage with treatment or how they might seek help in future (Nurse3).

Helping patients/families either by supporting them or by problem-solving or both surfaced for most participants for why they have difficult conversations.

Next, I discuss my analysis of these findings.

4. Discussion

This chapter's findings focused on participants' perceptions of interacting with patients/families during a difficult conversation. The main findings showed that participants' feelings and emotions predominated, influencing conversations, with fear as the primary influencer. Fear often led participants to withhold information or avoid difficult topics. The findings explained how some participants said they struggled to manage their feelings and emotions, leaving them with mixed experiences on how these conversations left them feeling post-conversation. Participants thought work experience, the duty of care, and the desire to help the patient/family, were also involved. This discussion will analyse the literature review and other reading material to help interpret these results.

4.1 Emotions, a crucial complexity

Conversations have layers of complexity and difficulty, especially with multifaceted health conditions (Owens et al., 2017; Berglund, Nassen and Gillsjo, 2015). An inner layer is the professional's feelings/emotions (Best, Butow and Olver, 2016). Best, Butow and Olver (2016) found that when doctors talked about spirituality with patients with advanced cancer,

conversations were more challenging if the professional got emotional than if only the

patient had an emotional reaction. My research is consistent with this existing research.

In trying to understand the complexity, I followed in the direction of the most reoccurring

theme, negative emotions, and sought theories to help explain further. Burkitt's (2002,

2014) work helps make sense of participants' accounts of the interactions between

professionals and patients/families. He argues that emotions are not just the physical effects

but also the dialogue with self and others, 'yet are deducible to neither' (2002, p.153). He

disagrees with the 'basic emotions' theory that stemmed from Charles Darwin's work, that

emotions 'are states of neurophysiology arousal that have emerged in human evolution' that

became '"hard-wired" into the brain' and are expressed by the body (2014, p.25-26). He

argues against this simplistic answer because it does not explain emotions' complexities and

expressions (p.25). Emotions are 'intricate phenomena' that are hard to understand but also

'consist of many different aspects of experience which are connected together' (p.14-15).

Therefore, 'a complex understanding of emotion allows us to understand how socially

meaningful relationships register in our body-minds and, at some level of awareness, are felt'

(p.15). As humans, we can have multiple feelings at once, be unclear about how we are

feeling, and in trying to use language, find it hard to say what we feel or know how to express

it with words (2002, p.160). We feel as we think and think as we feel with 'our thoughts,

memories and mental images' having 'an affective valence, moving us to feel something as

we think, remember' or imagine certain scenarios' (2014, p.58). Additionally, Burkitt

highlights the importance of each person's 'prior values, identifications with others and sense

of belonging or alienation in relation to various groups - intersecting social relations and

placing them in unique relation to others, or to situations and events' (p.150-151).

Therefore, these interchangeable thoughts and feelings mixed with the unique relations may

help explain how professionals from this study felt uncertain, cautious, and even afraid as they suspected or knew how patients/families *could* react due to previous experience.

In trying to understand the complexities further, I will next discuss feelings and emotions, expanding further on fear.

4.2 Feelings and emotions

Multiple studies found that professionals experience negative feelings and emotions such as sadness, anger and distress present when engaging in sensitive topics (Fulmer et al., 2018; Chandar et al., 2017; Best, Butow and Olver, 2016; Berglund, Nassen and Gillsjo, 2015; De Vleminck et al., 2014; Mellor et al., 2013; Slort et al., 2011; Bernhardt et al., 2010). One, in particular, fear, relates to several issues, such as professionals not wanting others to perceive they are giving up on patients or for patients to lose hope (Chandar et al., 2017; Pfeil et al., 2015; De Vleminck et al., 2014; Almack et al., 2012). Other issues are that professionals fear they may embarrass the patient or the patient might think poorly of them or lose confidence in them (Mellor et al., 2013; Bernhardt et al., 2010).

My study agrees with these findings, with the crux of participants' challenges being negative feelings and emotions. Professionals witnessed and perceived these from patients/families (discussed in Chapter 5), experienced them themselves or both.

Participants named feelings and emotions in the interviews as if they were the same, as did I when coding them for analysis. In trying to understand this inner complexity, I recognised a subtle difference between feelings and emotions and how they intertwine. Therefore, I sought new readings to help explain these differences. Burkitt (2014) says that feelings are physical sensations that are 'central to all experiences of emotion' and the 'social meaning we give to perceptual experiences and the context in which they arise' (p.7). He says, 'this is

why certain bodily feelings are felt as emotions while others are experienced as feelings'

(p.7). He explains that feelings do not always equate to emotion, although emotions come

from feelings providing a possible reason for how participants articulated emotions and

feelings in a fluid, interchangeable way, and how I grouped them.

Then there is language. Language, developed over time, and used to express how we feel,

also has limitations. *What* we say is not the only way we communicate our feelings. *How* we

say it matters because it also shapes *our* feelings and emotions *and* influences others,

resulting in words becoming 'part of the feelings' (p.71). Burkitt emphasises this shared

experience with others, this relational dependence. He wrote:

> The words give shape, sense and meaning to feelings and emotions that change as
>
> social relations change, and, with them, as forms of language and social practice
>
> change; as this occurs new feelings and emotions appear that make sense in the
>
> social relations of that particular time and place (p. 70).

Applying Burkitt, I think the experiences and the feelings and emotions in the experiences

participants shared resulted from at least four factors I will now explain. Two factors were

their feelings and emotions, as they remembered them to be, and feelings and emotions

from conversations before the one described. One participant gave evidence of this, saying,

'There's a snippet of our personal experience feeding into how you manage the situation and

how you communicate' (GP4). The two other factors are 'own interests' and what

participants anticipated would happen during that conversation or could have happened

(p.55). An example is 'fear', a strong theme identified in the literature, leads professionals to

avoid difficult conversations (Piggott et al., 2019; Lazenby et al., 2016; Mellor et al., 2013;

Ahluwalia et al., 2013; Almack et al., 2012; Selman et al., 2007). My study augments this, that

many participants experienced fear or discomfort and uneasiness due to various factors

resulting in the uncertainty of what to say. These cross over with interpersonal conflict as discussed in Chapter 5.

To help explain further, I looked to Burkitt (2014), who draws on the pragmatic philosopher William James' (1884) work in *What is an emotion?* They explained how one's experience influences current and future situations (Burkitt, 2014; James, 1884). This influence is because 'it is not the situation itself that governs what we feel, but our own relationships to that situation and the people in it' (Burkitt, 2014, p.135). Thus, the thoughts that come to mind and feelings are 'the symptoms of the emotions', which can influence individuals the same way as having had the experience (James, 1884, p.197).

Therefore, having or even imagining a difficult conversation can influence a current or future conversation because just the thought of how a conversation could go can 'have the same effect' (James, 1884, p.197). Cognitive psychology may argue the same, but it is not a focus of this study and is therefore not discussed. Burkitt explains that how we feel has to do with the:

> Relation between different thoughts and the tendencies within the stream of consciousness, connecting up our thoughts and experiences as *ours*, belonging intimately to ourselves. …Feelings are the vital aspects of experiences, the things that make us know we are *alive* and *living* the experiences that happen to us or living the thoughts that emerge in the stream of consciousness (p.58).

He argues that people cannot separate emotions from conversations, even when they want to.

Participants wanted to be professional by trying 'to keep the emotion out of it'; however, it was not always possible (GP3). They were also uncomfortable or afraid of how the other

person in the conversation would react augmenting the ideas of Burkitt and James and were unsure how to respond to the patient/family. I think they were afraid these reactions would become overwhelming. I suspect anticipated responses impacted the immediate conversation and future ones, leading professionals to avoid them.

Next, I will discuss understanding professionals' feelings and emotions.

4.3 Understanding and managing the emotions of difficult conversations

Some participants struggled to manage their feelings and emotions, highlighting the conversations' complexity. Some were frustrated by patients/families who appeared to resist help. I had to look beyond the current conversations to understand this finding.

In the literature on suicide, with applicability to other situations, Morgan (1979) called attention to the danger of 'malignant alienation', which occurs when the therapeutic relationship is failing between patient and professional, 'including loss of sympathy and support' (Watts and Morgan, 1994). It can result in blaming the patient/family (consciously or subconsciously), leaving the individual(s) feeling isolated and without help (Watts and Morgan, 1994). Although professionals may not see the benefit, there is value in 'bearing witness', meaning, 'attesting to the veracity or authenticity of something through one's personal presence', a demonstration of empathy and validating experiences (Cody, 2001, p.289). Some consider the act of bearing witness to be a professional's honourable obligation and, when not done, it can be harmful to the patient (Cody, 2001; Naef, 2006). This research found that for some participants, it was hard to discern between being unable to stop a disease's progression and doing nothing for a patient. As some explained, professionals come into their profession to make a difference; however, becoming ill is not always resolved by getting better. There is this conflict from within, 'the wanting to always

be able to fix things and always be able to make things better', leaving the professional distressed when they cannot (GP4). This area may be suitable for future exploration and research, especially within training. Next, I discuss managing feelings and emotions, the duty of care and wanting to feel helpful.

Almost all the professionals from this study said they wanted to help patients/families, and many felt an obligation or a sense of duty. However, all struggled with emotion management during difficult conversations. I first look at Arlie Russell Hochschild's theory of emotional labour to see if it is consistent and to help explain my findings. Afterwards, I look at Burkitt's (2014) counterargument to emotional labour.

4.3.1 Emotional labour

Emotional labour is where a worker masks her/his true feelings about a situation and expresses only what the employer expects (Grandey, Diefendorff and Rupp, 2013). Humans learn how to manage feelings and then portray them outwardly, often as something else that is socially acceptable in public (Theodosius, 2008; Hochschild, 1983). The difference between managing those emotions in everyday 'private' life and doing it for work in 'public' is essential to the concept of emotional labour (Theodosius, 2008, p.15). Moreover, knowing what emotions are acceptable to display are 'Standards used in emotional conversation to determine what is rightly owed in the currency of feeling', which Hochschild (1983) calls 'feeling rules' (p.18). Considering how emotional labour relates to this study, it may be that participants laboured over what emotions they could display. They not only had their internal feelings and emotions to manage due to the situation, for example, disappointment for not doing more for a patient. They also had to manage their emotional reactions to the

feelings and emotions displayed by patients/families, resulting in both the circumstances of the job and the people they care for impacting their emotions.

