

# **Communication with the relatives and friends of imminently dying patients in a hospice**

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Submitted for the degree of Doctor of Philosophy



## Declaration

I, Rebecca Jade Anderson confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Rebecca Jade Anderson

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11/02/2020

Date





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## **Abstract**

Communication between healthcare professionals and the relatives and friends of patients who are imminently dying is a key part of providing high quality end-of-life care. The primary aim of this thesis is to understand the practices used to accomplish prognostication and other relevant activities in these conversations. This aim is addressed by audio-recording 29 conversations between senior, experienced healthcare professionals and the relatives and friends of terminal-care patients in a hospice. Conversation analysis of recordings is used to identify interactional practices within these conversations. Three conversation analytic chapters explore terminal-phase prognostication sequences; closing the business-at-hand (exiting prognostic talk and transitions towards closings); and disagreements. These chapters demonstrate how healthcare professionals and relatives navigate the uncertainty which is inherent in end-of-life talk. They show how participants discuss potentially difficult topics and transition towards more certain talk on topics that allow an orientation towards action.

A secondary aim is to understand the perspectives of healthcare professionals and the relatives and friends of patients about what is important during communication with families at the end of life. This is addressed by interviewing 12 bereaved relatives and friends, and conducting a focus group and interview with five healthcare professionals. Thematic analysis identifies contextual factors such as hospice facilities and privacy that can impact experiences of communication, as well as more specific elements of communication that participants consider important, such as honesty about uncertainty and consultation during decision making.

The final aim is to provide recommendations for training to improve communication skills for less experienced healthcare professionals. This is addressed by combining the conversation analytic findings with the thematic analysis to give a comprehensive understanding of communication in this context. Recommendations for communication practices to be taught within a training programme are presented, alongside suggestions for the additional work required to implement training in practice.



## **Impact Statement**

Patients in the final hours or days of life are often unable to communicate. Their families and friends therefore need clear, honest information from healthcare professionals in order to make informed decisions about end-of-life care and prepare for the patient's death. Despite an awareness of the importance of communication at the end of life, complaints about poor communication are common within the NHS. In order to address this problem, the first step of the thesis was to identify what was already known about communication with relatives at the end of life by conducting a qualitative systematic review. This review was published in *Palliative Medicine* and has received a high level of attention in its first months since publication (at the time of writing its Altmetric score is in the 96<sup>th</sup> percentile of all outputs of the same age, and it has been cited four times). A podcast was recorded to supplement the article, increasing the ways in which people can engage with the research findings.

The research presented in this thesis is the first to record conversations with families in an inpatient hospice setting and therefore provides an original contribution to the field of clinical communication research. It does so by using conversation analysis of audio-recorded conversations between healthcare professionals and the relatives and friends of imminently dying patients, and thematic analysis of a focus group and interviews with healthcare professionals and bereaved relatives and friends. By combining these two qualitative methods, this thesis provides a comprehensive account of communication with relatives and friends of imminently dying patients. Findings have been presented at national and international conferences, and a second paper has been accepted for publication in *Palliative Medicine*. Findings will be presented to hospice staff at the recruitment site and a lay report will be sent to those participants who indicated they wanted to receive a summary of study results.

Current guidelines for communication at the end of life provide useful advice for clinicians, but focus mostly on communication with patients, not specifically with their families. They also often lack clear strategies for how to put guidelines into practice. In the final chapter of the thesis, specific recommendations for training are provided, based on the findings from this thesis alongside existing evidence from communication and healthcare research. Suggestions for how this training could be implemented, including how a training intervention could be co-produced, are also provided. This combination of analytical insights with practical steps required to put recommendations into practice therefore increases the potential impact of the findings.

In addition to the implications for training and practice, the findings provide analytical insights that may be of interest to other communication researchers, particularly within the field of conversation analysis. Whilst the conversations analysed were context-specific, at an interactional level, many of the communication practices examined can be found in everyday interactions. The permissions sought during the consent process also allow the use of the data for future research, meaning that further analysis of the corpus can be conducted.

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## Abbreviations

<b>ACP</b>	Advance care planning
<b>CA</b>	Conversation analysis
<b>CALM</b>	Managing Cancer and Living Meaningfully psychotherapeutic approach
<b>CARM</b>	Conversation Analytic Role-play Method
<b>CNS</b>	Clinical Nurse Specialist
<b>CPR</b>	Cardiopulmonary resuscitation
<b>DA</b>	Discourse analysis
<b>DVR</b>	Digital voice recorder
<b>HCP</b>	Healthcare professional
<b>FPP</b>	First pair part
<b>GMC</b>	General Medical Council
<b>GP</b>	General Practitioner
<b>ICU</b>	Intensive care unit
<b>JB</b>	Joanna Briggs Institute
<b>LACDP</b>	Leadership Alliance for the Care of Dying People
<b>NHS</b>	National Health Service
<b>NICE</b>	National Institute for Health and Social Care Excellence
<b>NICU</b>	Neonatal intensive care unit
<b>PICU</b>	Paediatric intensive care unit
<b>PIS</b>	Participant information sheet
<b>PPI</b>	Patient and public involvement
<b>SICU</b>	Surgical intensive care unit
<b>SPP</b>	Second pair part
<b>TCU</b>	Turn constructional unit



## Chapter 1 Introduction

This thesis examines communication between healthcare professionals (HCPs) and the relatives and friends of patients who are imminently dying in a hospice. Conversation analysis (CA) of audio-recordings is the primary approach of the thesis and is used to understand how participants organise their institutional activities through talk-in-interaction. Interviews with relatives and friends of patients, and a focus group and interview with HCPs, are used to elicit participants' perspectives on communication at the end-of-life. These findings on how HCPs and families communicate and what they believe is important in these conversations are combined to provide a fuller picture of this communication and suggest recommendations for training. The thesis is part of a wider programme grant, I-CAN-CARE<sup>1</sup>, which addresses the assessment and care of dying patients receiving sedative medicine, and ways to improve prognostic accuracy, communication and staff training. This PhD project contributes to the overall I-CAN-CARE programme but is a standalone study.

Communication is a vital part of all healthcare encounters. Clear communication is needed to ensure that doctors understand symptoms and make correct diagnoses; that investigations and procedures are explained so patients can be involved in decision making; and that countless other medical encounters progress smoothly. One area of medicine in which communication is particularly important is palliative care. Firstly, the communication of prognosis and the impact and purpose of different treatment options are vital parts of palliative care. Patients who have end-of-life discussions and are informed of their prognosis are more likely to die in their preferred place and less likely to have aggressive treatment in the last week of life (Lundquist, Rasmussen, & Axelsson, 2011; Wright et al., 2008). Communication and shared decision making are also key elements of compassionate care (Pfaff & Markaki, 2017), which is seen by many as the core value of palliative care (Larkin, 2016). Compassion and empathy are rated by patients and their families as vital aspects of palliative care (Nelson et al., 2010; Parker et al., 2007). The importance of compassionate care that addresses all aspects of the patient experience is reflected in the General Medical Council (GMC) definition of palliative care:

The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis

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<sup>1</sup> <https://www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research/research/supportive-and-end-of-life-care/i-can-care>

or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity (General Medical Council, 2010, p.84)

Palliative care can be provided at home, in care homes, in hospitals or in hospices. It can be provided by general health and social care professionals such as GPs, district nurses and social workers, and by specialist palliative care teams including palliative care doctors, clinical nurse specialists, counsellors and other specialist allied health professionals. This thesis focuses on experienced specialist palliative care doctors and nurses in a hospice setting.

As the GMC definition outlines, palliative care can be provided to patients at any stage of an incurable illness. It is important to draw the distinction between this and end-of-life care, which is one part of palliative care. The GMC defines end of life as follows:

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010, p.82)

This definition covers a broad range of circumstances. A further distinction must therefore be made between what the GMC defines as 'end-of-life care' and the final part of end-of-life care, referred to in this thesis as 'terminal care' or the 'terminal phase'. The term terminal care applies when patients are expected to die in the coming hours or days (although as outlined in section 1.1 below, this is not always easy to predict). These terms are used in different ways and often interchangeably across the literature and in practice. The literature presented in this chapter mostly focusses on end-of-life care generally, including, but not exclusively concerned with, the terminal phase. However the main research conducted for this thesis specifically examines communication in terminal care.

The majority of studies looking at communication in palliative care have focussed primarily on communication between HCPs and patients themselves (e.g. Almack, Cox, Moghaddam, Pollock, & Seymour, 2012; Andreassen, Neergaard, Brogaard, Skorstengaard, & Jensen, 2015; Kiely et al., 2012; Parry, Land, & Seymour, 2014). However there is a growing consensus that care for patients must also include considering the needs and preferences of those important to the patient (Clay & Parsh, 2016). This thesis therefore focusses on communication with the families of patients receiving terminal care. Over recent decades, the cultural meaning of the term 'family' has changed. Whilst kinship ties remain

important, increasingly the term ‘family’ goes beyond blood relatives to include non-related friends (Donovan, Heaphy, & Weeks, 2003; Luotonen & Castrén, 2018; Wall & Gouveia, 2014). From here onwards, the terms ‘relatives’ and ‘family’ are therefore used to refer to any main companions of a patient, whether or not the person is related to the patient.

This chapter provides the background to the development of the research presented in this thesis. It begins by demonstrating why HCP communication with relatives is so important at the end of a patient’s life, and the current difficulties with this communication (section 1.1). Current understanding about how communication with relatives should be done is outlined across two sections: Firstly, research on relatives’ communication preferences at the end of life is presented in section 1.2. This is followed by an outline of end-of-life communication guidelines in section 1.3. The next section reports what is known about how this communication is actually being accomplished at present (section 1.4). This section presents a systematic review, conducted for this thesis, of qualitative research into what and how communication occurs between relatives and HCPs at the end of life. Section 1.5 provides an overview of other relevant studies to date that have used CA in end-of-life and palliative care research. The aims of the thesis are outlined in section 1.6, and section 1.7 provides an overview of how the remaining chapters in the thesis will contribute to addressing these aims.

## **1.1 Importance of communication with relatives in end-of-life and terminal care**

Relatives of patients at the end of life need honest, clear communication from HCPs in order to prepare for the patient’s death, say their goodbyes and make decisions to ensure the patient has a ‘good death’. Research has shown that relatives value honest, clear and compassionate communication at the end of life, particularly when receiving prognostic information (Kirk, 2004; Nelson et al., 2010; Steinhauser et al., 2001; Steinhauser et al., 2000; Steinhauser, Voils, Bosworth, & Tulsky, 2014). The majority of surrogate decision makers questioned wanted to be given this prognostic information, even when there was significant uncertainty (Evans et al., 2009; Payne, Burton, Addington-Hall, & Jones, 2010). The impact that communication can have on relatives’ overall experience of end-of-life care is highlighted by both focus group and survey-based findings that overall satisfaction with their family member’s end-of-life care was strongly impacted by the communication they had experienced with healthcare providers (Hinkle, Bosslet, & Torke, 2015; Royak-Schaler et al., 2006).

This communication is especially important for relatives when the patient is approaching the terminal phase. At this point, patients often have reduced or no capacity and so relatives need to have conversations with HCPs about prognosis and make decisions about care. Communication from HCPs, including providing both information and psychosocial support, is vital for people to feel prepared for the death of their family member (Hebert, Schulz, Copeland, & Arnold, 2009; Loke, Li, & Man, 2013). This in turn can have long-term impacts on relatives' response to bereavement. When relatives are unprepared for a death, they have been shown to have worse psychological outcomes, including higher rates of post-loss depression and poorer adjustment (Barry, Kasl, & Prigerson, 2002; Kim, Carver, Spiegel, Mitchell, & Cannady, 2017; Nielsen et al., 2017). In the intensive care unit, surrogate decision makers' perceptions of clinician communication had a significant impact on their post-traumatic stress disorder symptoms (Wendlandt et al., 2019).

Despite the importance of this communication, HCPs describe struggling to know when to initiate end-of-life discussions and will often wait for patients or families to raise the issue (Almack et al., 2012). They have reported a lack of formal training on how to communicate with patients and relatives at the end of life (Bloomer, Endacott, Ranse, & Coombs, 2017; Buss et al., 2011; Travers & Taylor, 2016). A focus group study with UK undergraduate nursing and medical students found that education about communication in palliative care was limited to classroom teaching and that students felt they did not have opportunities to talk to dying patients or their families (Gillett, O'Neill, & Bloomfield, 2016), leaving them unprepared for this when they qualify. These concerns are not limited to inexperienced HCPs; in a survey of palliative care experts across nine countries, 83% agreed that more evidence based guidance on the best strategies to improve communication with relatives would improve end-of-life decision making (Raijmakers et al., 2012).

Prognosis in particular is a topic which clinicians report struggling to discuss with patients and their relatives. Prognosis is difficult to predict and research has shown that clinician predictions are often inaccurate (White, Reid, Harris, Harries, & Stone, 2016). HCPs cite this uncertainty and their lack of confidence as barriers to discussing prognosis with patients and relatives (Travers & Taylor, 2016; Udo, Lövgren, Lundquist, & Axelsson, 2018). When clinicians do discuss prognosis with relatives, there can still be issues with miscommunication. One study in a Dutch hospital found that when both HCPs and relatives reported having discussed end-of-life issues, relatives were more likely to be present when the patient died. However, reports of whether these discussions had taken place differed between HCPs and relatives; for the same patients, a higher proportion of HCPs than relatives were aware that the patient was dying and believed that the patient and relative had been informed about end-of-life issues (Witkamp, van Zuylen, Vergouwe, van der Rijt, & van der Heide, 2015).



Given the impact of communication on relatives and the difficulties expressed by HCPs, it is unsurprising that communication is a key feature of official complaints from relatives about end-of-life care. A report by the Parliamentary and Health Service Ombudsman in 2015 detailing investigations into complaints about end-of-life care, identified 'poor communication' as a key theme. (Parliamentary and Health Service Ombudsman, 2015). This included clinicians failing to have prognostic conversations with patients and families and not explaining prognosis in a way that they could understand. It was also clear that communication cut across all themes in the report. For example, the theme 'poor care planning' highlighted a need for clinicians to do more to discuss needs and preferences with patients and their families in order to help patients die in their preferred place and with a higher quality of life.

There is an increasing consensus on the need for research and training to improve communication with patients and relatives at the end of life. Following complaints about the Liverpool Care Pathway, the Neuberger report produced numerous recommendations including improving the identification of patients who are dying and undertaking research to determine the best way to present this information to patients, relatives and informal carers (Neuberger, Guthrie, & Aaronovitch, 2013). In response to this report, the Leadership Alliance for the Care of Dying People (LACDP) identified five key priority areas to improve end-of-life care. Three of these were: recognition and communication about when someone may die in the next hours or days; sensitive communication with patients and those important to them; and respecting the needs of family members and others important to the patient (LACDP, 2014). They also highlighted the need for training in sensitive communication for those working with people near the end of life. More recently, the Royal College of Physicians produced a report, 'Talking about dying: how to begin honest conversations about what lies ahead' (Bailey & Cogle, 2018). This report addresses barriers to communication, misconceptions about palliative care, CPR and advance care planning (ACP), and provides case studies for implementing change. Whilst the report mostly focuses on early ACP rather than conversations with relatives in the final days of life, it demonstrates the increasing recognition within the healthcare profession that communication is key to good end-of-life care.

## **1.2 Relatives' communication preferences at the end of life**

In order to improve end-of-life communication with relatives, it is important to hear from these relatives about their perceived communication needs. Parker et al. (2007) conducted a systematic review of patient and caregiver preferences for end-of-life communication in the advanced stages of a life-limiting illness. They found that caregivers generally wanted as much information as possible,

but that they felt it was important to understand the information needs of individuals and that this can change over time as goals, expectations and prognosis are all part of an ongoing and changing process. Caregivers expressed a need for information on what to expect in terms of symptoms and what is likely to happen in the patient's final days of life. They wanted honest communication with clear language that avoided euphemisms. In addition to these features of the communication, caregivers discussed their preferences for the style of communication, describing a need for HCPs to be compassionate and empathetic in their communication and give a sense that they would not abandon the patient and relatives.

Numerous studies have since found similar communication preferences from relatives. For example Payne et al. (2010) found that relatives of patients on an acute stroke ward wanted clarity and honesty about prognosis, but the way this information was delivered was equally important, as availability and 'good inter-personal skills' were flagged as key by relatives. In a study looking at preparing families for a bereavement, Hebert et al. (2009) found that communication was a key mechanism for dealing with uncertainty. In their study, families discussed both the content and relationship dimensions of communication as important. They described needing clear, consistent information about what to expect, but also that being available and appearing caring were important. The authors highlighted three types of preparation that families needed: cognitive (informational needs), affective (emotional needs) and behavioural (help with tasks such as funeral planning). They found that good communication was central to enabling all these types of preparation for death.

A more recent study involving interviews with current and bereaved caregivers of people with advanced cancer was conducted by Collins, McLachlan, and Philip (2018). Once again, honest prognostic information was highlighted as a key preference. Relatives described a need to be told when the patient is imminently dying, even if this may seem obvious to the HCP. In the last days in particular, relatives expressed a preference for clarity, suggesting that HCPs should be willing to use words such as 'death' and 'dying' and avoid euphemisms. Whilst this honesty and directness were central themes, relatives in this study also highlighted the need for HCPs to check how much they want to know about prognosis and the dying process. This reflects findings in other studies that most people wanted this information, but a minority of relatives would prefer less prognostic information (e.g. Apatira et al., 2008; Applebaum et al., 2018).

### 1.3 Current end-of-life communication guidelines

The importance of communication at the end of life is now widely recognised and research on relatives' communication preferences has fed into numerous evidence-based guidelines that have been produced to improve practice. In the UK, the National Institute for Health and Social Care Excellence (NICE) developed guidelines for improving the care of dying people, including a section on communication (NICE, 2015). Recommendations provided by an expert committee were based on their own experiences, and a review of qualitative, quantitative and intervention research studies. In Australia, Clayton et al. (2007) conducted a systematic literature review, a review of existing guidelines and expert opinion, and convened an expert panel to provide clinical practice guidelines for communicating prognosis and end-of-life issues. Bernacki and Block (2014) also produced a review and synthesis of best practice relating to communication about serious illness care goals as part of the American College of Physicians High Value Care Initiative. These guidelines all provided similar recommendations, suggesting open, honest communication; checking understanding; avoiding jargon and false hope; and promoting individualised communication.

These guidelines were developed to address communication with patients alone, or patients along with those important to them. Some also focus more on ACP earlier in the disease trajectory than is the focus of this thesis. A number of the recommendations within the guidelines are therefore not relevant to communication with relatives at the terminal phase, but Table 1.1 summarises those that do apply to these circumstances.

**Table 1.1** Summary of recommendations from Bernacki & Block (2014); Clayton et al. (2007); NICE (2015)

Recommendations for end-of-life communication with patients and their families from published guidelines
Establish the relative's current understanding, how much they want to know and how much involvement they want in decision making
Use open-ended questions
Avoid jargon and euphemisms, be willing to say 'death' and 'dying'
Avoid giving exact prognostic timeframes, explain uncertainty and acknowledge the difficulty of this
Be honest, do not give false hope but do not be blunt
Elicit concerns and ask about spiritual and emotional needs
Check their understanding of new information and encourage questions
Use nodding, open posture, noises of agreement
Describe what to expect in terms of symptoms and how they will be managed
Consider cultural differences but don't make assumptions based on this
Show compassion
Continue to provide updates as things change, emphasise opportunities for further discussion

These guidelines are a useful starting point to help clinicians to think about how they should be communicating about end-of-life issues. However, the recommendations focus primarily on what to do without giving clear, concrete strategies on how to do it. Clayton et al. (2007) and Bernacki and Block (2014) do provide some useful phrases for clinicians to use, but it is not clear whether the specific wording was based on evidence, or if there are certain points in the conversation where these phrases are most appropriate. Bernacki and Block (2014) also provide a conversation guide (a checklist of things to cover with patients), but this is geared towards ACP rather than discussions when the patient is imminently dying.

A further limitation of these guidelines is that they do not provide separate recommendations for communication with relatives. Whilst some recommendations are clearly relevant to both patients and relatives, we cannot assume that these groups will always have the same communication needs. For instance there is practical information (e.g. how to register a death) that relatives need but may not be appropriate to discuss with patients. A systematic review also found that caregivers generally wanted more information about the dying process than patients, particularly closer to the end of life (Parker et al., 2007).

In order to build on existing guidelines and provide recommendations for specific strategies to improve communication with relatives at the end of life, it is important to understand how this is currently being done. The first step towards this was to carry out a systematic review of research into the characteristics of communication with relatives at the end of life.

## **1.4 Existing research: A qualitative systematic review of communication between healthcare professionals and relatives of patients at the end of life**

This section describes a qualitative systematic review, published in Palliative Medicine (Anderson et al., 2019). The paper and supplementary information can be found in Appendix 2. The review protocol was registered with PROSPERO (registration number CRD42017065560).

### **1.4.1 Objectives**

The focus of the review was on literature examining what and how HCPs and relatives of patients communicate at the end of life. Prior to finalising the research objectives and approach, an initial scope of the literature was undertaken. This suggested that quantitative methods such as surveys could not explore what actually happens during these conversations in sufficient depth. Additionally, as discussed in section 1.1, HCPs and relatives sometimes have different recollections of

communication (Witkamp et al., 2015) and so it was important to include studies from both perspectives, as well as those using recordings and observations of naturally occurring conversations. Much of the literature used the term 'end of life' and did not differentiate terminal care from this, and so the term 'end of life' was used in the study objectives. This initial scoping therefore led to the following objective:

To review existing qualitative evidence about the characteristics of communication about prognosis and end-of-life care between HCPs and relatives of patients approaching the end of life:

- from the perspective of HCPs
- from the perspective of relatives
- as identified from observational studies

#### **1.4.2 Methods**

Four electronic databases (CINAHL plus, MEDLINE, PsycINFO and EMBASE) were searched in July 2017 and updated in July 2018, alongside hand-searching reference lists of five relevant reviews (Coombs, Parker, Ranse, Endacott, & Bloomer, 2017; Loke et al., 2013; Lowey, 2008; Noome, Beneken genaamd Kolmer, van Leeuwen, Dijkstra, & Vloet, 2016; Parker et al., 2007). Reference lists of included papers were searched and citation searching was performed using Scopus. There were no restrictions based on publication date and only peer-reviewed articles were included. Only English-language articles were included as there were no resources available for translation. Text and MeSH terms for the following word groups were searched in all four databases with the Boolean term AND: communication, relatives, healthcare professionals, settings with patients at the end of life, and qualitative methodology (see Appendix 2 for full electronic search strategy).

Studies were included if they used a qualitative method of data collection and analysis to research communication between HCPs and adult relatives of patients at the end of life, with a focus on what and how communication is done. The full eligibility criteria are provided in Appendix 2. The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research (see Lockwood, Munn, & Porritt, 2015) was used to assess the quality of included articles. This tool was chosen because it is suited to a wide range of qualitative methods including observational studies. Full text review, data extraction and quality appraisal were repeated and checked by a second reviewer (Megan Armstrong, Research Associate). Disagreements were resolved through discussion and referral to a third reviewer (Joe Low, supervisor) when required.

Data were synthesised following Thomas and Harden's (2008) steps of thematic synthesis. Participant quotes and authors' descriptions and interpretations were entered into NVivo 11 for initial line-by-line coding. These codes were grouped into descriptive themes to create a coding framework, which was applied to the whole dataset and refined as more themes emerged. Following discussions with other reviewers, these descriptive themes were developed into analytic themes. For example, the descriptive themes 'problem listing' and 'perspective display invitations' both highlighted a patient's deterioration and so this became an analytic theme. An interpretivist approach was taken towards the synthesis, which involves providing narrative descriptions to represent the subjective experiences of a range of stakeholders (Suri, 2013). A broad range of populations and clinical settings were therefore included in the review and are presented together within the synthesis.