Theodosius (2008) argues that in the context of healthcare, professionals also have a 'collaborative and therapeutic relationship built up' with each individual involved 'a passive participant in emotional exchange' (p.33). She argues, 'It is the power of emotions that can hurt or support' (p.48). Keeping the distinctions of context and therapeutic relationship in mind with emotional labour theory might help explain this study's finding that participants reported hiding their feelings and emotions. Participants viewed their duty of care to have difficult conversations as something they wished they did not have to do, which is interesting since, in healthcare, the news is not always good news. Although participants may manage their emotions during other conversations with patients, the level of intensity discussed in Chapter 4 impacts how strong their emotions are and, therefore, how the difficult conversations with higher intensities can be harder to manage. Participants reported how they must work at keeping their feelings out of intense, difficult conversations due to their duty of care, often leaving them feeling upset or sad with the burden weighing on them. They felt an obligation within the patient/family relationship to manage their feelings and emotions seen by the patient/family and be responsive instead to the patient's/family's feelings and emotions. In their roles, professionals are expected to demonstrate empathy, which is not just an acceptable emotion for them to display, but a required one for their job by their professional regulators for physiotherapists and nurses (NMC, 2018; HCPC, 2013). However, the other emotions they experienced during difficult conversations, such as fear or sadness, are not to be displayed. This requirement and emotion management and how these professionals serve the public all match emotional labour's criteria (Grandey, Diefendorff and

Rupp, 2013, p.7). It may mean that the consequences of participants feeling sad and

overwhelmed from these difficult conversations could link to stress, well-being and burnout.

All three professional groups under study have their respective professional body that binds

professionals to a code of practice. However, the level of employer control needed for

emotional labour over these three professional groups is different. Some healthcare

professionals meet Hochschild's (1983) criteria as they come into 'contact with the public'

and are required 'to produce an emotional state in another person' (p.147). However, the

third criteria of the employer exercising 'a degree of control over the emotional activities of

employees' may not fit as well with the GPs in this study (p.147). One could argue that GPs

are at the top of the community's hierarchy chain, have power and autonomy, and are

exceptions to the rule. However, GPs have professional standards, with outside expectations

to be responsive to patients (GMC, 2019). These standards may suggest that GPs do fall

under these control criteria as they establish how they are to behave through regulatory

expectations. Theodosius (2008) says, 'The current consumer-oriented approach within the

NHS has resulted in a shift in the balance of power between carer and patient' (p.42).

Therefore, the GPs, physiotherapists and nurses in this study have patients/families that are

also customers: customers who can complain. There is an expectation for professionals to be

responsive to customers, engage them in decisions and avoid complaints. One could argue

that this shift in power helps even out the playing field, giving the patient/families some

power to compete with the dependency and need of the one providing care.   Erickson and

Stacey (2013) suggest that we must consider the individual's 'relative power and agency

within interactional context' and that these 'may vary depending on the type and target of

one's emotion management' (p.187). They also believe it is still unclear if emotional

management or, as they refer to it as, 'emotional practice', challenges or fortifies the power arrangement (p.187).

Hochschild (1983) found the consequences of emotional labour are stress, alienation and burnout. However, this study did not look at these elements. There are debates about emotional labour, and next, I looked at one from Burkitt (2014), offering a counterargument.

Burkitt (2014) has an issue with Hochschild's definitions of public and private life, saying they are not just unclear and confusing, but he believes they are not separate; they overlap. He says, 'So-called private emotions like love and grief are socially formed, often through social practices constructed in the public sphere of social activity' (p.127). He sees feelings and emotions overlap and defines a feeling as a 'bodily sensation which is central to all experiences of emotion' as well as 'the social meanings we give to perceptual experiences and the context in which they arise' (p.7). They help 'orient us in various contexts and give meaning and sense to situations', including 'our relation to the world around us, including the other people in that world' (p.53). Burkitt stresses that emotions are feelings, which he sees as relational, involving the environment in which one lives and the lingering 'Emotional disposition, both bodily and psychological, that people bring with them from past situations into new ones that may not have relevance to that emotion' (p.9). We all manage our emotions throughout the day, which is 'emotion work' and differs from emotional labour (p.126).

However, one may argue that emotional labour is one position of emotion work. Instead of dismissing emotional labour for healthcare professionals, Erickson and Stacey (2013) offer an alternative. They recognise Hochschild's goals but offer a framework derived from 'Bourdieu's (1977, 1990b) general science of social practice' called 'emotion practice', which

they consider helpful to match the complexities in healthcare (p.179,190). Erickson and Stacey said that emotion practice 'is not hampered by linguistic and methodological assumptions in the same way as emotional labour and emotion management' (p.190). Instead, the authors suggest a change in studying emotional management to 'incorporate considerations of context', which they feel is often missing and needed to understand the outcomes (p.179). They also suggest recognising 'the differences across contexts while also working to avoid dualistic, either/or conceptualisation' (p.180).

Emotional labour, emotion work, or emotion practice offer different ways of interpreting how feelings and emotions impact professionals' difficult conversations. They highlight the complexity of emotions and how they 'cannot be reduced to any one element that goes into their making' (Burkitt, 2014, p.171).

My interest in this research topic came from teaching communication skills. Interestingly, advanced communications curricula, including those I taught, focus on managing patients'/families' emotions and not on recognising and managing one's own (Tan et al., 2021; Brighton et al., 2018; Parry and Brown, 2009). However, Pollock and Wilson (2015) found that although professionals valued learning about communication skills, they felt the skills were mostly inherent. This study suggests that although professionals can have lots of experience, they sometimes struggle to have difficult conversations. This may be due to the inherent skill set, but it can also be due to lack of practice and/or the need for better training, possibly influencing emotions. Future research could explore this latter point.

4.4 Powerlessness

Some studies found that professionals felt disempowered helping patients (Sellars et al., 2017; Berglund, Nassen and Gillsjo, 2015; Bernhardt et al., 2010). Sellars (2017) found a

main component to be an unsupportive healthcare system, including policies and resources such as time and compensation and culture of treatment until a judgment can be made regarding futility. Berglund, Nassen and Gillsjo (2015) found that although professionals wanted to help and often felt powerless to fix or cure, they could discern when patients needed them to shift from focusing on the condition and specifics to supporting them with general overall welfare. This shift was 'challenging and required courage' of the professional (p.7). Similarly, for ACP conversations, professionals found the outcome for the patient to be empowerment, but at the expense of the professional's susceptibilities (Sellars et al. 2017, p.322). To manage these vulnerabilities, Bernhardt et al. (2010) suggest the need to look at the consequences of inter-professional conflict to ease distress and help develop resiliency, 'and enhance their capacity to be with their patients' emotions without being overwhelmed by them' (p.295).

These concepts of courage and resiliency can be applied to having difficult conversations. This study's findings support how professionals can feel powerless and have their convictions confronted. Professionals want to help and were taught to cure and improve lives but are confronted with the reality that this is not always possible. To be successful, it could be that professionals need the courage to shift away from focusing so much on the ideology of curing and fixing patients whilst addressing their feelings and emotions to help them with difficult conversations. More investigation into this subject may prove beneficial.

5. Summary

This chapter focused on answering my research objective of how participants perceived themselves with difficult conversations. It found that professionals' feelings and emotions

are crucial complexities and there are other influencers such as work experience, a duty of care and wanting to feel helpful.

Existing literature and this study identified fear as a reason professionals avoid difficult conversations. This study adds the suggestion that professionals' fear often comes as a response or perceived response of the patient/family reaction, from not wanting to make things worse or receiving a complaint.

Participants expressed challenges in managing their feelings and emotions, which could be argued as the crux of how emotion practice can help or harm them (Theodosius 2008). Furthermore, although professionals want to feel helpful, sometimes they feel powerless; this chapter explored how professionals may need a paradigm shift. Instead of thinking nothing can be done, maybe they need to shift their expectations to see the value in bearing witness and supporting patients/families when there are no further treatments.

The next chapter is the conclusion of this thesis, summarising the main findings, discussing the research's strengths, limitations, contributions, and implications. It ends with an overview of my learning journey.

Chapter 7: Conclusion

1. Introduction

This final chapter provides a conclusion to this research study. It highlights the research design, the study's strengths and limitations and the key findings, particularly how the study aided in answering my research question. The chapter then shares my learning journey and ends with the contributions and implications, including new questions and suggestions for future research.

My interest in this topic stems from facilitating communication skills workshops and initially my plan included an evaluation of a workshop. Recognising the need to stand back and understand the issues and experiences for professionals engaging in difficult conversations, I shifted my focus. As an educator, it was important to equip professionals with skills to engage in conversations with patients/families that can become difficult. After seeing professionals, some newly qualified, some senior and many in-between, repeatedly communicate poorly and ask for help, I wanted to dig deeper into the reasons behind professionals' struggles to improve practice, training and my approach as a trainer. I was interested in better understanding how they consider conversations difficult to challenge my assumptions and to reverse roles to learn from them. In the end, curiosity sparked my interest; wanting to understand and recognise the possibilities helped oxygenate that curiosity, and the hope to impact others fuelled the research.

My experience gave me ideas and engagement with the literature helped me clarify them and frame my research approach. The research question was to explore the individual realities of how professionals (community nurses, GPs and physiotherapists) define and

characterise conversations as difficult around deteriorating health and end-of-life and their perceptions of what makes conversations difficult, including how they interact with patients/families during these conversations. Included was a question about exploring differences between professional groups.

2. Methods and adaptations

Concentrating on professionals for an intensive investigation, I used a qualitative approach to add 'to experience directly' and improve understanding (Stake, 2000, p.25). I used a grounded theory approach for data collection and to compare as I went through ongoing analysis (see Chapter 3, sections 3-4).

Initially, the study had a mixed-methods design with a survey and an additional objective to explore learning from the educational workshop. The research design evolved over the research process away from evaluation to allow me to stay in a more explorative mode and I amended the design to qualitative (see Chapter 3, section 2). I recruited physiotherapists, GP, and nurses and the methods used were semi-structured phone interviews at two points in time, field notes and my research diary (see Chapter 3 section3).

The next section explains this research's strengths and limitations.

3. Strengths and limitations of this research

Approaching this topic using qualitative research is a strength as it is dynamic and recognises unexpected material to arise in the exploration process. An interpretivist approach brought great value because it supported my responsiveness to participants' communication styles, their varying viewpoints, and how they conveyed their ideas. Professionals' views help provide learning about the characteristics of conversations that become difficult because

they provide an understanding and clarity of their experiences, which is a strength of this study. Although a deep dive into how professionals see things can shine a light on their thoughts and experiences, there is also a limitation by excluding those on the other side of these conversations, the patients/families. The exclusion was intentional, as this research did not cover it in its scope. Another limitation is the potential sampling bias as participants were recruited from attendants at a workshop on improving communication skills with those present at the workshop potentially different than professionals who did not attend (Robson, 2011). Those recruited may have been an overrepresentation of professionals who were already attuned to their understandings of conversations that become difficult, or more interested in the topic, or have more trouble with these conversations compared to other professionals. In addition, it also excluded other disciplines that could have provided a fuller view of these conversations in community care but was limited to the disciplines that attended a workshop on recruitment days. Potential sampling bias would have impacted the size and diversity of the sample.

Not collecting demographics such as race and religion is a limitation that could have provided more nuanced findings. However, there are limitations regarding how much can be covered, and due to the small sample size, it is questionable how much value these would bring to this study. Additionally, including demographics would bring some ethical confidentiality considerations, as disclosing this information could have made it easier to identify participants. Future research enquiry into these demographics is recommended.

Some may see not generalising statistically as a limitation; however, that is not the aim of this study as the numbers are too small. Instead, it aims to provide a 'thick description' (Lincoln

and Guba, 2000, p.40) and providing evidence in this context can be used as an analogy or theoretical inference for other professionals (Robson, 2011).

Another strength was using grounded theory approach that provided a systematic and explicit structure for data collection and coding (Robson, 2011). It allowed me 'active involvement in the process' by acting on data 'rather than passively read[ing] them' (Charmaz, 2006, p.59). There is a limitation, though, as Strauss and Corbin (1998) say, that my culture, gender and experience could have impacted the analysis. However, she also says this is inevitable. To challenge the limitation, I used reflexivity to think through and remind myself throughout the research process of my biases.

Being an insider researcher has advantages and disadvantages. As a participant rather than a bystander, having inside knowledge helped with in-depth data collection and opened new avenues for analysis. Being well versed in the topic and having experience working with professionals helped me gain trust quickly with participants and allowed me to navigate conversations easily. However, there are limitations to being an insider researcher. Being on the inside could have inhibited me from only seeing what I was expecting, with my bias and assumptions interfering. To challenge my perspective, I used other research findings to inform what else, outside my thinking, to look out for in the data. As I analysed the data, I consistently tested my assumptions by looking out for and into outliers, contemplating how they were different from what I expected. Through reflective practice, I stretched my thinking throughout the research process.

Next, I provide the key findings from the study.

4. Key findings

4.1 How participants characterised conversations as difficult

Participants from all three disciplines struggled to define "difficult conversations" but readily gave examples, providing context and descriptions. Although palliative and end-of-life care use the term, on reflection, it was not very helpful for these participants who saw conversations as gradations or levels of difficulty, formally related to their individualised sense of roles and responsibilities. This may be due to experience with difficult conversations or their role and may be mitigated with training. Participants described conversations that become difficult as sensitive subjects with negative feelings and emotions involved, and many said they are often due to conflicting expectations. The professional groups overlapped; however, the examples given differed between them.

To help interpret professionals' challenges to define difficult conversations, I applied Luntley (2009, 2011a, 2011b), focusing on professionals' knowledge tied to their actions of doing, which is why they struggled to articulate the idea without showing the practice. I also applied Burkitt (2014), focusing on the influence of complex feelings and emotions from the past, present and imagined, especially on language. Luntley and Burkitt may help explain the complexity in articulating a definition of difficult conversations and help me (see Chapter 4, section 4).

Participants gave various examples, with their roles being a distinguishing factor (see Chapter 4, section 3). However, all three disciplines agreed that some conversations were most challenging: unexpected conversations with unpredictable emotions (for either party in the

conversation), conversations involving conflicting expectations between the professional and the patient/family, or both.

The definition developed throughout the study by incorporating what I discovered in the literature review, integrating the findings of professionals' conceptualisation, examples and explanations, and including additional literature to help explain the findings. Difficult conversations are sensitive subjects where a professional has an emotional reaction to either the content of the conversation or (and most likely to) the reaction/the potential reaction of the patient/family, fuelled by a challenge to an expectation.

4.2 What makes conversations difficult

Participants emphasised two explanations for what they think make conversations difficult in practice. The first was strong emotional reactions (from patient/family and/or self) because the professional did not always know what to do or say. It was worse when the professionals could not predict reactions. The other reason was differing expectations between the professional and the patient/family, described in three ways. One was a disagreement; another was a lack of trust between the parties. The third was when patients/families expected to get better or a cure, and the professional explained the opposite. For GPs, interpersonal conflict was also persistent; they wanted to cure a patient when they knew they could not. Often there was a combination of adverse reactions and a mismatch of expectations (see Chapter 5, sections 2-3). I highlight the lack of training on how to have effective conversations around sensitive subjects, awareness and understanding of grief and loss, conflict resolution and coping skills.

Less frequent explanations for what makes conversations difficult are time, professionals thinking about their mortality or the mortality of their friends/family, and uncertainty of

diagnosis, prognosis or treatment (see Chapter 5, sections 4-6). The pressure of time, which participants said was needed to build trust, especially stood out for the GPs, who reported not having enough time for most consultations, let alone difficult conversations (see Chapter 5, section 4).

One interpretation of the reactions and/or a mismatch of expectations I considered was that professionals in this study found it challenging when patients/families did not conform to the 'sick role' character (Parsons, 1991). Professionals expecting patients to be passive and accepting can feel threatened when this does not occur due to the need to maintain power and control. However, there is another tension with societal changes reflected in the NHS with patients as active consumers, having them step out of their expected role in contrast to the professionals themselves still expecting passivity and accepting behaviour (DH, 2013; Brown, 2008). Possible challenges were participants relinquishing the 'sick role' or even sharing the role of expert (see Chapter 5, section 7).

Some participants spoke about patients/families being 'in denial' of their circumstances. One aspect of this may be their way of coping with the situation or information presented, although few participants recognised it. Another may be tension between patients'/families' reactions not conforming to professionals' expectations to accept expert statements (Parsons, 1991). A compatible explanation I used is the relationship of power between professional and patient/family laced with feelings and emotions that impact the professional's expectations and frustrate the patient (Burkitt 2014). This suggests that the reasons or complexities that make conversations difficult are not just about the patient/family, but they are significant. It highlights the substantial role of professionals' feelings and emotions which are covered further in the next section (see Chapter 5, section 7).

4.3 Perceptions of interactions

A central finding in this study was that professionals' feelings and emotions, especially fear, were highly influential. When they were positive, such as feeling empathic compassion, participants reported they could use those positive feelings and emotions during the conversation as a tool, leaving them with confidence and satisfaction post-conversation. When their feelings were negative, such as sadness, anger, guilt, frustration, anxiety and stress, participants reported a negative impact on the conversation, how they felt after it and future conversations (see Chapter 6, section 2). Therefore, there is a need for professionals to have training on how to cope with these emotions.

The anticipation of evoking strong negative emotions from a patient/family, or emotions one professional has her/himself, can prevent the conversation from happening altogether. Understanding why conversations can become challenging and often why conversations do not happen is complex. This study supports the findings in the literature review that professionals avoid potential emotions that difficult conversations can elicit because they are not taught how to deal with these feelings and emotions (see Chapter 6, section 4). A difficult conversation may be more about a professional's training, suggesting an important need for better training on coping with one's emotions for the sake of the patient/family and the professional.

Fear was central to understanding why people find conversations difficult and distressing. One reason was that participants feared the unpredictable emotional reaction from the patient/family. Another was that participants feared they might cause harm to the patient/family or were afraid of complaints. Perhaps behind the fear is the disruption or imagined disruption to the order professionals took for granted in the professional and

patient relationships (Parsons, 1991). The fear generated dread for participants for the next difficult conversation and often led them to delay and avoid challenging topics or only cover the surface of a sensitive topic (see Chapter 6, section 4).

Another reason professionals in this study avoided difficult conversations was because some did not want to displease the patient/family. Participants also spoke about enablers: their experience, a sense of duty of care, and/or their desire to feel helpful as other factors (see Chapter 6, section 3).

My study supports many of the studies in the literature review that professionals' have negative emotions during difficult conversations and so avoid them. I used two theories to explore fear. One was Burkitt's (2014) work on how strong feelings, emotions and values influence how we act and respond to others and experiences, whenever and wherever they occur (in person or our heads) and shape our reality and relationships. The other was Parsons' (1991) work to help explain how the professional holds power and control in the patient and professional relationship. I used both to suggest that professionals' past experiences and inner dialogue/visuals imagined, about disruption to the relationship's status quo, were influencing participants in difficult conversations and leading them to avoid them (see Chapter 6, section 4). Participants wanted to help patients/families by either supporting or fixing problems and felt a duty of care (see Chapter 6, sections 3.2-3.3). Perhaps the findings can be explained as a feeling of a paradox for professionals. Although many professionals go into their profession to help others and to save lives, the reality is that humans can deteriorate and die. Professionals can feel powerless when unsure or unable to solve a problem (see Chapter 6, section 4.4). What was helpful, many said, was training and experience in difficult conversations, which improved their confidence, although some

participants said that certain conversations will always be difficult, no matter the amount of experience (see Chapter 6, section 3.1). Cody (2001) suggests it could be a need for professionals to recognise the benefits of 'bearing witness' when there are no solutions (p.289). Furthermore, future research on how to include this in training is needed.

I explored emotional labour theory (see Chapter 6, section 4.3.1) to see how it may explain professionals in this study masked their true feelings and managed their emotions, which may have left them distressed, sad and tired (Theodosius, 2013; Hochschild, 1983). Burkitt (2014) is critical of emotional labour and says it is a misleading understanding of emotions and highlights how emotions cannot be distinguished between a purely public and purely private life because they cross over into each other. My study suggests emotional labour could have influenced the professionals' well-being, burn-out and job satisfaction; however, this was not this study's focus, so I cannot draw a clear conclusion on this point. These are not the only ways one could explain these findings, nor the intricacy of every conversation that becomes difficult.

5. My learning journey

Wanting to learn new research skills and apply them within my practice was my motivation for doing a professional doctorate instead of a PhD. The learning was vast throughout this research process as a professional developing as a researcher. I had two main strands of learning, with the first being practical application. I applied new knowledge at work, such as ethical considerations for a quality improvement project or designing interview questions for a programme evaluation. In analysing the data of a programme, I approached the answers to qualitative open questions using the coding and memo techniques learned. Also, my teaching approach changed as I considered how to include and present others' research

findings and went further to do a quick literature search for more recent data. I did not implement any changes to the Difficult Conversations workshops as I was not as involved during that time. The most outstanding learning was the second strand, about recognising and working through my beliefs and bias around qualitative research. I can see this now after reflecting throughout this journey, but it was not evident initially. I started to recognise a bias when I formally moved away from mixed methods research by dropping the survey. However, I noticed the internal struggle more when I analysed the data.