### 1.4.3 Results

The search strategy identified 3986 results, from which 1791 duplicates were removed. Following screening, 31 papers from 25 individual studies were accepted for inclusion in the review (see Figure 1.1 and Table 1.2).

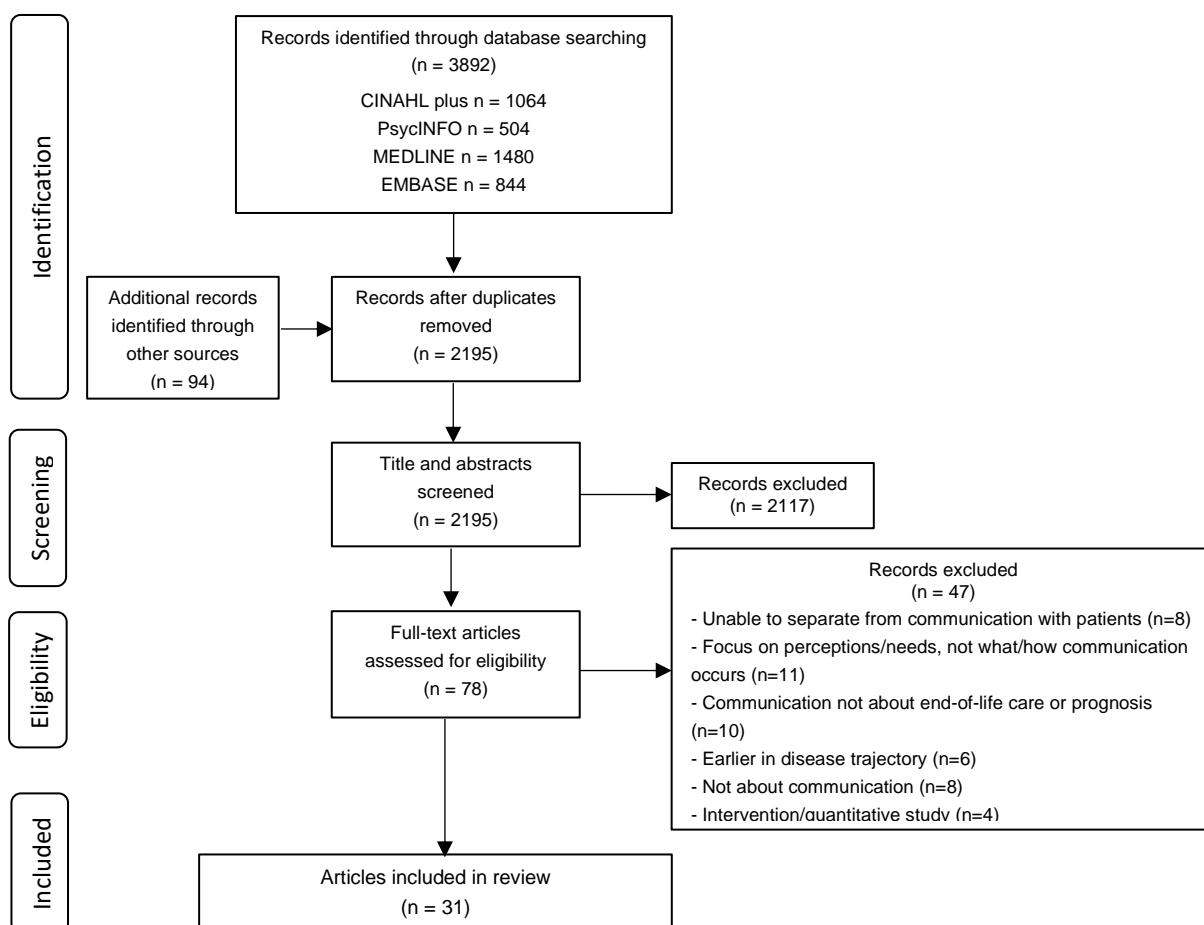


Figure 1.1 PRISMA diagram of included articles (reproduced from Anderson et al., 2019)

Fourteen of the included papers used observational methods (non-participant observations or video/audio-recordings), ten used HCP interviews or focus groups, five used relative interviews, and two ethnographic studies used a mixed approach. The majority of articles were based in adult acute care (18 articles); eight were in paediatric or neonatal intensive care units (ICUs); three in palliative care settings (adult inpatient, adult home hospice and paediatric palliative care consultations); and two in other settings (older adult wards and family physicians).

The full results from the JBI quality appraisal checklist are provided in Appendix 2. The quality appraisal suggested that the main limitations related to authors not describing their potential influence on the findings and interpretation. However in addition to points identified by the checklist there were also some reporting issues, as papers were inconsistent in their reporting of the numbers of HCPs and relatives involved in conversations (see demographics table in Appendix 2).

**Table 1.2** Summary of included papers (adapted and reproduced from Anderson et al., 2019)

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<b>Observational studies</b>					
<sup>a</sup> Aldridge and Barton (2007)  USA	Compare the 'description of current status' in end-of-life discussions with family members that did and did not result in a change from therapeutic to comfort care	Surgical ICU	Critical care intensivists, surgeons and families of current SICU patients	Secondary analysis of audio-recordings of family conferences  Discourse analysis	Highlighting negative outcomes and direct summaries implying terminal status led to more decisions to move to comfort care  Decisions were less likely to be made when more positive outcomes were described and possible treatment was discussed
<sup>a</sup> Barton, Aldridge, Trimble, and Vidovic (2005)  USA	1. Describe the structure and variations within each phase of the end-of-life discussion  2. Look specifically at interaction between physicians and families within each phase	Surgical ICU	Critical care intensivists, surgeons and families of current SICU patients	Secondary analysis of audio-recordings of family conferences  Discourse analysis	Description of current status used to develop consensus on terminal status. Some used perspective display questions.  Framed decision as expressing patient's wishes. If no consensus on terminal status was established, decisions were not made  Explained logistics of dying (often initiated by family) with more direct language
<sup>a</sup> Barton (2007)  USA	Describe how physicians and families construct an ethical frame to present the decision to withdraw life support as the 'right' decision	Surgical ICU	Critical care intensivists, surgeons and families of current SICU patients	Secondary analysis of audio-recordings of family conferences  Discourse analysis	Process of dying and comfort care repeated by doctors and families  Doctors repeated problem listing and emphasised the decision as being a consensus between the medical team  Families discussed personhood and consciousness- doctors repeated 'best interests' and described the decision as ethical because of loss of consciousness  Both families and doctors described the decision as 'right'
<sup>b</sup> Curtis et al. (2002)  USA	Establish a framework that will allow future analyses and studies to describe and understand the communication in family conferences in which the issue of withholding or withdrawing life support is discussed	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences  Limited application of grounded theory	Discussed substituted judgement. Encouraged the family to describe personhood to elicit patient wishes  Described the dying process (often raised by family)  Stressed continuing care, patient comfort, and supported decision to withdraw treatment  Varied in directness and use of strategies (e.g. repeating what family says, allowing silence, confirming understanding)



Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<sup>b</sup> Curtis et al. (2005)  USA	Identify missed opportunities for physicians to provide support or information to families during family conferences	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences  Limited application of grounded theory	15/51 family conferences had examples of missed opportunities:  Some avoided answering difficult questions and didn't ask for clarification about families' vague concerns  Failed to explore/acknowledge expressions of emotion  Missed chances to explore comments about patient treatment preferences
de Vos et al. (2015)  Netherlands	1. How do physicians and parents communicate about decisions to withhold or withdraw life sustaining treatment  2. To what extent do parents share in the decision making process?	Paediatric ICU	Physicians and parents of children currently in PICU	Audio-recording of conversations  Qualitative coding	Discussed deterioration. 1/3 asked for parents' perspective on child's condition. Parents demonstrated good understanding when asked  Physicians expressed a team preference. Parents often gave their preference unprompted  Most presented as medical decision and didn't ask parents. Parents expressed concern about suffering and physicians reassured them of comfort and peace  Nurses often spoke with parents at the bedside after the meeting (not recorded)
Ekberg, Danby, Herbert, Bradford, and Yates (2017)  Australia	Explore how discussions about deterioration are managed within actual paediatric palliative care consultations	Paediatric palliative care service (inpatient, outpatient, telehealth and home)	Specialist palliative care consultant and parents of children in a paediatric palliative care service	Video-recordings of consultations  Conversation analysis	Solicited the family's agenda to allow the opportunity for them to raise prognosis/ deterioration  Used topic shading (brought up another issue where deterioration may be relevant). This allowed the family to raise deterioration if they wished to
<sup>b</sup> Engelberg, Wenrich, and Curtis (2008)  USA	Describe physicians' responses to families' questions about the meaning of critically ill patients' movements	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences  Limited application of grounded theory	6/51 family conferences had unresolved questions about patient movement:  Majority responded with clinical information (physiological reasons))  Acknowledged emotions (e.g. with active listening)  Only one physician explored emotions and gave the family more time to consider

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<sup>b</sup> Hsieh, Shannon, and Curtis (2006)  USA	Identify inherent tensions that arose during family conferences in the intensive care unit, and the communication strategies clinicians used in response	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences  Qualitative content analysis from a dialectic perspective	Contradictions identified included: killing vs allowing to die; death as benefit vs burden; patient wishes vs family wishes  Physicians' decision-centred strategies: argued against one side (e.g. killing), argue for one side (e.g. patient over family wishes) or avoided  Physicians' information-seeking strategies: acknowledged the contradiction; clarified family's statements; emphasised patient wishes; segmented decision
Kawashima (2017)  Japan	Explicate the structure of interactions between medical professionals and patients' family members in a Japanese emergency room, when the patient is seriously ill and may be at the point of death	Emergency room	Physicians and family members of patients at risk of imminent death in an emergency room	Video recordings of consultations  Conversation analysis	Storytelling: Physicians described what has happened or asked relatives what has happened to forecast bad news  Online commentary: Physicians used sight and touch to explain symptoms  Paradoxical proposals: Physicians sometimes put forward continuing treatment despite suggestion that treatment is futile, giving time for families to make the decision or express deontic authority  Physicians left sentences unfinished to allow for co-completion of final decision  Following online commentaries/paradoxical proposals, families themselves sometimes raised the possibility of stopping treatment
Miller, Coe, and Hyers (1992)  USA	Examine the decision making process to withhold or stop life support	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recordings of family conferences  Conversation analysis	Framing of options 'shaded' (e.g. not all options presented) in 6/15 cases  Framed decision as consensus between HCPs, family and patient wishes  When couldn't agree, gave family time to decide (but imposed time limit)
Pecanac (2017)  USA	Explore how clinicians introduce the need to make a decision about the use of life-sustaining treatment and how surrogates respond	ICU	Physicians and families of current ICU patients	Audio-recordings of family conferences/  Conversation analysis	Clinicians used 'perspective-display invitations' to elicit the surrogate's view of patient preference as basis for shared decision making  Direct questions were more successful than tacit invitations  Perspective display invitations were reformulated when unsuccessful

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<b>Shaw, Stokoe, Gallagher, Aladangady, and Marlow (2016)</b>  UK	Explore decision making related to the move from active to palliative care in the neonatal intensive care unit	Neonatal ICU	Consultants and families of babies currently in NICU	Audio-recordings of discussions  Conversation analysis	Identified 2 different ways doctors initiated the decision making process:  1. Making recommendations: Presented strong recommendation as coming from the medical team in the best interests of the baby. Parents often asked challenging questions, about options and responded negatively to explanations  2. Providing options: Presented as a joint plan for parents and doctors to make. Told parents the decision can be deferred and options for the decision were provided. Parents could ask questions without appearing challenging
<b><sup>b</sup>West, Engelberg, Wenrich, and Curtis (2005)</b>  USA	Identify the categories of expressions of non-abandonment and develop a conceptual model describing the ways this is expressed by families and clinicians, in ICU family conferences concerning withdrawing life-sustaining treatments or the delivery of bad news	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences  Limited application of grounded theory	44/51 family conferences contained expressions of non-abandonment from either the family or clinician:  Clinicians: Highlighted continuing care; emphasised physician availability; gave the family the choice of when treatment is removed  Family: expressed decision as reducing suffering and following patient wishes; expressed a desire to be at the bedside
<b>Family perspective</b>					
<b>Abib El Halal et al. (2013)</b>  Brazil	Explore parents' perspectives of the quality of care offered to them and their terminally ill child in the child's last days of life	Paediatric ICU	Parents of children who died in PICU	Interviews  Thematic content analysis	Parents reported HCPs using medical jargon  Decisions were communicated but families not involved  Lack of communication around the time of death
<b><sup>c</sup>Gordon et al. (2009)</b>  USA	Examine bereaved parents' perspectives of their and clinicians' communicative roles and responsibilities in the PICU	Paediatric ICU	Parents of children who died in PICU	Secondary analysis of interviews  Discourse analysis	Varied in how much parents were included in decisions  Some struggled to understand uncertainty. Clarity varied (e.g. medical jargon)  Some felt clinicians created false hope by saying child was going to be ok  Parents were sometimes "rude" or shouted at clinicians

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<b>Lind (2017)</b>  <b>Norway</b>	Examine and describe relatives' experiences of responsibility in the ICU decision making process	ICU	Relatives of patients who died in ICU	Secondary analysis of interviews  Narrative analytical approach	3 variants of involvement in decisions:  1. Informed not involved: families told of decision with a medical explanation  2. Informed and asked for approval (directly or waiting for a nod/yes)  3. Involved- shared decision making: Discussed what the patient would want
<b>Meert et al. (2008)</b>  <b>USA</b>	Describe parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the PICU	Paediatric ICU	Parents of children who died in PICU	Secondary analysis of interviews  Qualitative coding	Honest communication built trust and prepared parents. Others held back prognostic information leading to false hope  Honesty was either communicated with empathy which was appreciated or as 'matter of fact' which felt cold and insensitive  Some felt HCPs used medical jargon or too much information was given at once
<b>Odgers (2018)</b>  <b>Australia</b>	Explore the family's experience of EOL care for their relative during the dying process	Acute hospital	Next of kin to patients who died in acute hospital	Interviews  Thematic analysis	Some felt doctors were not clear and honest with them (e.g. used euphemisms and were indirect about prognosis)  Others had open conversations including discussing patient wishes
<b>HCP perspective</b>					
<b>Bach, Ploeg, and Black (2009)</b>  <b>Canada</b>	Bring to light the role of critical care nurses in decision making at the end of life	ICU and cardio-respiratory care unit	Critical care nurses	Interviews  Grounded theory	Nurses clarify information and help families see the whole picture  Act as a go-between for the physicians and families  Felt that honesty is important (but balanced with hope)
<b>Bartel et al. (2000)</b>  <b>USA</b>	Describe physicians' experiences in attempting to provide optimal care for families of children who suffer sudden, acute life threatening conditions	Paediatric ICU	Resident, attending and fellow PICU physicians	Interviews and focus groups  Qualitative coding	Provide families with options and let them make the final decision  Denial common in families- physicians repeat information and give time  Highlighted the role of nurses/social workers taking time with families  Identify a family spokesperson  Try to give clear summaries, non-medical language, staged information and not give false hope

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<b>Bloomer et al. (2017)</b>  <b>Australia and New Zealand</b>	Explore how nurses navigate communication with families during treatment withdrawal processes	ICU	Critical care nurses	Focus groups  Inductive content analysis	Look for non-verbal cues that a relative does/doesn't want to talk and verbal signs of understanding  Identify a spokesperson  Use staging of information to give families time to digest it  Following family meetings check understanding and discuss the process of death
<b>Epstein (2008)</b>  <b>USA</b>	Explore nurses' and physicians' end-of-life experiences in the new-born ICU	New-born ICU	NICU registered nurses, nurse practitioners and resident and fellow physicians	Interviews  Hermeneutic circle approach	Physicians delayed conversations to give families time to understand patients' terminal status  Nurses felt false hope could be promoted  Nurses informally/gently discussed options with parents in more detail  Physicians begin more indirectly but use direct language if families don't understand  Explain what changes to expect in dying process  Involve parents in decision but take responsibility themselves
<b>Kehl (2015)</b>  <b>USA</b>	Describe how hospice clinicians prepare family for the final days of life	Home hospice	Nurses, nursing assistant, social workers, bereavement counsellors and chaplain	Interviews  Conventional content analysis	Discuss signs/symptoms of death and time to death (including uncertainty)  Repetition to ensure the message gets through, staged preparation over time  Use active listening/questions to tailor content and delivery  Building trust improves acceptance of messages
<b>Liaschenko, O'Conner-Von, and Peden-McAlpine (2009)</b>  <b>USA</b>	Understand factors that influence ICU nurses' inclusion of families in end-of-life care	Critical care unit	Experienced critical care nurses	Focus groups  Content analysis	Nurses bring together information from different physicians to provide the 'big picture'. Draw attention to quality of life consequences of treatment  Highlight deterioration and prepare families for death

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<b>Peden-McAlpine, Liaschenko, Traudt, and Gilmore-Szott (2015)</b>  USA	Describe the communication practices experienced intensive care nurses use with families to negotiate consensus on withdrawal of aggressive treatment and/or shift to palliative care	ICU	ICU nurses comfortable with dying patients/families	Unstructured interviews  Narrative approach	Changes in the patient's status can trigger conversations  Nurses check understanding and explain consequences of treatment after discussions with physicians  Ask about the patient, emphasise quality of life and what they would want  Help families see deterioration. Tailor to what the person is ready to hear
<b>Rejno, Silfverberg, and Ternstedt (2017)</b>  Sweden	Deepen the understanding of stroke team members' reasoning about truth-telling in end-of-life care due to acute stroke	Acute stroke ward	Physicians, registered nurses and enrolled nurses	Interviews  Qualitative content analysis	Truth above all: Approach discussions with complete honesty and direct language to prepare them and establish trust  Hide truth to protect: Withhold certain distressing information if don't feel it's necessary to tell; wait until have clearer info/ better environment to discuss; some nurses waited for doctor to give the bad news
<b>Richards et al. (2018)</b>  USA	Understand how neonatal and paediatric critical care physicians balance and integrate the interests of the child and family in decisions about life-sustaining treatments	Paediatric and Neonatal ICU	Attending paediatric critical care physicians	Interviews  Content and thematic analysis	Limiting options: don't mention treatment options that they believe to be futile  Being directive: when feel parents can't make decisions physicians take control to relieve burden and give families 'permission' to remove life support  Staying neutral: by providing options and avoiding giving own opinion  Allowing parents to come to own conclusions: e.g. delay decisions/ discussions and give time so that parents can see that their child is dying
<b>Tan and Manca (2013)</b>  Canada	Describe conflict experiences that family physicians have with substitute decision-makers of dying patients and identify factors that facilitate or hinder the end-of life decision making process	Family physicians	Family physicians	Interviews  Grounded theory	Staged information as trust increases; gauge surrogate's understanding; use patient's previous statements to help decisions  Bringing other professionals in can help resolve conflict

Author (year) Country	Research question/ aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<b>Mixed Perspectives</b>					
<b>(Caswell, Pollock, Harwood, &amp; Porock, 2015)</b>  UK	Understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers	Hospital wards caring for older adults	HCPs and bereaved relatives of older patients who died	Ethnographic: Interviews, focus groups, non-participant observations and review of case notes	Doctors discussed prognosis, nurses translated into lay language  Staff thought often one conversation wasn't enough but didn't always have a second conversation  Observations showed it was rare to explain process of dying
				Constant comparative method	Euphemistic/vague language meant carers didn't always understand that their relative was dying
<b>Meeker, Waldrop, Jin Young, and Seo (2015)</b>  USA	Examine the nature of family meetings as conducted in an inpatient hospice care unit in order to generate an inductive theoretical model	Hospice inpatient unit	Nurses, social workers, physicians and family members of current hospice inpatients	Ethnographic: observations of family meetings, informed by HCP interviews	HCPs elicited understanding to ensure their views were aligned on prognosis (e.g. discuss prior symptoms that signal dying). Families described patient's personhood  Explained process of dying, paced info in line with family responses
				Constant comparative method of grounded theory	Separated the person from the illness (e.g. explaining agitation), gave time to ask questions

<sup>a</sup> Papers using data from Cassell (2005), <sup>b</sup> Papers using data from Curtis et al. (2002), <sup>c</sup> Papers using data from Meert et al. (2007)

Detailed demographic information is provided in Appendix 2

Abbreviations: SICU, Surgical intensive care unit; ICU, Intensive care unit; PICU, Paediatric intensive care unit; HCP, Healthcare professional; NICU, Neonatal intensive care unit

Seven key themes were identified from the thematic synthesis: highlighting deterioration; involvement in decision making; post-decision interactional work; tailoring; honesty and clarity; specific techniques for information delivery; and roles of different HCPs. These are summarised below with details of which qualitative approaches contributed to the development of the theme. The full analysis is available in the paper (Anderson et al., 2019; Appendix 2), with supporting extracts from the original papers in the supplementary material.

#### *Highlighting deterioration*

HCPs listed patients' previous and ongoing problems or used perspective display invitations (Maynard, 1992) to elicit descriptions from the relatives about what had happened so far. This enabled relatives to recognise that the patient was dying and provided HCPs with information about their level of understanding and acceptance. This practice was often used during conversations about withdrawing life-sustaining treatments. Highlighting deterioration was identified through HCP interviews/focus groups and observational studies.

#### *Involvement in decision making*

In non-collaborative decision making, HCPs presented decisions as something they had already determined or as a recommendation for families to agree with. HCPs sometimes described this approach as removing the burden of decision making from families, but it often left families not fully understanding the decision. In contrast, in collaborative decision making HCPs involved relatives in decision making and asked for their opinion. This was done through invoking patient wishes, presenting options rather than recommendations and giving families time and control over decisions. Non-collaborative decision making was mostly identified in observational studies and relative interviews, and was more common in paediatric settings. Collaborative decision making was identified in all study types.

#### *Post-decision interactional work*

HCPs and relatives both emphasised the continuing care of the patient (e.g. by discussing comfort care, ongoing HCP availability, and relatives' desire to be present at the patient's death). HCPs and relatives justified decisions to withdraw treatment as 'right', citing having tried everything and referring back to patient wishes. Relatives often asked about consciousness and the dying process; HCPs were generally willing to do so but sometimes avoided this talk. This interactional work was mostly identified through observational studies and HCP interviews/focus groups. Relative interviews



and observations found HCPs' emphasis on continued care and availability to be lacking at times, resulting in families feeling that HCPs' involvement would reduce following a move from active to comfort care.

### *Tailoring*

HCPs tailored the content, delivery and timing of communication according to family characteristics including the following: their level of understanding and willingness to talk about dying (assessed by verbal and non-verbal cues); previous experiences with death; cultural background; and the patient's current symptoms. The practice of tailoring information was identified through HCP interviews/focus groups and observational studies.

### *Honesty and clarity*

HCPs varied in their level of honesty and clarity when discussing end-of-life issues. HCPs reported the need to be honest in order to build trust, but also to balance this with allowing families some hope. Nurses and relatives suggested doctors sometimes gave false hope leading to unnecessary aggressive treatments. Some relatives reported a lack of clarity, whilst others felt HCPs had been too blunt. Both the presence and absence of honesty and clarity in HCP communication were identified in all study types.