I am a medical social worker by training. With a background based in health, I am accustomed to using and being surrounded by quantitative research in practice. I used the common catchphrase of "evidence-based practice" and had expectations of the hierarchy of evidence to decide the findings' quality (Murad et al., 2016). Before starting the doctorate programme, I conducted interviews and held focus groups for work, making me curious about qualitative research and seeing its value. Wanting to take advantage of what qualitative research can offer I first approached this research with a mixed design. However, through reflective practice I realised that due to my alliance and familiarity with quantitative data, I had, and often still have, a deep-seated bias that, while interesting, qualitative data is not as good or reliable. This was not an ideal place to be when conducting qualitative research. It created doubt and excessive scrutiny to analyse data, and I found myself, at times, struggling, contemplating why I did not back up the qualitative findings with quantitative.

I recognise now that the years of experience in health had me approaching my research with specific biases and challenging my decisions. I was working through a tension, a pushing and pulling between my beliefs and subconscious, about the benefits of quantitative and

qualitative research. I kept thinking, 'Who am I to state these as the findings?' since they came from my chosen themes. I was the one that interpreted others' words and ways of speaking and decided meaning. I may have felt similar if this was a quantitative study since I am a novice researcher; however, the ability to fall back on the quantity or statistics often seems more straightforward. I used my reflective diary to explore these insecurities. Through reflections, this internal struggle influenced my confidence, making me develop an inner critical eye. I did not recognise it at the time but choosing grounded theory for data collection and analysis helped my internal voice to question myself, focus and recognise biases (Corbin and Strauss, 2015).

The methodology journey gave me confidence as I progressed. An example of this was when 'mortality' became a theme during one of the first interviews. I was curious if others thought about their mortality during conversations with patients/families. Using grounded theory gave me a sense of permission to include a question on mortality in second interviews with subsequent participants, which, in the end, gave me more insight. Because qualitative research is dynamic and recognises the research process's importance, it allows unexpected material to arise. The benefits of grounded theory rooted me in exploration; however, it was not without a struggle. This challenge was a steady critical friend; as I progressed the research, it watched internally, and I used reflexivity throughout to make sense of the struggle. It forced me to question myself at some points about the validity of using the grounded theory approach, and I found the internal debate reassured me that I was on the right track. I recognised the power of using grounded theory. Using this critical friend helped me to feel confident that I am making a valid contribution to knowledge by providing perspectives on difficult conversations. It also helped me find my academic voice.

Over the years, I was often asked to do tasks without training but desired to do them well. Reflecting on why I started this doctorate programme, I remember being asked by a senior colleague to join him in running an education research project. He saw something in me that I did not see in myself. He had recognised my earlier work changing the service delivery of a large hospice programme and invested time and energy in me to learn, practice and discover new potential.

I had the hunger to learn more. Applying my research learning to my work gave me different perspectives and understandings, enriching my overall learning experience. Although I have come to the end of this research the journey does not end. There is still so much to learn as there are many opportunities to apply research in practice to help improve practice.

6. Contributions and Implications

I came into this study with my ideas about difficult conversations. I brought forward questions I was interested in about professionals' understandings and the situations they face. Through the literature review and then the investigation, I developed these ideas into new understandings and new theories.

In understanding how professionals characterise and approach difficult conversations, studies from the literature review, and this study supports, that there were no set definitions but a focus on examples and explanations of barriers with emotions playing a large role. My study identified that although some situations tend to be difficult for many, professionals feel there are layers of complexity to difficult conversations with varying intensity levels. This research's principal theoretical contribution is that although participants' perceptions of others' reactions in conversations influence the conversations, the impact of their own feelings and emotions is much more significant and is the crux of a difficult conversation.

189

This new theory argues that the negative feelings/emotions that arise in these sensitive discussions stem from uneasiness and fear of them overwhelming the professional.

The findings of this study contribute to knowledge by giving context, understanding and a new theory, giving a voice to professionals' experiences and personalised accounts of circumstances in having difficult conversations, and revealing the complexities of difficult conversations for professionals. Although this was a small-scale study, it furthers the understanding of professionals' struggles and helps explain their avoidance.

This study aimed to understand the experiences and perspectives of different professional groups and develop new thinking which provides a theoretical contribution. I have provided new ideas that move from a more stable yet inaccurate reflection of peoples' relationships to difficult conversations to a much more fluid and relational dynamic, leading me to develop a more nuanced way of thinking about this topic which is my main theoretical contribution. Physiotherapists and some nurses from this study, for instance, did not associate the conversations they have with patients/families with the term "breaking bad news"; however, they did give examples of performing the action. It is important to consider this since the term is readily used in publications, training and research for multi-professionals and not always in the strict context of diagnosing or treating a terminal illness. When engaging with these groups in training, for example, other words, words they identify with, may work better in the future. The workshop title, Difficult Conversations, could be changed, for example. Different disciplines in the study had differing experiences, suggesting that supporting professionals in practice and learning may need varied or tailored approaches. However, it should be supposed that feelings and emotions are in a constant state of movement where they coincide with our thoughts, no matter the type of conversation professionals struggle with, as Burkitt (2014) suggests. In that case, and highlighting the theoretical contribution, it

is the feelings and emotions that one needs to address, not the type of conversation. Besides, there were similarities in what makes conversations difficult for all three disciplines.

These findings may have implications on policy, practice, education, and training. For policy and practice, consideration is needed around time and building in reflective practice. Increasing time for professionals to have these conversations can have great implications for both the patients' and professionals' experience and could potentially save time in the long run by ensuring communication is effective earlier on. Establishing reflective practices that could include opportunities for professionals to debrief difficult conversations, such as implementing reflexive techniques and supervision, could benefit the professionals and their clients.

The learning from this research brought me new thinking and questions. In the past, when teaching professionals about difficult conversations, my focus was on improving skills such as how to speak, body language, demonstrating empathy and effective listening. There was only an acknowledgement of professionals' feelings/emotions. Other communication skills education and training also focus on managing others' emotions (Tan et al., 2021; Brighton et al., 2018; Parry and Brown, 2009). Therefore, a significant revelation was to discover that perhaps a crucial connection was missing; professionals' feelings/emotions go hand in hand with communication skills. This suggests there may be broader implications for this new theory on education and training, and that a main missing link is how difficult conversations impact the professional and the need to recognise and manage one's emotions. The main missing link stresses the value of this new theoretical contribution and given this specific area, which is laden with feelings and emotions, was a predominant finding that warrants further investigation.

I hope to dissemination these contributions to influence change. Dissemination will include publishing in peer reviewed journals, seeking out conferences and forums to present and using my role as a guest lecturer to share the learning. Dissemination avenues would be those that reach authorities, so this learning can be considered for embedding into curriculum in higher education.

For me, the insights from this research point me in new directions with new questions to explore. How can having professionals be aware of their feelings/emotions influence conversations and their decision-making? Can teaching professionals how to recognise feelings/emotions in practice be enough? Would grief and loss counselling and conflict resolution help? Or do professionals need to develop courage and learn how to cope with these feelings and emotions to build resiliency and help engage more in conversations that can become difficult? These are all questions future research could explore.

I plan to keep an eye on research in this area, and if I have an opportunity to write future curricula on communication skills, I intend to focus on how one's feelings/emotions influence conversations. I hope to explore how professionals can recognise their feelings/emotions in practice and explore the transferability of how other disciplines approach them in practice. Also I would like to explore and experiment with what helps professionals adjust to the changing social system with those with lived experience. There are many other curiosities that I would like to investigate, but I have one that I would really like to focus on at some point. I want to explore what happens when professionals, regardless of discipline and setting, always asked patients/families about their goals of care/treatment/visit. I wonder if starting with the patient/family first would help transfer power or at least be a constant reminder for professionals on where to start and end. In the meantime, my next step is to seek a role where I can utilise my research skills and improve upon them.

References

AHLUWALIA, S.C., LEVIN, J.R., LORENZ, K.A. and GORDON, H.S., 2013. Patient Education and Counseling, May 2013, Vol.91(2), pp.200-205; 'There's no cure for this condition': How physicians discuss advance care planning in heart failure. *Patient education and counseling,* **91**(2), pp. 200-205.

ALMACK, K., COX, K., MOGHADDAM, N., POLLOCK, K. and SEYMOUR, J., 2012. After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care,* **11**(1), pp. 1-10.

AMIEL, G., UNGAR, L., ALPERIN, M., BAHARIER, Z., COHEN, R. and REIS, S., 2006. Ability of primary care physician's to break bad news: A performance based assessment of an educational intervention. *Patient education and counseling,* **60**(1), pp. 10-15.

APPLEBY, J. and ROBERTSON, R., 2015. *Public satisfaction with the NHS in 2014.* on-line: The King's Fund.

BAILE, W.F., BUCKMAN, R., LENZI, R., GLOBER, G., BEALE, E.A. and KUDELKA, A.P., 2000. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist,* **5**(4), pp. 302-311.

BAIRD, B., CHARLES, A., HONEYMAN, M., DAVID, M. and PREETY, D., 2016. *Understanding pressures in general practice.* on-line: The King's Fund.

BARBALET, J.M., 1999. William James' Theory of Emotions: Filling in the Picture. *Journal for the theory of social behaviour,* **29**(3), pp. 251-266.

BECK, R.S., DAUGHTRIDGE, R. and SLOANE, P.D., 2002. Physician-patient communication in the primary care office: a systematic review. *The Journal of the American Board of Family Practice,* **15**(1), pp. 25-38.

BERGLUND, M., NÄSSÉN, K. and GILLSJÖ, C., 2015. Fluctuation between Powerlessness and Sense of Meaning-A Qualitative Study of Health Care Professionals' Experiences of Providing Health Care to Older Adults with Long-Term Musculoskeletal Pain. *BMC geriatrics,* **15**(1), pp. 1-10.

BERNHARDT, B.A., SILVER, R., RUSHTON, C.H., MICCO, E. and GELLER, G., 2010. What keeps you up at night? Genetics professionals' distressing experiences in patient care. *Genetics in Medicine,* **12**(5), pp. 289.

BEST, M., BUTOW, P. and OLVER, I., 2016. Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality. **14**(5), pp. 519-531.

BLACKHALL, L.J., 2013. Do patients need to know they are terminally ill? No. *The BMJ,* **346**, pp. f2560.

BLAXTER, L., HUGHES, C. and TIGHT, M., 2010. *How to research.* 4th edn. Maidenhead, New York: Open University Press McGraw-Hill Education (UK).

BRÄNNSTRÖM, M., FORSSELL, A. and PETTERSSON, B., 2011. Physicians' Experiences of Palliative Care for Heart Failure Patients. *European journal of cardiovascular nursing: journal*

of the Working Group on Cardiovascular Nursing of the European Society of Cardiology; Eur J Cardiovasc Nurs, **10**(1), pp. 64-69.

BRIGHTON, L.J. and BRISTOWE, K., 2016. Communication in palliative care: talking about the end of life, before the end of life. *Postgraduate Medical Journal,* **92**(1090), pp. 466-470.