### *Specific techniques for information delivery*

HCPs used repetition within conversations and across several conversations to promote relatives' understanding. Pacing (giving time for information to be taken in) and staging (giving smaller chunks of information across several conversations) were used by HCPs to avoid overwhelming relatives with information. However this was not always possible if the patient had a rapid deterioration. These techniques were identified through HCP interviews/focus groups and observational studies.

### *Roles of different healthcare professionals in communication*

Doctors were viewed by both HCPs and relatives as responsible for prognostic and decision-making conversations. Nurses provided more individualised communication, brought together information from different sources, and translated technical language. Other allied health professionals (particularly social workers) were identified as playing important roles, but included articles focussed primarily on doctors and nurses. These roles were identified in all study types, but mostly from HCP interviews/focus groups and observational studies.

#### **1.4.4 Implications for the development of the thesis**

A full discussion of the systematic review findings can be found in Anderson et al. (2019; Appendix 2), but this section describes how the findings relate to the development of the aims and approaches taken in the research presented in this thesis. In order to identify gaps in knowledge and the best approaches to fill these gaps, this section considers the settings and populations examined in existing research and the qualitative approaches utilised.

The majority of papers were based in acute care settings, meaning there was a focus on discussions about withdrawing active treatment. There were only three papers based in palliative care and these were all in different settings (adult inpatient hospice, home hospice, and paediatric palliative care consultations), making it difficult to compare findings with acute care. However, there are reasons to believe that there could be differences between these settings. Firstly, the content is likely to differ, as decision making related to active treatment withdrawal is less common in palliative care. Whilst palliative care teams are sometimes involved early on in a patient's disease when decisions about halting curative treatment are being made, these conversations will primarily be with the patients themselves. By the time a relative is the key decision-maker due to the patient lacking capacity in the terminal phase of illness, these treatment decisions should already have been made. This is particularly true in a hospice inpatient setting as hospices generally only admit people with life-limiting conditions and do not provide curative treatment. Due to the focus on decision making in acute care studies, there are gaps in knowledge about how HCPs and relatives communicate about other issues that are relevant in terminal care, such as prognostication (and the related uncertainty) and relatives' wellbeing.

Despite these differences, the systematic review identified some useful practices that may be relevant to hospice settings. The theme 'highlighting deterioration' was identified as a way to enable families to see the patient's deterioration, make decisions and help HCPs gauge relatives' levels of understanding. Ways to involve families in decision making such as providing options rather than recommendations and eliciting patient wishes were also identified. Whilst HCPs in hospice settings are less likely to discuss withdrawal of life-sustaining treatments, these themes could also be relevant to prognostication and decisions about other aspects of care in a hospice. However it is unclear from the existing literature how the use of these and other strategies such as repetition and emphasising continued care might differ across settings.

Palliative care clinicians are also likely to have more time to talk to relatives and more experience of discussing end-of-life issues than those in acute care. This is reflected in the higher satisfaction and lower unmet needs reported by families in hospice settings compared to other settings (Addington-Hall & O'Callaghan, 2009; Bainbridge & Seow, 2018). In order to find examples of good practice from which recommendations for training can be drawn, this thesis will therefore examine the communication practices of senior, experienced hospice clinicians. The systematic review found a significant role for nurses that differed from doctors, as they were key to providing individualised care. Whilst several studies interviewed nurses about their experiences, no observational studies focussed primarily on nurse communication<sup>2</sup>. The research presented in this thesis will therefore include an examination of a senior nurse as well as doctors' communication.

There were some practices for which clear implementation strategies were not identified in the literature. For instance, HCPs emphasised the need to communicate directly and honestly whilst balancing this with hope, but there were also numerous examples where they struggled to do so. This demonstrates that knowledge of what to do (gained from guidelines, training or experience) is a useful start, but that evidence on clear strategies about how to do so is lacking. The existing literature also focuses much more on HCPs' communication than that of relatives. Whilst there were some references to how relatives communicated (e.g. different responses to HCPs providing options vs making recommendations; Shaw et al., 2016), these were not common in the literature. Examining how relatives ask questions and respond to different HCP communication practices would provide evidence for which HCP strategies are more effective in which circumstances. This could also help HCPs to recognise how relatives express things such as a desire for further information or a lack of understanding. This thesis therefore focuses on how both HCPs and relatives communicate and interact together, and attempts to provide more concrete strategies to improve this communication.

The findings from the systematic review revealed the contributions of the different qualitative approaches and their strengths and limitations. Interviews with family members sometimes revealed inconsistency in communicative practices described by HCPs, as they recalled experiences where useful practices, such as emphasising continued care, were lacking. They provided information about the content of end-of-life conversations but less about how communication was actually accomplished. This is unsurprising as relatives are not as likely as HCPs to have considered their own communicative strategies. HCPs had more insights into their own practice, as they have these types

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<sup>2</sup> Since the completion of the systematic review, an audio-recording based paper on nurse communication in intensive care family meetings has been published (Pecanac & King, 2019). See section 1.5 for details.

of conversations regularly. As part of their professional practice it is important for them to carefully consider how they communicate this sensitive information. However, there may be some communicative practices that HCPs are not aware they use.

Unlike interviews and focus groups with relatives or HCPs, observational studies do not rely on the recollection, interpretation and clear articulation of events by participants. Interviews and focus groups are also more likely than observations to be influenced by the researcher's agenda, as they decide which questions to ask, where to prompt and probe, and their receipts of interviewee's answers can encourage or discourage elaboration (Antaki, Houtkoop-Steenstra, & Rapley, 2000; Potter, 2002).

Whilst non-participant observations in the two ethnographic studies in the review provided rich insights into naturally occurring interactions, field notes are subject to the researcher's own interpretations and decisions about which aspects should be recorded. In contrast, audio or video-recordings of these conversations can reveal interactional practices with a higher level of detail and accuracy. Whilst the choice of what to focus on and how to analyse these features can be influenced by the researcher, the actual content recorded is not. However, one-off recordings can only capture a snapshot of communication compared to HCPs who can describe strategies they use across several conversations. This snapshot can also only identify the communication that does occur, whereas relatives can report which topics were never discussed with them.

It is therefore important to obtain HCPs' and relatives' perspectives alongside recordings of the actual conversations in order to get a fuller picture of communication with relatives at the end of life. There are numerous different approaches to analysing recordings of conversations, but in a systematic review, Parry et al. (2014) advocate using CA due to its systematic, empirical approach and ability to show links between HCP communication practices and patient responses and outcomes. This fits well with the gap identified by the review in terms of studies focusing on relatives' responses to HCP behaviours.<sup>3</sup>

The qualitative systematic review identified key practices that could be used to improve communication with relatives of patients at the end of life. It has shown that more research is needed in non-acute settings and the need to capture conversations about end-of-life issues beyond treatment withdrawal decisions. The review has demonstrated that a range of perspectives should be sought in order to get a clearer idea of how communication happens with relatives at the end of life.

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<sup>3</sup> See Chapter 2 for a more in depth discussion of the strengths of CA for this project

This should include talking to relatives and HCPs and obtaining recordings to get an accurate portrayal of this communication. Clear strategies are needed to help HCPs implement useful communicative techniques in practice. Analysis must therefore focus on both HCP and relative communication and how participants in these conversations respond to different communication practices. These findings led to this thesis taking a conversation analytic approach to studying conversations between senior, experienced HCPs and relatives of patients receiving terminal care in a hospice. CA findings will be supplemented by interviews/focus groups with relatives and HCPs. The next section describes existing CA studies on discussions of end-of-life issues.

## **1.5 Conversation analytic studies at the end of life**

Studies using CA to explore end-of-life talk with relatives in acute settings and in paediatric palliative care were discussed in the systematic review above and their findings summarised in Table 1.2 (Ekberg et al., 2017; Kawashima, 2017; Miller et al., 1992; Pecanac, 2017; Shaw et al., 2016). Since the publication of the review, further CA papers have been published from the data used in Ekberg et al.'s (2017) study of paediatric palliative care consultations and Pecanac's (2017) study of ICU family meetings. Ekberg et al. (2019) showed that it is not always necessary to refer explicitly to death and dying in order to discuss them. Dying was only made explicit when referring to another family's child, when death was ancillary to the topic of conversation, or when the local context made it important for understanding (e.g. discussing a procedure that needs to be done following death). Pecanac and King (2019) found that in family meetings, nurses provided few contributions and when they did speak, this was mostly through self-selection. When others selected nurses as the next speaker, it was usually to provide clarification or logistical information.

These studies provided useful insights into HCP communication with relatives at the end of life, but the review established that no previous studies have used CA to examine communication with relatives of patients in the final hours or days of life in a hospice. However, several other studies have used CA to understand end-of-life discussions with patients in a range of settings. The most relevant to this thesis is the VERDIS project<sup>4</sup>, in which hospice consultations between highly experienced doctors, their patients and patients' companions were video-recorded. Four key CA papers have been published from the VERDIS project to date. The first paper showed that doctors created multiple opportunities in the conversation to enable patients to raise their own end-of-life concerns, without assuming that patients wanted to discuss this (Pino et al., 2016). Doctors therefore did not necessarily

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<sup>4</sup> <https://www.health.org.uk/research-projects/insight-2013-video-based-communication-research-and-training-in-decision-making-in>

overtly raise the topic of death and dying, but could still help patients talk about their end-of-life concerns. Analysis from the VERDIS project has also explored how patients request life expectancy estimates (Pino & Parry, 2018). In the majority of these consultations, patients requested life expectancy information following the doctor providing an opportunity for them to influence the consultation agenda, and these requests were formatted as declarative statements, not interrogatives. The analysis showed how patients, doctors and companions 'prepared the conversational environment' by establishing the patient's current understanding, perspective and readiness to hear the prognosis. This demonstrates the collaborative nature of these conversations and how doctors, patients and companions cautiously navigate this difficult topic.

Another paper from the VERDIS project explored how doctors addressed potential problems with patients' advance care plans. Land et al. (2019) showed how doctors used hypothetical scenarios to highlight these possible problems whilst maintaining patient autonomy. Finally, the most recent publication considers how empathy is used by doctors when there is disparity between their perspective and the patient's perspective (Ford, Hepburn, & Parry, 2019). In this paper, the authors demonstrated that empathy was used to acknowledge the difficulty of the patient's situation whilst still conveying the medical perspective, and to reassure overly pessimistic patients whilst not dismissing their concerns. They describe how empathy is used to integrate the medical perspective with the patient's experience-based or 'lifeworld' perspective.

Beyond this one recent project, there has been little CA work done within a hospice setting. However, a number of CA studies in different settings have provided insights relevant to end-of-life talk. Lufey and Maynard's (1998) study of recordings of an oncologist informing patients of a lack of treatment options, found the physician displayed cautiousness in this bad news delivery. He used perspective display invitations to elicit patients' perspectives, and his initial questions were euphemistic, gradually becoming more explicit but never directly referring to 'dying'. The extent to which the news was 'unpacked' depended on the response of the patient (i.e. whether the patient resisted this talk or acknowledged the bad news allowing further elaboration).

Further CA work in oncology clinics was conducted using data from a randomised trial of an e-Health system for use with non-small cell lung cancer patients (Gustafson et al., 2013). Using audio recordings of consultations discussing scan results, Singh et al. (2017) found that these consultations typically followed an order of symptom talk, scan talk, treatment talk and logistic talk, with the least amount of time spent on talk about scan results. They found that prognosis was rarely explicitly addressed and when it was, this was mostly initiated by patients or caregivers. When patients asked about scans,

physicians stated that the current treatment was no longer effective (using 'exhausted current treatment' statements) and used these statements to pivot talk towards other treatment options, meaning that opportunities to increase prognostic awareness were missed (Cortez, Maynard, & Campbell, 2019). Another paper from this same dataset described doctors' use of 'appreciation sequences' (Maynard, Cortez, & Campbell, 2016). In these sequences, physicians would make statements about the good the treatment had done so far (i.e. extending life beyond what may be expected), despite the current bad news or ultimately terminal diagnosis. Physicians in these consultations pursued displays of gratitude (acknowledgement or agreement with the physician's statement) from patients.

Outside of consultations with medics, CA has been used to examine end-of-life talk in therapy sessions. Therapy sessions using the Managing Cancer and Living Meaningfully (CALM) approach for patients with advanced cancer were recorded and analysed using CA. Shaw et al. (2017) found that in these sessions, open questions about patients' experiences, feelings or understanding often resulted in patients engaging in end-of-life talk. Similarly to Pino et al.'s (2016) findings, these questions did not necessitate end-of-life talk, but instead gave patients the opportunity to raise the issues. Whilst their questions were not explicitly about death and dying, questions with references to candidate negative emotions made end-of-life talk more relevant. A further paper using these data examined mentalization across one patient's seven CALM sessions (Shaw et al., 2019). The therapist in these sessions used 'meaning expansion enquiries' to invite the patients to consider alternative perspectives on their experiences and feelings about disease progression. These were questions about the meaning of the patient's utterances, which implicitly cast doubt on the assumptions underpinning the utterance without directly challenging it.

The studies described in this section have demonstrated CA's ability to identify practices used by HCPs and patients to engage in, or avoid engaging in, talk relating to end-of-life issues. This thesis will build on this literature by using CA to understand how HCPs discuss end-of-life issues with relatives of patients rather than the patients themselves, and will focus on conversations happening later in the disease once the patient has reached the terminal phase. Prior to the very end of life when a patient has lost capacity, the relative's role is primarily as a companion to the patient (with the exception of parents of paediatric patients who will be more involved in decision making throughout the illness progression). Whilst this role is clearly important and HCPs are encouraged to consider the family's needs, the conversations in this thesis are unique in that it is chiefly at the terminal phase that relatives become the key people involved in shared decision making and receiving information from HCPs.

The CA studies described in the systematic review (section 1.4) did focus on relatives, but they were not based in a hospice and addressed either ACP, or decision making, particularly relating to the withdrawal of life sustaining treatments. This thesis will instead consider how experienced hospice clinicians discuss issues relating to prognosis and end-of-life care with relatives of patients who are lacking capacity and have reached the terminal phase of their illness.

## **1.6 Aims**

The previous sections of this chapter have demonstrated a gap in the literature relating to communication between experienced HCPs and relatives of patients at the terminal phase in a hospice setting. In order to address this gap and identify useful communication practices, an in-depth examination of what actually happens in these conversations is required. This leads to the primary aim of the thesis:

To understand the practices used to accomplish prognostication and other relevant activities in conversations between expert healthcare professionals and the relatives and friends of patients who have reached the terminal phase of their illness in a hospice

To develop a clear understanding of this communication, it is important to know not just what happens in these conversations, but also to understand the perspectives of those involved in these conversations. A secondary aim of the thesis is therefore:

To understand the perspectives of expert healthcare professionals and the relatives and friends of patients about what is important during communication in a hospice at the end of life, including the terminal phase

Finally, the key reason for examining these conversations is to find ways to improve communication between HCPs and relatives in terminal care. As the previous sections have demonstrated, it is not enough to know what to do, HCPs need clear guidance on how to implement useful communication strategies. For this reason, a further secondary aim is:

To provide recommendations for training to improve communication skills for less experienced healthcare professionals communicating with relatives and friends of patients about end-of-life care and prognosis



## **1.7 Overview of the thesis**

This section provides an overview of how the remaining chapters in the thesis support the aims outlined above.

CA is the main methodological approach utilised in this thesis and so Chapter 2 provides an overview of the CA approach. It gives a brief background to the development of CA as a discipline, followed by a description of its defining features and the differences between pure and applied CA. Some key CA practices relevant to the analysis presented in the thesis are explained, and the strengths of CA for this project are set out. Following this, Chapter 3 (Methodology) describes and justifies the procedures for recruitment and consent, data collection and analysis for both the CA and interview/focus group studies. This chapter also describes the hospice setting in which the studies took place and the approvals processes.

Chapter 4 is a descriptive chapter, which gives an overview of the sample and content of recorded conversations. This provides the context for Chapters 5, 6 and 7, which are conversation analytic chapters exploring: Terminal-phase prognostication sequences (Chapter 5); Closing the business-at hand: exiting prognostic talk and transitions into closing sequences (Chapter 6); and Disagreement during talk about prognosis and comfort care (Chapter 7). Each of these chapters has its own discussion placing the analysis in the context of existing research.

Chapter 8 presents the analysis from the interview and focus group study. This chapter examines what relatives consider important for good communication and their experiences of communication at the hospice. It looks at how HCPs view their own communication and what they believe is important for good communication. These perspectives are brought together in the analysis to provide a more in-depth view of communication in a hospice. The discussion considers the findings in the context of existing research and the CA findings from Chapters 5-7.

Finally, Chapter 9 is the thesis discussion. This chapter summarises the CA and interview/focus group findings and considers the contributions and implications of the findings for end-of-life interaction research. Findings from the analysis are used as the basis for recommendations for future HCP training to improve communication with relatives of patients at the terminal phase. The challenges and limitations of the thesis are discussed alongside suggestions for future research, and the strengths of the thesis are outlined. A final concluding summary is then provided.

## **Chapter 2 The conversation analytic approach**

As stated in Chapter 1, the research aims of this thesis will be addressed primarily using a conversation analytic approach, alongside qualitative interviews and a focus group. The interviews and focus group are discussed in more detail in Chapter 3, but this chapter focuses on conversation analysis (CA). An overview of CA as a discipline and its approach to analysing interactional data are provided, and the distinction between pure and applied CA is discussed in relation to this project. Practices relevant to the current analysis are described and the strengths of using CA for this project are presented.

### **2.1 Conversation analysis as a discipline**

CA emerged as a discipline in the 1960s, led by the work of Sacks and his colleagues Jefferson and Schegloff, and influenced by the work of Goffman and Garfinkel (e.g. Garfinkel, 1963, 1967; Goffman, 1955, 1983). Goffman established the view of social interaction as organised and as an important area for study in itself. His concept of the interaction order describes how everyday social interactions are the basis for all social institutions (Goffman, 1983). The development of CA was, however, most clearly grounded in Garfinkel's ethnomethodology. Ethnomethodology is concerned with how everyday social actions are accomplished by members of society (ten Have, 2007). Garfinkel was interested in the unwritten social rules in play during interactions. His 'breaching experiments' highlighted these rules by demonstrating people's negative reactions when rules were broken (e.g. insisting a person specified what they meant when using common phrases such as 'how are you' resulted in anger from the conversational partner; Garfinkel, 1963 as cited in Heritage, 1984).

Prior to Garfinkel's ethnomethodology and Sacks' work on recorded conversations, social interaction was considered to be disorganised and therefore not possible to study through the analysis of naturally occurring talk (Heritage, 1984). Ethnomethodology's focus on the rules of interaction and the methods people use to perform social actions were highly influential in the first CA studies looking at telephone calls to a suicide prevention helpline (Sacks, 1992)<sup>5</sup>. In this work Sacks introduced the idea, now fundamental to all CA work, that the action performed by an utterance is dependent upon its sequential positioning (ten Have, 2007). CA is now a method used widely within ethnomethodology as well as being a field of study in itself.

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<sup>5</sup> Much of Sacks' research is recorded in the publication of his 1964-72 lectures. The version cited throughout this thesis is Sacks (1992)

The defining features that separated CA from other fields were the perspectives that ordinary conversations are highly organised; analysis should be based on recordings of naturally occurring interactions; and analysis should be based on evidence within the interaction rather than any external considerations (Atkinson, 1985). CA uses a unique transcription system developed by Gail Jefferson (see Hepburn & Bolden, 2012; Jefferson, 2004), which captures temporal aspects of the interaction and the ways in which words are spoken (see Chapter 3 for a more in-depth discussion of Jeffersonian transcription and Appendix 13 for a full list of transcription symbols).

CA examines naturally occurring conversations ('talk-in-interaction') and studies the ways in which speakers perform social actions (e.g. announcing, asking, agreeing) through turns at talk (Hutchby & Wooffitt, 2008). The primary focus of CA is how turns at talk are organised into sequences which make up the interaction. In their 1973 paper, Schegloff and Sacks set out some of the features of sequential organisation in talk (Schegloff & Sacks, 1973). In this paper, readers were invited to ask the question 'why that now' in order to try to understand why an utterance has been constructed in that specific way and at that specific point. This is the fundamental question for conversation analysts and means turns are not examined in isolation, but in the context of their preceding and subsequent turns. Each turn projects certain relevant next turns (they provide 'sequential implicativeness'). These pairs of utterances, where the first utterance requires a particular type of response are referred to as 'adjacency pairs'. For example, an invitation from one speaker (the 'first pair part'; FPP) projects either an acceptance or rejection ('second pair parts'; SPP) from the other speaker. How the second speaker responds to the first speaker's turn displays their understanding of the prior turn, both to the first speaker and to the conversation analyst. This 'next-turn proof procedure' (Hutchby & Wooffitt, 2008) therefore directs the analyst to which social actions are accomplished based on the evidence within the interaction, rather than speculating at the intentions of the speakers.

## **2.2 Pure and applied CA**

The first studies in CA, including Sacks' initial studies of phone calls to a suicide prevention helpline (Sacks, 1992) and Schegloff's study of police complaint calls (Schegloff, 1968), were based on data from institutional settings. However early CA researchers switched their focus to more 'mundane' everyday conversations in order to identify universal conversational practices and rules (ten Have, 2007) such as turn-taking (Sacks, Schegloff, & Jefferson, 1974; ten Have, 2007), closing a topic

(Schegloff & Sacks, 1973) and repair<sup>6</sup> (Schegloff, Jefferson, & Sacks, 1977). This type of non-institutional CA, often referred to as 'pure CA', is concerned with studying the social organisation of talk-in-interaction within any setting and without any kind of agenda beyond this.

Applied CA (see Antaki, 2011) in contrast looks at how CA can be applied to specific settings. Antaki (2011) describes six types of applied CA including: foundational (using CA to adapt other fields of study); social-problem (contributing to the understanding of social problems such as sexism and racism); communicational (understanding disordered speech); diagnostic (analysing a person's talk to diagnose a disorder); institutional (contributing to the understanding of how institutions work); and interventionist (using CA to address problems within interactions). The final two of these types of applied CA described by Antaki, institutional and interventionist, are the focus of this thesis. The analysis presented is mostly institutional, as it examines how conversational tasks are accomplished in a particular institutional setting (conversations with relatives in a hospice). However, there is also an interventionist element as the overall analysis aims to provide suggestions for improving communication in this setting.

Institutional conversations are usually more task-oriented and the setting can place certain restrictions on the interaction. Professionals may be required to avoid displaying certain reactions such as surprise or affiliation with what has been said (Drew & Heritage, 1992). For example if a patient complains about another medical professional to a doctor, they are less likely to agree with this assessment than, for instance, a friend. However institutional conversations can be analysed in the same ways as non-institutional conversations and conversational practices that are not specific to the setting can be identified from applied research.

The prevalence of applied CA research has increased, as conversation analysts look to how their research can be applied in a range of institutional settings such as courtrooms (e.g. Komter, 2012), mediation services (e.g. Stokoe & Sikveland, 2016) and classroom interactions (e.g. Mori, 2002). However the institutional setting which has received most attention from applied CA researchers in recent years is healthcare. CA has been used extensively to study aspects of medical encounters, including the delivery of a diagnosis (Heath, 1992), addressing unmet patient concerns (Heritage, Robinson, Elliott, Beckett, & Wilkes, 2007; Stuart et al., 2019), how parents display resistance to treatment recommendations (Stivers, 2005), and the use of digital technologies in consultations

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<sup>6</sup> Repair refers to "an organized set of practices through which participants in conversation are able to address and potentially resolve problems of speaking, hearing or understanding" (Sidnell, 2010, p. 110). Repair can be initiated by either conversational participant (the speaker of the problematic utterance or the hearer) and also performed by either participant (Schegloff, Jefferson, & Sacks, 1977).