BRIGHTON, L.J., SELMAN, L.E., GOUGH, N., NADICKSBERND, J.J., BRISTOWE, K., MILLINGTON-SANDERS, C. and KOFFMAN, J., 2018. 'Difficult Conversations': evaluation of multi-professional training. *BMJ Supportive & Palliative Care,* **8**, pp. 45-48.

BROWN, J., 2008. How clinical communication has become a core part of medical education in the UK. *Medical education; Med Educ,* **42**(3), pp. 271-278.

BURKITT, I., 2014. *Emotions and Social Relations.* 1st edn. London, Thousand Oaks, New Delhi, Singapore: Sage.

BURKITT, I., 2002. Complex Emotions: Relations, Feelings and Images in Emotional Experience. *The Sociological review,* **50**(2), pp. 151-167.

BURTON, J. and LAUNER, J., 2003. Supervision and support in primary care. *Supervision and Support in Primary Care.* Radcliffe Medical Press Oxford, pp. 3-14.

BYRNE, P.S. and LONG, B.E.L., 1976. *Doctors talking to patients: a study of the verbal behaviour of general practitioners consulting in their surgeries.* London: H.M. Stationery Office.

CARE QUALITY COMMISSION, 2016. *A Different Ending: Assessing inequalities in end of life care.* CQC.

CHAN, S.W., TULLOCH, E., COOPER, E.S., SMITH, A., WOJCIK, W. and NORMAN, J.E., 2017. Montgomery and informed consent: where are we now? *BMJ,* **357**, pp. j2224.

CHANDAR, M., BROCKSTEIN, B., ZUNAMON, A., SILVERMAN, I., DLOUHY, S., ASHLEVITZ, K., TABACHOW, C., LAPIN, B., EWIGMAN, B., MAZZONE, T. and OBEL, J., 2017. Perspectives of Health-Care Providers Toward Advance Care Planning in Patients With Advanced Cancer and Congestive Heart Failure. *The American Journal of Hospice & Palliative Care,* **34**(5), pp. 423.

CHARMAZ, K., 2006. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* London, Thousand Oaks, New Delhi: Sage.

CLARK, D., 2014. *'Total pain': the work of Cicely Saunders and the maturing of a concept.* University of Glasgow.

CLAYTON, J., BUTOW, P., ARNOLD, R. and TATTERSALL, M., 2005. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer,* **103**(9), pp. 1965-1975.

CODY, W.K., 2001. The ethics of bearing witness in healthcare: a beginning exploration. *Nursing science quarterly; Nurs Sci Q,* **14**(4), pp. 288-296.

Complaints about the NHS in England Quarter 4 2018-19. 2019. on-line: Parliamentary and Health Service Ombudsman.

CORBIN, J. and STRAUSS, A., 2015. *Basics of Qualitative Research.* 4th edn. Thousand Oaks, CA: Sage.

CORBIN, J. and STRAUSS, A., 1990. Grounded Theory Research: Procedures, Canons, and Evaluative Criteria. *Qualitative Sociology,* **13**(1), pp. 3.

Cutcliffe, J.R., 2000. Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), pp. 1476–1484.

DARZI, A., 2008. *High Quality Care for All: NHS Next Stage Review Final Report.* Crown.

DE VLEMINCK, A., PARDON, K., BEERNAERT, K., DESCHEPPER, R., HOUTTEKIER, D., VAN AUDENHOVE, C., DELIENS, L. and VANDER STICHELE, R., 2014. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. *PLOS ONE,* **9**(1).

DENNESS, C., 2013. What are consultation models for? *InnovAiT: Education and inspiration for general practice,* **6**(9), pp. 592-599.

DEPARTMENT OF HEALTH, 2016a. *Our Commitment to you for end of life care The Government Response to the Review of Choice in End of Life Care.* London: Crown.

DEPARTMENT OF HEALTH, 2016b. *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values- A mandate from the Government to Health Education England: April 2016 to March 2017.* England, UK: Crown.

DEPARTMENT OF HEALTH, 2013. *The NHS Constitution for England.* Updated 1 January 2021 edn. online: Gov.UK.

DEPARTMENT OF HEALTH, 2012. *Liberating the NHS: No decision about me, without me - Government response to the consultation.* on-line: Gov.UK.

DEPARTMENT OF HEALTH, 2010. *The NHS Constitution for England.*

DEPARTMENT OF HEALTH, 2008-last update, End of Life Care Strategy – promoting high quality care for all adults at the end of life [Homepage of COI for the Department of Health], [Online].
Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf [July/14, 2013].

DEPARTMENT OF HEALTH, 1991. *The Patients' Charter.* on-line: Her Majesty's Stationery Office.

DEPARTMET OF HEALTH AND SOCIAL CARE, 2015-last update, 2010 to 2015 government policy: long term health conditions [Homepage of GOV.UK], [Online].
Available: https://www.gov.uk/government/publications/2010-to-2015-government-policy-long-term-health-conditions/2010-to-2015-government-policy-long-term-health-conditions [Feb. 6, 2020].

DEPARTMET OF HEALTH AND SOCIAL CARE, 2015. *What's important to me. A Review of Choice in End of Life Care.* The Choice in End of Life Care Programme Board. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf [July, 2022].

DEY, I., 1993. *Qualitative Data Analysis: A User Friendly Guide for Social Scientists.* 1st ed. edn. London: Taylor & Francis Group.

DUNNE, K., 2004. Grief and its manifestations. *Nursing standard; Nurs Stand,* **18**(45), pp. 45-53.

EDWARDS, A. and TALBOT, R., 1999. *The Hard-pressed Researcher: A research handbook for the caring professions.* 2nd edn. London: Routledge.

ERICKSON, R.J. and STACEY, C.L., 2013. Attending to mind and body: Engaging the complexity of emotion practice among caring professionals. In: A. GRANDEY A., J. DIEFENDORFF M. and D. RUPP E., eds, *Emotional Labor in the 21st Century.* 1st edn. New York: Routledge, pp. 175-196.

EVANS, T. and HARDY, M., 2017. The ethics of practical reasoning-exploring the terrain. *European journal of social work,* **20**(6), pp. 947-957.

EVANS, T. and HARDY, M., 2010. *Evidence and knowledge for practice.* Cambridge: Polity Press.

FISHER, M. and RIDLEY, S., 2012. Uncertainty in end-of-life care and shared decision making. Critical care and resuscitation. *Journal of the Australasian Academy of Critical Care Medicine,* **14**(1), pp. 81-7.

FOOT, C., GILBURT, H., DUNN, P., JABBAL, J., SEALE, B., GOODRICH, J., BUCK, D. and TAYLOR, J., 2014. *People in control of their own health and care.* on-line: The King's Fund.

FRANCIS, R., 2013. *Foundation Trust Public Inquiry, Francis R: Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry.* The Mid Staffordshire NHS Foundation Trust.

FRIEDSON, E., 1970. *Profession of Medicine: A Study of the Sociology of Applied Knowledge.* Chicago: University of Chicago Press.

FULMER, T., ESCOBEDO, M., BERMAN, A., KOREN, M.J., HERNÁNDEZ, S. and HULT, A., 2018. Physicians' Views on Advance Care Planning and End-of-Life Care Conversations. *Journal of the American Geriatrics Society,* **66**(6), pp. 1201-1205.

GENERAL MEDICAL COUNCIL, 2022. *Treatment and care towards the end of life: good practice in decision making.* on-line: GMC.

GENERAL MEDICAL COUNCIL, 2020. *Guidance on professional standards and ethics for doctors Decision making and consent.* General Medical Council.

GENERAL MEDICAL COUNCIL, 2019-last update, Good Medical Practice [Homepage of General Medical Council], [Online]. Available: http://www.gmc-uk.org/guidance [November/6, 2021].

GIBBS, G.R., 2007. *Analysing Qualitative Data.* 1st edn. London: Sage Publications.

GIBSON, A. and GIBSON, N., 2016. *Human growth, behaviour and development. Essential theory and application in social work.* London: Sage.

GLASER, B.G. and STRAUSS, A.L., 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New Brunswick (U.S.A.) and London (U.K.): Aldine Transaction.

GLASER, B.G. and STRAUSS, A.L., 1965. Temporal aspects of dying as a non-scheduled status passage. *American Journal of Sociology,* **71**(1), pp. 48-59.

GRANDEY, A., DIEFENDORFF, J. and RUPP, D.E., 2013. Bringing emotional labor into focus. In: A. GRANDEY A, J. DIEFENDORFF and D. RUPP E., eds, *Emotional labor in the 21st century: Diverse perspectives on emotion regulation at work.* 1st edn. New York: Routledge, pp. 3-27.

GREENGROSS, P., GRANT, K. and COLLINI, E., 1999. The history and development of the UK National Health Service 1948 - 1999.

GRIFFITHS, J., EWING, G., WILSON, C., CONNOLLY, M. and GRANDE, G., 2015. Breaking bad news about transitions to dying: A qualitative exploration of the role of the District Nurse. *Palliative medicine,* **29**(2), pp. 138-146.

HANCOCK, K., CLAYTON, J., PARKER, S.M., WALDER, S., BLTTOW, P., CARRICK, S., CURROW, D., GHERSI, D., GLARE, P., HAGERTY, R. and TATTERSALL, M., 2007. Discrepant perceptions about end-of-life communication: A systematic review. *Journal of pain and symptom management; J.Pain Symptom Manage.,* **34**(2), pp. 190-200.

HANCOCK, K., CLAYTON, J., PARKER, S.M., WALL DER, S., BUTOW, P., CARRICK, S., CURROW, D., GHERSI, D., GLARE, P., HAGERTY, R. and TATTERSALL, M., 2007. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliative Medicine,* **21**(6), pp. 507-517.

HARGIE, O., BOOHAN, M., MCCOY, M. and MURPHY, P., 2010. Current trends in communication skills training in UK schools of medicine. *null,* **32**(5), pp. 385-391.

HART, C., 2018. *Doing a literature review: Releasing the research imagination.* 2nd edn. London, Thousand Oaks, New Delhi, Singapore: Sage.

HEALTH AND CARE PROFESSIONS COUNCIL, 2013. *Standards of proficiency: Physiotherapists.* London: Health & Care Professionals Council.

HINSHAW, D., B., 2022. The Challenge of Truth-Telling in Cancer Care, United States. In: M. SILBERMANN and A. BERGER, eds, *Global Perspectives in Cancer Care: Religion, Spirituality, and Cultural Diversity in Health and Healing.* New York: Oxford University Press, pp. 45-56.

HOCHSCHILD, A.R., 1979. Emotion work, feeling rules, and social-structure. *American Journal of Sociology,* **85**(3), pp. 551-575.

ILLICH, I., 1975. *Medical Nemesis.* London: Calder & Boyars.

JAMES, W., 1884. What is an Emotion? *Mind,* **9**(34), pp. 188-205.