(Seuren et al., in press; Stevenson et al., 2019). CA is being used to address some of the most pressing issues facing healthcare today, such as inappropriate antibiotic prescribing (Heritage & Stivers, 1999; Mangione-Smith, Stivers, Elliott, McDonald, & Heritage, 2003), accurately diagnosing dementia (Elsei et al., 2015) and weight loss interventions (Albury, Stokoe, Ziebland, Webb, & Aveyard, 2018). CA is also increasingly being used in the design of health communication training and has shown promising results (see Pilnick et al., 2018 and section 2.4).

Whilst pure and applied CA researchers can have different priorities in their analysis, universal practices have been identified through both pure and applied CA. Some of the key practices relevant to the analysis in this thesis are presented in the next section.

## **2.3 Key CA practices relevant for this thesis**

### **2.3.1 *Topic organisation***

In CA, a topic is not analysed simply by looking at what subject is being discussed, but by observing how participants within a conversation accomplish topicalising this subject. This topic transition occurs either through linking a new topic to previous utterances, or through a more disjunctive topic change to unrelated talk (Maynard, 1980).

In his lectures, Sacks highlighted that it is routine to gradually move from one topic to another in what he termed a 'stepwise move' (Sacks, 1992). He described how speakers routinely connect a new topic to the previous utterance and so do not need to explicitly close one topic and open another. This is done through 'pivotal utterances', which begin by linking with the previous topic, and then move to something which links the beginning of the pivotal utterance to the topic that is being transitioned to (Sacks, 1992). Jefferson (1984) further developed the concept of stepwise topic transition by identifying how this can be used to transition out of a troubles-telling<sup>7</sup> gradually, rather than abruptly introducing a new topic that might be treated as problematic in some way.

It is not always possible to link a new topic to previous utterances. Button and Casey (1984, 1985, 1988) identified three sequence types used to initiate a new topic in sequential environments where stepwise transition is not possible. Topic initial elicitors (Button & Casey, 1984) invite the other person to initiate a new topic and do not specify what that topic may be (e.g. 'anything else?' or 'what's new?'). In contrast, the other sequence types Button and Casey identified do nominate a potential

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<sup>7</sup> see section 2.3.5 for a discussion of troubles-tellings

next topic. In itemised news enquiries, speakers ask about their co-participant's news (e.g. 'how's your dad?') and in news announcements speakers tell their own news and nominate it as a potential next topic (e.g. 'I saw Bob yesterday') (Button & Casey, 1985). All of these sequence types are interactively and mutually organised, as the co-participants can choose to talk on the topic or to curtail that talk (Button & Casey, 1984, 1985, 1988).

A number of markers of topic change have been identified in CA research. For example 'so' is frequently used to launch or relaunch a topic (Bolden, 2009) and figures of speech are often found in turns which summarise a topic and move towards topic transition (Drew & Holt, 1998; Holt & Drew, 2005). Jefferson (1993) also demonstrated that speakers would often provide an assessment, commentary or acknowledgement token (e.g. 'yeah') prior to changing the topic. The potentially problematic nature of topic transition is demonstrated by the increased amount of repair found at topic shift (Schegloff, 1979), particularly where the topical link to the prior turn is not clear (Drew, 1997).

This brief overview of topic organisation highlights that it is a complex and mutually organised process. Conversations with relatives at the end of life inevitably involve the discussion of 'difficult' topics. It would therefore be valuable to see how participants navigate these topics including how they are initiated and moved on from, as well as any problematic topic transitions. The analytic chapters in this thesis discuss how different practices of topic organisation are utilised by both HCPs and relatives. In particular, Chapter 5 and Chapter 6 examine how topic organisation is used to initiate and exit prognostic talk. Chapter 6 also looks at how HCPs and relatives transition out of the business of the conversation and towards closings, which are discussed below.

### **2.3.2 Closings**

All conversations have an ending, but they can only be brought to a close at certain points within the interaction; it would clearly be inappropriate to leave a conversation immediately following a greeting or in the middle of a topic without any accounting for this. Schegloff and Sacks (1973) described the ways in which interactions are brought to a close. First, they described the 'terminal exchange' made up of an adjacency pair, for example a 'bye' responded to with 'bye', or 'thank you' responded to with 'you're welcome'. Here, both speakers establish that the conversation is over and no further utterances are relevant.

Schegloff and Sacks (1973) observed that the terminal exchange is just the final part of a 'closing section', which also includes pre-closings. Possible pre-closings occur at the close of a topic where a

speaker does not take the opportunity to raise any further topics (e.g. 'well' with a downward intonation). The second speaker can either choose to respond with the introduction of further talk, or can reciprocate the pre-closing, allowing the interaction to move onto the terminal exchange. These pre-closings provide a warrant for the closing of the conversation as neither party has any more to add. There are several practices which can shut a topic down and "mark that topic as a possibly last one" (Schegloff & Sacks, 1973, pp., p.306), leading to pre-closings. These include summing up, making arrangements, and action formulation (Barnes, 2007; Button, 1991; Gafaranga & Britten, 2004; Schegloff & Sacks, 1973; West, 2006). Outside of topic boundaries, speakers can explicitly announce a warrant for closing the conversation, for example having to get back to work or letting the other person get back to what they were doing (Schegloff & Sacks, 1973; Sidnell, 2010).

In healthcare, much CA work on closings has been carried out in primary care settings. In one of the first CA studies on closings in healthcare, Heath (1986) showed that once the business of the consultation was complete, physicians made proposals to end the consultation which, if accepted, were followed by the patient making embodied moves to break co-presence prior to the terminal exchange. Building upon this work, a paper by Robinson (2001) focused on the transition out of the business of the conversation and into closings, identifying 'arrangement-related business-preclosing sequences' and 'final-concern business-preclosing sequences' as ways to do this. It highlighted that whilst final concern sequences provide a formal opportunity to raise additional concerns, arrangement sequences do not (Robinson, 2001). Following this, Heritage et al. (2007) found that patients' unmet concerns were reduced if they were asked if there was 'something else you wanted to address in the visit' at the end of a primary care consultation compared to the more negatively polarised 'anything else'. However a recent UK-based feasibility study did not find a difference in unmet concerns between these groups, possibly due to the much lower proportion of patients leaving with unmet needs in the patient population as a whole (Leydon et al., 2018).

The existing literature described in Chapter 1 has considered how end-of-life conversations are initiated, with little focus on how they end. Chapter 6 in this thesis therefore examines how practices such as those described above are applied to transition out of the business of the conversations and towards closing.

### **2.3.3 Preference organisation**

As described in the explanation of adjacency pairs in section 2.1, turns at talk project various possible responses (e.g. either 'yes' or 'no' could be acceptable in response to a polar question). In addition to

this, Sacks (1987)<sup>8</sup> demonstrated that the design of an utterance can exhibit a structural preference for one of these possible responses. Pomerantz (1984) later named these possible responses 'preferred' and 'dispreferred' responses. This preference refers to the ways in which the turns at talk are designed and the type of action being performed, not to the personal preferences or wishes of the speaker (Schegloff, 2007). Certain actions will generally project certain preferred responses (e.g. assessments generally prefer agreement; Pomerantz, 1984). For others it depends on the design of the turn. For example 'would you like a drink?' exhibits a structural preference for a 'yes' response, whereas 'you didn't want a drink did you?' exhibits a structural preference for a 'no' response.

Preferred responses tend to be produced immediately following the previous turn. In contrast, dispreferred responses typically follow delays (e.g. 'well' or a pause), appreciation/apology (e.g. "that's awfully sweet of you"; Sidnell, 2010, p. 79), and/or accounts (explanations for the dispreferred response) (Pomerantz, 1984; Sacks, 1987; Sidnell, 2010). Additionally, if the second speaker signals an upcoming dispreferred response (e.g. with 'well'), the first speaker will often then reformulate their utterance to reduce the level of disaffiliation (Schegloff, 2007).

This demonstrates that conversational participants work collaboratively to maximise affiliation and reduce conflict. This is relevant in the data presented in this thesis, as HCPs and relatives make various assessments (e.g. prognosis) and proposals (e.g. medication use), to which the other must respond. Preference organisation is displayed throughout the data, but is especially relevant to Chapter 7, in which disagreements between HCPs and relatives are discussed.

### **2.3.4 *Displays of epistemic authority and rights***

When using CA to analyse institutional interactions, Heritage recommends examining features which may be specific to the setting such as interactional asymmetries (e.g. differences in participation in the conversation and in knowledge; Heritage, 2004). Given the different knowledge and experience of HCPs and relatives, epistemic authority (who has the right to claim which knowledge) is of particular relevance to the conversations being examined in this thesis.

Heritage and Raymond (2012) discuss the 'epistemic gradient' which describes the difference in the level of knowledge between parties in an interaction. The larger the difference in knowledge between the two participants, the steeper the epistemic gradient is said to be. For example in the conversations included in this thesis, when discussing medication, HCPs could be said to have higher epistemic

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<sup>8</sup> From a public lecture in 1973



authority than relatives due to their expertise in palliative medicine. However Heritage (2013) points out that whilst medics may have rights to the ‘epistemics of expertise’, patients have rights to the ‘epistemics of experience’. The same is likely to apply to relatives in this situation as they have greater experience with the patient themselves than the clinician.

It is important to highlight that epistemic rights and authority are not assumed during the analysis and are only relevant if oriented to by the participants in the conversation. Rather than being pre-existing due to societal roles, the epistemic gradient is established by the participants in the conversation via turn design. Heritage and Raymond (2012, p. 180) refer to the following different formulations of the same question to demonstrate this: (1) Who did you talk to? (2) Did you talk to John? (3) You talked to John, didn’t you? (4) You talked to John? Each of these displays a different epistemic footing of the questioner and therefore an increasingly shallow epistemic gradient.

In addition to the epistemic gradient, Heritage and Raymond (2012) highlight the orientation to the relevance of a question and the appropriateness of a response. Asking a question suggests the questioner has a right to this knowledge and the informant has an obligation to provide it. However once again, turn design can modify the implied rights to knowledge. Curl and Drew (2008) demonstrated that the way a request for information is formulated projects the person’s entitlement to that information. They found that using ‘could you’ or ‘I want’ during requests claims a stronger entitlement than ‘I wonder if’.

The orientation to both HCPs’ and relatives’ epistemic rights and authority as part of accomplishing different tasks is present throughout the conversations in this project. This is discussed in detail in relation to requesting and providing prognostic information in Chapter 5.

### **2.3.5 Troubles talk**

Troubles talk refers to a participant describing a trouble or problem (‘troubles-telling’) and the response of their co-participant. Jefferson argued that rather than simply being a topic of conversation, troubles-telling is a sequential phenomenon with its own organisation. She put forward a candidate troubles-telling template to demonstrate the “rough ordering” and “recurrent elements” of these sequences (Jefferson, 1988, p.420). This candidate template includes an account of the trouble by the troubles-teller, followed by a display of affiliation from the troubles-recipient (e.g. an empathetic statement). If the co-participant does not provide an affiliative response and instead provides advice, they are resisting the role of troubles-recipient and this can lead to interactional difficulties and often the rejection of that advice. Conversely, in “service encounters” where a person

seeks a service from a professional (e.g. medical consultations), the person with the trouble is positioned more as an advice seeker than a troubles-teller, and so the appropriate response is advice giving, not affiliation (Jefferson & Lee, 1981, 1992). This priority of the institutional task over displays of affiliation and empathy has been found in a range of service encounters, such as primary care visits and calls to a student loans company (Ekström, Lindström, & Karlsson, 2013; Ruusuvuori, 2005).

However the distinction between everyday conversations and institutional service encounters is not so clear-cut. Ruusuvuori (2005, 2007) discusses situations in which the line between the institutional task and showing compassion is somewhat blurred. In these situations, not providing an affiliative or empathetic response can cause interactional problems (see Hepburn & Potter, 2007). Ruusuvuori (2007) observed how proposals of affiliation with patients could be integrated with problem-solving and used to close troubles-tellings and move back to the medical agenda. In these conversations, addressing emotions supported the institutional task-at-hand.