JOHNSON, C.G., LEVENKRON, J.C., SUCHMAN, A.L. and MANCHESTER, R., 1988. Does physician uncertainty affect patient satisfaction? *Journal of general internal medicine,* **3**(2), pp. 144-149.

KABA, R. and SOORIAKUMARAN, P., 2007. The evolution of the doctor-patient relationship. *International Journal of Surgery,* **5**(1), pp. 57-65.

KELLY, M., 2004. Research Design and Proposals. In: C. SEALE, ed, *Researching Society and Culture.* 2nd edn. London: Sage, pp. 129-142.

KENNEDY, I., 2003. Patients are experts in their own field. *BMJ; BMJ,* **326**(7402), pp. 1276.

KING'S FUND, 1998. *Learning from the NHS internal market: a review of the evidence .* London: King's Fund.

LAZENBY, S., EDWARDS, A., SAMURIWO, R., RILEY, S., MURRAY, M.A. and CARSON-STEVENS, A., 2016. End-of-life care decisions for haemodialysis patients – 'We only tend to have that discussion with them when they start deteriorating'. *Health Expectations,* **20**(2), pp. 260-273.

LEWIS, J. and MCNAUGHTON NICHOLLS, C., 2014. Design Issues. In: J. RITCHIE, J. LEWIS, C. MCNAUGHTON NICHOLLS and R. ORMSTON, eds, *Qualitative Research Practice A Guide for Social Science Students and Researchers.* 2nd edn. London: Sage, pp. 47-76.

LINCOLN, Y.S. and GUBA, E.G., 2000. The only generalization is: There is no generalisation. In: R. GOMM, M. HAMMERSLEY and P. FOSTER, eds, *Case Study Method.* London, Thousand Oaks, New Delhi: Sage Publications.

LUNTLEY, M., 2011a. What do nurses know? *Nursing Philosophy; Nurs Philos,* **12**(1), pp. 22-33.

LUNTLEY, M., 2011b. Expertise - Initiation into learning, not knowing. In: L. BONDI, D. CARR, C. CLARK and C. CLEGG, eds, *Towards Professional Wisdom.* 1st edn. London: Ashgate Publishing, pp. 27-43.

LUNTLEY, M., 2009. Understanding Expertise. *Journal of applied philosophy,* **26**(4), pp. 356-370.

MARCUS, JOEL AND MOTT, FRANK E, 2014. Difficult Conversations: From Diagnosis to Death. *Ochsner Journal,* **14**(4), pp. 712-7.

Marie Curie. Telling someone that they're dying 6 February, 2020-last update. Available: https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/individual-needs/telling-someone-that-they-are-dying.

MASON, J., 2002. *Researching your own practice: The discipline of noticing.* London: Routledge Falmer.

MEEHAN, E., FOLEY, T., KELLY, C., BURGESS KELLEHER, A., SWEENEY, C., HALLY, R.M., DETERING, K. and CORNALLY, N., 2020. Advance Care Planning for Individuals With Chronic Obstructive Pulmonary Disease: A Scoping Review of the Literature. *Journal of pain and symptom management; J Pain Symptom Manage,* **59**(6), pp. 1344-1361.

MEHTA, A. and CHAN, L.S., 2008. Understanding of the concept of 'total pain': a prerequisite for pain control. *Journal of Hospice & Palliative Nursing,* **10**(1), pp. 26-32.

MELLOR, R.M, GREENFIELD, S.M., DOWSWELL, G., SHEPPARD, J.P., QUINN, T. and MCMANUS, R.J., 2013. Health care professionals' views on discussing sexual wellbeing with patients who have had a stroke: a qualitative study. *PLoS ONE,* **8**(10), pp. e78802.

MILTON, D., 2004. *Talcott Parsons and the Theory of the 'Sick Role'.*

MURAD, H.M., ASI, N., ALSAWAS, M. and ALAHDAB, F., 2016. New evidence pyramid. *BMJ Evidence-Based Medicine,* **21**, pp. 125-127.

NAEF, R., 2006. Bearing witness: a moral way of engaging in the nurse–person relationship. *Nursing philosophy; Nurs Philos,* **7**(3), pp. 146-156.

NATIONAL PALLIATIVE AND END OF LIFE CARE PARTNERSHIP, 2022. *The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021–2026 in England.* NHS England. Available: https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/ [April 30, 2022].

NEUBERGER, J., 2013. *More Care, Less Pathway: A Review of the Liverpool Care Pathway, Independent Report.* on-line: Crown.

NHS ENGLAND, 2022. *Universal Principles for Advance Care Planning (ACP).* on-line: NHS England and NHS Improvement; AgeUK; ASPCP; Association for Palliative Medicine; Association of Ambulance Chief Executives; ASPOPC; BMA; Care England; CHCC; Compassion in Dying; Faith Action; Hospice UK; Macmillan; Marie Curie; Motor Neurone Disease; National Bereavement Alliance; National Guardian; National Nurse Consultant Group Palliative Care; National Voices; NHS; PCPLD Network; The Queen's Nursing Institute; Resuscitation Council UK; RCGP; RCOT; Royal College of Physicians; Skills for care; SCIE; Sue Ryder. Available: https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf [7 May 2022].

NICE, 17 June, 2021-last update, Shared decision making.
Available: https://www.nice.org.uk/guidance/ng197/resources/shared-decision-making-pdf-66142087186885 [4th June, 2022].

NICE, 16 October, 2019-last update, End of life care for adults: service delivery.
Available: https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#advance-care-planning [7 May, 2022].

NICE, 16 December, 2015-last update, New guidelines to improve care for people at the end of life. Available: https://www.nice.org.uk/news/article/new-guidelines-to-improve-care-for-people-at-the-end-of-life [8th April, 2022].

NOVACK, D.H., PLUMER, R., SMITH, R.L., OCHITILL, H., MORROW, G.R. and BENNETT, J.M., 1979. Changes in physicians' attitudes toward telling the cancer patient. *Jama,* **241**(9), pp. 897-900.

NURSING & MIDWIFERY COUNCIL, 2018. *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates.* London: Nursing & Midwifery Council.

OFFICE FOR NATIONAL STATISTICS, 2018. *Living Longer: how our population is changing and why it matters Overview of population ageing in the UK and some of the implications for the economy, public services, society and the individual.* on-line: Office for National Statistics.

OFFICE FOR NATIONAL STATISTICS,2020. *People with long-term health conditions, UK: January to December 2019*. 26 March, 2020-last update. Office for National Statistics. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/adhocs/11478peoplewithlongtermhealthconditionsukjanuarytodecember2019 [8th April, 2022].

OFFICE OF NATIONAL STATISTICS, 16 September, 2021-last update, Deaths in the UK for each year 2000 to 2020.
Available: https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/deathsintheukforeachyear2000to2020 [8th April, 2022].

OGDEN, J., FUKS, K., GARDNER, M., JOHNSON, S., MCLEAN, M., MARTIN, P. and SHAH, R., 2002. Doctors' expressions of uncertainty and patient confidence. *Patient education and counseling,* **48**(2), pp. 171-176.

OISHI, A. and MURTAGH, F.E.M., 2014. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals. *Palliative medicine; Palliat Med,* **28**(9), pp. 1081-1098.

OKEN, D., 1961. What to Tell Cancer Patients: A Study of Medical Attitudes. *Journal of the American Medical Association,* **175**(13), pp. 1120-1128.

ORMSTON, R., SPENCER, L., BARNARD, M. and SNAPE, D., 2014. The Foundations of Qualitative Research. In: J. RITCHIE, J. LEWIS, C. MCNAUGHTON NICHOLLS and R. ORMSTON, eds, *Qualitative Research Practice A Guide for Social Science Students & Researchers.* 2nd edn. London: Sage, pp. 1-25.

OWENS, J., ENTWISTLE, V.A., CRIBB, A., SKEA, Z.C., CHRISTMAS, S., MORGAN, H. and WATT, I.S., 2017. 'Was that a success or not a success?': a qualitative study of health professionals' perspectives on support for people with long-term conditions. *BMC family practice; BMC Fam Pract,* **18**(1), pp. 39.

PANAGOPOULOU, E., MINTZIORI, G., MONTGOMERY, A., KAPOUKRANIDOU, D. and BENOS, A., 2008. Concealment of Information in Clinical Practice: Is Lying Less Stressful Than Telling the Truth? *JCO,* **26**(7), pp. 1175-1177.

PARLIAMENTARY AND HEALTH SERVICE OMBUDSMAN, 2015. *Complaints about Acute Trusts 2014-15.* online: Parliamentary and Health Service Ombudsman. Available: https://www.ombudsman.org.uk/sites/default/files/NHS_Complaint_stats_report_2014-15.pdf [January 2022].

PARLIAMENTARY AND HEALTH SERVICE OMBUDSMAN, 2015. *Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care.* London: Parliamentary and Health Service Ombudsman. Available: https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity. [August, 2022].

PARRY, R. and BROWN, K., 2009. Teaching and learning communication skills in physiotherapy: What is done and how should it be done? *Loughborough University. Journal contribution,* **95**(4), pp. 294-301.

PARSONS, T., 1991. *The Social System.* 2nd edn. London: Routledge.

PFEIL, T.A., LARYIONAVA, K., REITER-THEIL, S., HIDDEMANN, W. and WINKLER, E.C., 2015. Oncologist, January 2015, Vol.20(1), pp.56-61; What Keeps Oncologists From Addressing Palliative Care Early on With Incurable Cancer Patients? An Active Stance Seems Key. *Oncologist,* **20**(1), pp. 56-61.

PIGGOTT, K., Lynn, PATEL, A., WONG, A., MARTIN, L., PATEL, A., PATEL, M., LIU, Y., DHESY-THIND, S. and YOU, J.J., 2019. Breaking silence: a survey of barriers to goals of care discussions from the perspective of oncology practitioners. *BMC Cancer,* **19**(1), pp. 1-8.

POLKINGHORNE, D.E., 2005. Language and Meaning. *Journal of Counseling Psychology*, 52(2), pp. 137–145.POLLOCK, K. and WILSON, E., 2015. Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life. *Health services and delivery research,* **3**(31), pp. 1-138.

PORTNOY, D.B., HAN, P.K., FERRER, R.A., KLEIN, W.M. and CLAUSER, S.B., 2013. Physicians' attitudes about communicating and managing scientific uncertainty differ by perceived ambiguity aversion of their patients. *Health Expectations,* **16**(4), pp. 362-372.

PRIMARY CARE STRATEGY AND NHS CONTRACTS GROUP, April, 2019-last update, 2019/20 General Medical Services (GMS) contract Quality and Outcomes Framework (QOF) Guidance for GMS contract 2019/20 in England [Homepage of NHS England], [Online]. Available: https://www.england.nhs.uk/wp-content/uploads/2019/05/gms-contract-qof-guidance-april-2019.pdf [May 1, 2019].

PROUTY, C.D., MAZOR, K.M., GREENE, S.M., ROBLIN, D.W., FIRNENO, C.L., LEMAY, C.A., ROBINSON, B.E. and GALLAGHER, T.H., 2014. Providers' perceptions of communication breakdowns in cancer care. *Journal of General Internal Medicine,* **29**(8), pp. 1122-1130.

RICHMOND, C., 2005. Dame Cicely Saunders, founder of the modern hospice movement, dies. Available: https://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1 [8th April, 2022].

ROBSON, C., 2011. *Real World Research.* 3rd edition edn. Chichester: John Wiley & Sons.

ROYAL COLLEGE OF GENERAL PRACTITIONERS AND MARIE CURIE, 2019-last update, RCGP and Marie Curie UK General Practice Core Standards for Advanced Serious Illness and End of Life Care [Homepage of RCGP], [Online]. Available: https://rcgp.org.uk/learning-resources/daffodil-standards [June 1, 2019].

SALDANA, J., 2016. *The Coding Manual for Qualitative Researchers.* 3rd edn. London, Thousand Oaks, New Delhi, Singapore: Sage.

SAUNDERS, C., 2006. *Cicely Saunders: Selected Writings 1958-2004.* Oxford University Press.

SCHATTNER, A., RUDIN, D. and JELLIN, N., 2004. Good physicians from the perspective of their patients. *BMC Health Serv Res,* **4**(26).

SCHWARTZ-SHEA, P. and YANOW, D., 2012. *Interpretive Research Design, Concepts and Processes.* New York, London: Routledge Taylor & Francis Group.

SEALE, C., 2004. *Researching society and culture.* 2nd edn. London, Thousand Oaks, New Delhi, Singapore: Sage.

SELLARS, M., TONG, A., LUCKETT, T., MORTON, R., POLLOCK, C., SPENCER, L., SILVESTER, W. and CLAYTON, J., 2017. American Journal Of Kidney Diseases, 2017 Sep, Vol.70(3), pp.315-

323; Clinicians' Perspectives on Advance Care Planning for Patients With CKD in Australia: An Interview Study. *American Journal Of Kidney Diseases; Am.J.Kidney Dis.,* **70**(3), pp. 315-323.

SELMAN, L., HARDING, R., BEYNON, T., HODSON, F., COADY, E., HAZELDINE, C., WALTON, M., GIBBS, L. and HIGGINSON, I.J., 2007. *Improving end-of-life care for patients with chronic heart failure: 'Let's hope it'll get better, when I know in my heart of hearts it won't'.* BMJ Publishing Group Ltd and British Cardiovascular Society.

SKILLS FOR HEALTH, 2017. *End of Life Care Core Skills Education and Training Framework.* Health Education England, Skills for Health, and Skill for Care. Available: https://www.skillsforhealth.org.uk/info-hub/end-of-life-care-2017/ [7th July, 2022].

SLORT, W., BLANKENSTEIN, A.H., DELIENS, L. and VAN DER HORST, H.E., 2011. Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *The British journal of general practice: the journal of the Royal College of General Practitioners,* **61**(585), pp. 167.

SOKOL, D.K., 2006. How the Doctor's Nose has Shortened over Time; A Historical Overview of the Truth-Telling Debate in the Doctor–Patient Relationship. *J R Soc Med,* **99**(12), pp. 632-636.

STAKE, R.E., 2000. The Case Study Method in Social Inquiry. In: R. GOMM, M. HAMMERSLEY and P. FOSTER, eds, *Case Study Method.* 1st edn. London, Thousand Oaks, New Delhi: Sage, pp. 19-26.

STRAUSS, A. and CORBIN, J., 1998. *Basics of qualitative research techniques.* 2nd edn. Thousand Oaks: Sage.

SWIFT, A. and PUNSHON, G., 2019. *District Nursing Today The View of District Nurse Team Leaders in the UK.* On-line: The Queen's Nursing Institute, International Community Nursing Observatory.

TAN, X., FOO, M.A., LIM, S., LIM, M., CHIN, A., ZHOU, J., CHIAM, M. and KRISHNA, L., 2021. Teaching and assessing communication skills in the postgraduate medical setting: a systematic scoping review. *BMC Medical Education,* **21**(1).

THEODOSIUS, C., 2008. *Emotional labour in health care: the unmanaged heart of nursing.* London; New York: London; New York: Routledge.

VERMEIR, P., VANDIJCK, D., DEGROOTE, S., PELEMAN, R., VERHAEGHE, R., MORTIER, E., HALLAERT, G., VAN DAELE, S., BUYLAERT, W. and VOGELAERS, D., 2015. Communication in healthcare: a narrative review of the literature and practical recommendations. *International journal of clinical practice,* **69**(11), pp. 1257-1267.

WAGNER, E., AUSTIN, B. and VON KORFS, M., 1996. Improving outcomes in chronic illness. *Milbank Quarterly,* **4**(2), pp. 12-25.

WALCZAK, A., BUTOW, P.N., BU, S. and CLAYTON, J.M., 2016. A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work? *Patient education and counseling,* **99**(1), pp. 3-16.

WATTS, D. and MORGAN, G., 1994. Malignant alienation. Dangers for patients who are hard to like. *British journal of psychiatry; Br J Psychiatry,* **164**(1), pp. 11-15.

WEBSTER, S., LEWIS, J. and BROWN, A., 2014. Ethical Considerations in Qualitative Research. In: J. RITCHIE, J. LEWIS, C. MCNAUGHTON NICHOLLS and R. ORMSTON, eds, *Qualitative Research Practice A Guide for Social Science Students and Researchers.* 2nd edn. London: Sage, pp. 77-110.

WORKFORCE AND FACILITIES NHS DIGITAL, 2019. *Data on Written Complaints in the NHS 2018-2019.* on-line: NHS Digital.

WORLD HEALTH ORGANISATION, 2002. *Innovative Care for Chronic Conditions: Building Blocks for Action: Global Report.* Geneva: Noncommunicable Diseases and Mental Health Cluster.

YIN, R., K, 2018. *Case Study Research and Applications Design and Methods.* 6th edn. Los Angeles: Sage.

YOU, J.J., DOWNAR, J., FOWLER, R.A., LAMONTAGNE, F., MA, I.W.Y., JAYARAMAN, D., KRYWORUCHKO, J., STRACHAN, P.H., ILAN, R., NIJJAR, A.P., NEARY, J., SHIK, J., BRAZIL, K., PATEL, A., WIEBE, K., ALBERT, M., PALEPU, A., NOUVET, E., DES ORDONS, A.R., SHARMA, N., ABDUL-RAZZAK, A., JIANG, X., DAY, A. and HEYLAND, D.K., 2015. JAMA Internal Medicine, 1 April 2015, Vol.175(4), pp.549-556; Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians. *JAMA Internal Medicine,* **175**(4), pp. 549-556.

Appendices

Appendix A: Search output

Source / Database	Search term	excluded criteria	Items found	Items selected for consideration (including title and abstract)	Combined with:	Items found	Items selected for consideration (using title and abstract)	Items identified as relevant to this theme (using full text)
AMED	difficult conversations	none	5	0				0
	significant conversations	none	234		primary care	7	0	0
	communication skills	none	406		primary care	0		0
	allied AND communication	none	64	4			1	0

	prior to 2007						
breaking bad news AND nurses	prior to 2007	0					0
breaking bad news AND physiotherapist OR physio OR physiotherapy	prior to 2007	0					0
breaking bad news AND doctors	prior to 2007	2	0				0
giving bad news	prior to 2007	47	47	primary care or community care	0		0
perceptions AND professionals	prior to 2007	159		primary care or community care	0		0
professionals perceptions	prior to 2007	28	5				0
professionals views	prior to 2007	17	4				0

communication AND professionals views	prior to 2007	4	2					0
communication AND professionals perceptions	prior to 2007	2	0					0
therapists AND perceptions AND communication	prior to 2007	18	2					0
doctors AND perceptions AND communication	prior to 2007	1	0					0
nurses AND perceptions AND communication	prior to 2007	13	7					0
nurses view OR nurses perceptions AND communication	prior to 2007	6						0
attitudes AND communication	prior to 2007	98	25				1	0
dealing with emotions	prior to 2007	3					1	0

	dealing with emotions, subtheme attitude of health personnel	prior to 2007	1392		primary care	28	7	0
	own mortality	prior to 2007	7	1				0
Physiotherapy Evidence Database (PEDro)	difficult conversations	prior to 2007	0					0
	significant conversations	prior to 2007	0					0
	breaking bad news	prior to 2007	0					0
	communication skills	prior to 2007	14	1				0
	professionals perceptions	prior to 2007	0					0
	professionals views	prior to 2007	4	1				0

	attitudes AND communication	prior to 2007	2	0				0
	giving bad news	prior to 2007	0					0
	own mortality	prior to 2007	0					0
	countertransference	prior to 2007	0					0
	dealing with emotions	prior to 2007	0					0
	communication AND professionals	prior to 2007	24	0				0
	professionals experience	prior to 2007	0					0
Medline, HMIC,	difficult conversations	prior to 2007	514		primary care	13	4	2

EMBASE, PsycINFO searched through Ovid	significant conversations		8	0					0
	communication skills AND primary care	prior to 2007	494		nursing	44	3	1
					GP OR General Practitioner	119	5	2
					physio OR physiotherapist OR physical therapist	6	0	0
	breaking bad news	prior to 2007	675		primary care	10	2	1
	giving bad news	prior to 2007	157		primary care	3	0	0
	own mortality	prior to 2007	196		primary care	2	0	0
		prior to 2007			GP OR General Practitioner	0		0

		prior to 2007			nurses	12	7	0
		prior to 2007			physio OR physiotherapist OR physical therapist	0		0
		prior to 2007			doctors	6	1	1
	professionals views	prior to 2007	520		primary care	66	3	1
	professionals emotions	prior to 2007	4	1				1
	dealing with emotions	prior to 2007	106		primary care	4	2	0
	perceptions AND professionals	prior to 2007	15761		primary care	568	too large/re-searched as	

						professionals perceptions	
professionals perceptions	prior to 2007	893		primary care	38	1	0
countertransference	prior to 2007	37679		primary care	8	1	0
countertransference AND GPs OR General Practitioners	prior to 2007	3					0
countertransference AND physios or Physical Therapists	prior to 2007	0					0
countertransference AND Nurses	prior to 2007	16	2				1
clinicians thoughts	prior to 2007	11	1				0
clinicians beliefs	prior to 2007	81		primary care	13	0	0

clinicians emotions	prior to 2007	2				2	1
clinicians feelings	prior to 2007	9	1				0
attitudes and communication	prior to 2007	23884		primary care	893	too large/Researched as attitudes about communication	
attitudes about communication	prior to 2007	8	2				0
challenging communication	prior to 2007	65	4				0
end-of-life and conversations	prior to 2007	1418		primary care	38	8	3

Appendix B: Search protocol annex

As my research is looking at professionals in primary care, specifically, Physiotherapists, Nurses and GPs, the search had to be extensive and inclusive, not to exclude any potential literature. I searched terms first by themselves, then combined them with 'primary care' or 'community care' to help focus the returns on the targeted population under study. I used main terms combined with individual professional groups, such as 'Nurses', 'Physiotherapists' or 'GP'. There are various ways to say the professional groups of interest. Therefore, I did several combination searches with other terms such as 'doctors', 'allied' (for allied health professionals), 'physical therapists' (used in the US), and spelling out 'General Practitioner' to aid in capturing related articles. Recognising synonyms and specific examples exist, other terms were tried independently, then again in combination.

Exclusion criteria were non-English, children, and for the majority, before 2007, to keep the search relevant as it was ten years from when I initially started the literature review. I removed duplicates as I went to help maintain order. Using literature written in English only limited the number of countries and cultures included in this review. In the beginning, suspecting there were not many representing Physiotherapists, I searched explicitly in the Allied and Complementary Medicine Database (AMED), but this produced minimal relevant studies. I then searched through lists of databases to see if there was another specific to or included physiotherapy and came across the Physiotherapy Evidence Database (PEDro). Unfortunately, it produced no related studies. I then searched for any Physiotherapy association and found the Charted Society of Physiotherapy website. I used this website to see the profession's perspective and what guidelines, methods, or recommendations existed around difficult conversations. This website listed resources, guidance and blogs for

Physiotherapists' reference. One search found an article published in the Physiotherapy journal; the rest were pamphlets and blogs. The focus of the article and the other documents was on the Physiotherapists' role in palliative care or cancer care. Still not satisfied, I searched the journal Physiotherapy directly but was unsuccessful. Next, I did a generic Google and Google Scholar search, which provided many returns. However, the returns were mostly about the benefits, the access, and interventions of physiotherapy, and Physiotherapists' exposure to training around palliative/end-of-life.

The search also considered the research methodologies that help strengthen the overall picture. I reviewed the title and abstracts with articles found to narrow down appropriate literature and later skimmed through them to ensure relevance. Often here is where I removed many articles since most did not relate to this study. For example, there were multiple studies on communication skills, specifically training or behavioural application of communication skills. These studies, however, were often about a broad topic regarding general consultations or specific topics such as antibiotic use, interprofessional working or self-management.

The articles were read through in their entirety to determine valid use for this review. The search resulted in 14 articles found. Furthermore, I reviewed references listed in the articles and selected many for further consideration. The same criteria were used in these studies as well. An additional nine articles were selected through filtering, hand-selecting, and filtering again, with 23 articles for this review.

Appendix C: Information sheet and consent form

Information sheet

Department of Social Work Royal Holloway, University of London

An exploration of how professionals view difficult conversations in practice and how an experiential, multiprofessional education influences their practice.

Researcher: JJ Nadicksbernd, 07738 080841 JJNadicksbernd@gmail.com

This study is an exploration of how professionals view difficult conversations in practice and how an experiential multiprofessional education influences their practice. "Difficult conversation" in this context is a talk or discussion where participants feel it to be hard, usually uncomfortable and challenging, needing extra effort and often needing skill to navigate through it. In other words, it is when a conversation is about a topic that is tough to bring-up, or to engage in, based on the emotional content.

If you choose to take part, you will be asked to give permission to the social enterprise Difficult Conversations to supply the researcher a copy of the two surveys you complete during the workshop (one prior to and one post training). In addition, you will be asked to partake in two interviews of about 45-60minutes, one post workshop, and again three months post workshop.

The surveys will take place at the workshop location and administered by those providing the workshop and a copy will be given to the researcher. You are asked to put your name on both surveys. The interviews will take place either at the site of where the workshop took place or in a location convenient for you.

Participation is voluntary and your participation is confidential, only seen by my academic supervisor and myself. There is no anticipation of causing any distress, however due to the nature of the topic, if you feel upset or emotional, it is okay and if you would like to take a break or to stop, you can do so at any time. You can decide not to answer any question if you prefer not to and can withdraw at any time without giving a reason and without affecting the education you receive.

Your signed consent form and contact details will be stored separately from the responses you provide.

You may retain this information sheet for reference and contact me with any queries.

Consent form

Study: An exploration of how professionals view difficult conversations in practice and how an experiential, multiprofessional education influences their practice

Researcher: JJ Nadicksbernd

Please indicate for **each** of the following items:

I have read the information sheet about this study   YES   NO

I have had the opportunity to ask questions   YES   NO

I have received satisfactory answers to any questions YES   NO

I understand that I am free to withdraw from the study at any time, without giving a reason   YES   NO

I agree to participate in this study.   YES   NO

I agree to let the social enterprise Difficult Conversations share my pre and post surveys with the researcher.   YES   NO

Signed…………………………

Name …………………………..

Date …………………………..

NB: This Consent form will be stored separately from the responses you provide.

Please note: There should be no data collected on the consent form as this will be stored separately from data.

Appendix D: Interview schedules

Interview Schedule I

Interview length: 45-60 minutes

Date:

Time:

Introduction

Thank you for your time and for being willing to take in this research. The information you give will be protected and treated as strictly confidential. For accuracy I would like to record this interview, is it okay with you?

This research is about exploring how professionals view difficult conversations in practice and how an experiential, multi-professional education influences professionals' practice. Due to the nature of the topic, if you feel upset or emotional, it is okay and if you would like to take a break or to stop the interview, we can do so at any time.

I have a series of questions to ask, but feel free to interject or ask for clarification.

Interviewee:

Age:

Profession/Role:

Amount of years in profession:

1. What does difficult conversations mean to you (please define it)?

　　　Probe: Can you give me an example?

2. Tell me about the difficult conversations you have in practice? Probe: types,

   characteristics, emotions they elicit, any feelings?

   Probe: Can you give me an example?

   Probe: How often do they generally happen?

   Probe: Are there other characteristics or emotions?

3. Are there differences between patients and family members?

4. Are there differences between younger and older patients?

5. Please tell me the sources for why difficult conversations occur.

   Probe: Any differences from a someone who has experienced poor service for

   example?

6. Why do you think they are difficult?

7. How well do you think these conversations generally go for you as a_____. What about

   the patient/family member, how well do you think it goes for them? Is there anything

   you would change?

8. Can you give me an example when a conversation didn't go well?

   Probe: How often would do you have a conversation that doesn't go very well?

9. When a loved one is in the consultation, how do you engage with him/her, if at all?

10. If you could change the way these difficult conversations go in the future, what would you change?

   Probe: within your power to change? for other within your power factors?

   Probe: Is there anything outside of your power, that if you had a magic wand what would you do to make these go better? Probe: other magic factors?

   Probe: (with answers given) How would you use these (time, tools, etc.)?

11. Can you tell me about any other training you have had on how to have difficult conversations? (probe –setting such as school, on the job, mentor, etc.)

12. Why did you attend the Difficult Conversations workshop?

13. What were you hoping to get out of it?

14. Did you? How so? Probe: Something else you were hoping to get out of it? Other objectives?

15. What do you consider to be your main learning from the workshop, if any? Probe: personal learning need, style of the workshop, multi-professional, case examples, why do you think?

16. Will you and how will you use any learning from this workshop? (probe-in future practice, specific topics)

      Probe: Any other uses?

17. Are there other types of learning you think would be helpful such as self-directed learning, online learning, (other non-workshop activities)?

18. If you were to engage in a difficult conversation right now, tell me about your level of confidence.

19. We have covered a great deal of information, but do you think there is anything we missed or anything you would like to add?

Interview Schedule II

Interview length: 45-60 minutes

Date:

Time:

Introduction

Thank you for your time and for allowing me to interview this second time for this research. The information you give will be protected and treated as strictly confidential. For accuracy I would like to record this interview, is it okay with you?

This research is about exploring how professionals view difficult conversations in practice and an experiential, multi-professional education influences professionals' practice. Due to the

nature of the topic, if you feel upset or emotional, it is okay and if you would like to take a

break or to stop the interview, we can do so at any time.

I have a series of questions to ask, but feel free to interject or ask for clarification.

1. What does difficult conversations mean to you (please define it)?

2. Since we last spoke, about how many difficult conversations have you had?

3. What were the sources for why these difficult conversations occurred?

    Please describe them for me.

        Probe: Tell me more. What was happening? Types? Characteristics? Emotions they

        elicit. Any feelings? An example? Are there other characteristics or emotions?

4. Why do you think they were difficult?

5. How did you approach these conversations?

6. How well did these conversations go for you? What about the patient/family member,

    how well do you think it goes for them?

7. [if not already given] Can you give me an example when a conversation didn't go well?

        Probe: How often would do you have a conversation that doesn't go very well?

8. Is there anything you wish you did differently?

9. If you could change the way those difficult conversations went, what would you change?

        Probe: within your power to change? Other factors within your power?

Probe: Is there anything outside of your power, that if you had a magic wand, what would you have changed to make these go better? Probe: other magic factors?

Probe: (with answers given) How would you use these (time, tools, etc.)?

10. Was there anything different from those conversations than with conversations before the workshop? How so?

11. (came from I) Age of pts- do you think there is a difference between generations for DC? Older, middle, and young?

12. (came from D) Do you ever think about your own mortality or of you aging during these conversations, and what are your thoughts?

13. (came from H)- Can you tell me about any support within your profession or work environment with these difficult conversations?

14. Fear- what do you do to move yourself forward when you are afraid?

Probe- If a conversation is frightening, you may avoid it, but if you don't, what is it that you do to make yourself still continue with the conversation?

Probe-How do you deal with your nerves during a difficult conversation?

15. Time- how do you work around the time pressures?

Probe- What recommendations would you suggest dealing with time pressures?

16. The System- What recommendations would you suggest for how the system works/runs?

Probe- do you have any ideas on systematically things could run differently? Would make things easier for the patient or for professionals?

17. What do you think about interprofessional working in the community? What would you recommend? (came from H second interview, but also, I mentioned something similar)

18. If you were to engage in a difficult conversation right now, tell me about your level of confidence.

19. Now after 3 months, what do you consider to be your main learning from the workshop or application of lessons learned from the workshop, if any?

Probe: personal learning need, style of the workshop, multi-professional, case examples, why do you think?

20. [If they did not comment in interview 1] What are you views on having a training with multiprofessionals on this topic?

21. We have covered a great deal of information, but do you think there is anything we missed or anything you would like to add?