The development of palliative care was a shift away from a purely biomedical model towards an additional focus on the psychological, social and spiritual concerns of patients and their families (Saunders, 2000). In Chapter 8 of this thesis we see from discussions with HCPs that they do not draw clear lines between their roles of providing medical care and showing compassion and support for families. Displaying empathy through affiliation is therefore more relevant here than in some service encounters, and we will see examples of this throughout the analytic chapters. Despite this, Chapter 6 shows that some restrictions of the service encounter remain whilst addressing emotional issues, as HCPs remain focused on practical problem solving.

## **2.4 Strengths of conversation analysis to address the research aims**

The CA method's use of recordings of naturally occurring conversations gives a unique insight into what actually happens in these interactions and how communicative tasks are accomplished. As discussed in Chapter 1, more traditional qualitative methods such as interviews with the participants in the conversation would give a retrospective interpretive account of the conversation, whereas a recording shows what happened with complete fidelity and appropriate detail. The conversations being studied in this project are taking place at a particularly sensitive and potentially emotional time and so this, along with other experiences of communication within the hospice, could impact participants' recollection of the conversation. Interviews at the time of the conversation could also have caused considerable burden on the participants. Whilst this thesis does include interviews (see Chapters 3 and 8 for details), the purpose of these is to address the secondary aim of the thesis by

exploring participants' perceptions of communication at the hospice more generally and what is important to them. These interviews do not address the primary research aim of understanding the practices used by participants in these conversations and how they accomplish prognostication and other relevant activities through social interaction.

In relation to the secondary aim of providing recommendations for future training materials, a CA approach has additional benefits. As referenced in section 2.2, CA has been used in communication training in a number of different settings (Barnes, 2019; Pilnick et al., 2018). One example is Stokoe's (2014) CARM training, which allows participants to watch a real interaction, role play what they might do next, then see what actually happened and discuss what makes a successful interaction. CARM has been applied for mediation services, police interviews, the commercial sector and continues to be used in range of other settings (Stokoe, 2014). In palliative care, the VERDIS project team have used findings from their study of conversations between palliative care specialists and patients to develop 'Real Talk' training resources to complement existing training programmes. Initial evaluation of Real Talk has shown a positive response from both trainers and trainees, particularly to the use of real world video clips (Parry et al., 2018; Whittaker, Watson, & Pino, 2019). These types of training programmes provide unique benefits over traditional communication training, as using recordings of actual interactions provides much more realistic examples than using hypothetical situations in role plays (Stokoe, 2013).

The use of recordings is not limited to CA, for instance discourse analysis (DA) also studies talk, often using recordings of naturally occurring conversations. However DA does not generally consider the sequential organisation of conversations. This means there is no focus on the sequential implicativeness of each participant's turn and therefore it does not examine how the interaction is co-constructed by both/all participants. Much existing research on doctor-patient/doctor-family communication from a range of methodologies focuses on how the HCP presents information to the lay individual (Andreassen et al., 2015; Ha & Longnecker, 2010; also see the qualitative systemic review in Chapter 1). For this thesis, the contributions of both the HCP and relative, how their turns impact each other and therefore their collaboration in tasks such as establishing prognosis, were key to addressing the research aim. CA studies have provided new insights into how participants contribute and collaborate in medical interactions. For example Stivers (2005) identified ways in which parents displayed resistance to doctors' treatment recommendations, resulting in the doctors providing further explanations and negotiating with parents about their child's treatment. As highlighted in the systematic review in Chapter 1 (Anderson et al., 2019), there are few CA studies examining HCP talk with relatives at the end of life. However those CA studies that have explored this

(Ekberg et al., 2017; Kawashima, 2017; Pecanac, 2017; Shaw et al., 2016) have produced valuable insights into the input of both the relatives and clinicians, which could not have been achieved through other methods.

In addition to CA's emphasis on sequential organisation, CA and DA differ in terms of their analytic focus. DA permits the analyst to consider the influence of broader social and cultural structures and the mental states of the participants on the discourse (Wooffitt, 2005). Therefore DA is more concerned with asking broader 'why'-type questions than CA, which instead focusses on 'what' and 'how'. The primary aim of this study is to understand the communicative practices used in conversations between HCPs and relatives. This aim is therefore much more suited to a CA approach where findings are focused on what and how communication is done and where the analysis is restricted to what is evident in the data. CA is also more appropriate to address the secondary aim of providing recommendations for future training and guidance. Troublesome or effective features at the level of the interaction that may be identified by an applied CA approach can be addressed in communication training, as described earlier in this section (Barnes, 2019; Pilnick et al., 2018). Wider social issues that may come out of a DA approach (e.g. power dynamics) are much more complex to address and therefore not modifiable through such training.

The next chapter describes how an applied CA approach was used in practice, alongside interviews and a focus group, to explore communication between HCPs and relatives of patients who have reached the terminal phase of their illness in a hospice.

## **Chapter 3 Methodology**

This chapter outlines the methodological approach taken to understand communication between healthcare professionals (HCPs) and relatives of terminal-care hospice inpatients. The setting of the data collection site is briefly described, followed by an in-depth description of recruitment, consent, data collection and analysis procedures. Ethical approval for the study was granted by the UCL Research Ethics Committee on 18<sup>th</sup> July 2017 (ref 11519/001), as detailed in section 3.4.1. The protocol for the study was presented as a poster at the 2017 Marie Curie Palliative Care Research Conference (Anderson et al., 2017).

### **3.1 Setting**

The data for the research project were collected at one London-based adult hospice. Participants were recruited from the hospice's two inpatient wards. The hospice also has a day therapy unit, which was not a part of the study. Each inpatient ward has 17 beds (13 individual rooms and one four-bedded bay). The inpatient wards admit patients with any incurable, life-limiting condition for terminal care, symptom control, rehabilitation or respite. In the year 2017-2018, 434 patients were admitted to the inpatient unit, with 58% dying in the hospice and 42% being discharged home or to another care facility. The average length of stay was 18 days. There are no restrictions on when patients can be visited and visitors are able to stay overnight on the wards, particularly in the last days of a patient's life.

Each inpatient ward is supervised by one consultant who carries out two ward rounds per week. The rest of the medical team's availability fluctuates depending on training rotations and funding, but across the two wards during data collection, typically included: one specialist registrar; two to four foundation year or GP trainee doctors; and two clinical nurse specialists (each with two days per week on the wards). This was in addition to ward sisters, registered nurses, healthcare assistants, occupational therapists, physiotherapists and a dietician. The hospice also employs social workers, a clinical psychologist, counsellors, and a chaplain, and has volunteers and complementary therapists.

### **3.2 Recruitment and consent procedures**

This section details the inclusion and exclusion criteria, and the recruitment and consent procedures for senior HCPs and relatives. The consent procedures for other staff members present at the recordings are then outlined.

### **3.2.1 Recruitment and consent procedure: Senior healthcare professionals**

The study included senior, experienced doctors and nurses based at the participating hospice. The eligibility of senior HCPs was assessed at consent and the inclusion criteria for HCPs were:

- Qualified member of staff based on the inpatient wards of the hospice data collection site
- Senior doctors: at consultant or specialist trainee (registrar) level
- Senior nurses: Band 7 or above

The exclusion criterion for HCPs was:

- Less than three months' experience at specialist trainee level

The requirement to have at least three months' specialist experience was decided upon following discussions with clinicians in order to ensure all HCP participants had sufficient expertise and seniority in palliative care.

Prior to the start of the study, I presented the project at regular doctors' meetings within the hospice, giving senior doctors the opportunity to ask questions and raise any potential issues relating to the research. Once ethical approval had been granted, I attended a further meeting in order to formally invite doctors to participate in the study and to obtain consent. Eligible doctors who started working at the hospice midway through recruitment were approached individually to discuss participation. Eligible senior nurses were identified by the medical director of the hospice and were approached about participation via email. I then met with them one-on-one to discuss the project and obtain consent for participation.

Prior to the consent visit, HCPs were sent a copy of the participant information sheet<sup>9</sup> (PIS). The aims of the study and procedures for the recording of conversations were explained in detail and HCPs were given the opportunity to ask questions. It was stressed that participation was optional and that even if staff did consent they could withdraw their consent at any time. In particular, if they thought a recording was disrupting or altering their interactions with relatives, they were advised that they could halt the recording and should not feel pressured to make any further recordings. They were told

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<sup>9</sup> See Appendices 3-10 for anonymised copies of participant information sheets and informed consent forms, which were developed with input from PPI members and with reference to previous documents used in the VERDIS project

they would be invited to take part in a focus group towards the end of the study, but that consenting to the first part of the study did not commit them to taking part in the focus group.

HCPs were asked to give initial consent to take part in the study. They were asked not to record any conversations until at least one day after providing initial consent, in order to give them time to consider their decision to participate in the study. In addition to this initial consent, at least one day following each recorded conversation, I approached the HCP to obtain written consent for the use of the specific recording. As well as standard permissions relating to the use of the data for this and future research projects, the consent form also gave the HCP the choice to grant or refuse permission to use the recording for the following purposes:

1. Data analysis sessions with other communication researchers
2. Presentations about the research to professional audiences
3. Designing and implementing communication skills training including playing audio recordings during training

They were also given the option to have their recorded voice altered for these uses.

Following the completion of data collection of the recorded conversations, all HCPs whose recorded conversations were included in the corpus were invited by email to take part in a focus group. At the focus group, they were asked to sign a further consent form.

### ***3.2.2 Recruitment and consent procedure: Relative and friend participants***

The eligibility of relatives was checked by participating HCPs and later confirmed at the consent appointment. The inclusion criteria were:

- Person(s) identified by clinical staff as a main companion of an inpatient who was lacking capacity, not anticipated to regain capacity (as judged by clinical staff), and who was believed to be imminently dying
- Capacity to give informed consent
- Able to participate without causing distress (as judged by clinical staff)
- Able to engage in conversational English expressively and receptively
- Aged 18 or over

The exclusion criteria for relatives/friends were:

- Involvement in the study would cause psychological harm to the relative/friend, in the estimation of the clinical team
- Lacking capacity to consent
- Unable to engage in conversational English expressively and/or receptively

The first inclusion criterion included the proviso that the person's relative was 'believed to be imminently dying'. No particular time-scale was specified because prognosis is difficult to predict. For this reason, the criterion allowed the inclusion of relatives of patients whom the HCP believed may live for weeks but who could also die within the coming days.

Those who were unable to engage in conversational English were excluded due to the impact of this on the analysis. Conversation analysis (CA) transcribes talk in a high level of detail. Therefore the use of an interpreter or misunderstandings due to a lack of English language knowledge would impact this analysis. In addition, funds were not available for translating transcripts from different languages.

Once relatives had been identified by HCPs as eligible, a two-stage procedure was used for recruitment and consent. Participating HCPs approached eligible relatives at the point when they were about to have a conversation with them about a patient who was lacking capacity and believed to be imminently dying. They briefly explained that the recording would be used in a research project to understand communication with relatives with the aim of providing recommendations to improve communication for less experienced clinicians. Participants were asked for verbal consent to audio-record the conversation, given a PIS to read following the conversation, and told they would be approached by a researcher to discuss the study in more detail.

At least one day later, I approached participants to obtain full written consent. The aims and procedure of the study were explained and participants were given the opportunity to ask questions. It was made clear the recording would not be listened to until consent was given and that if they chose not to provide consent, the recording would be deleted. Their right to withdraw their data at a later date was also explained. Participants were then asked to sign a consent form. As with the HCP consent form, this gave the option to opt in/out of different uses and to ask for their recorded voice to be altered (see section 3.2.1).

This two-stage consent procedure was decided upon because it was not possible to know in advance when these conversations would be taking place, due to the uncertain nature of prognostication.



Furthermore, Speer and Stokoe (2014) found when a call-taker asked for consent after recording a call, the consent sequence was expanded as the caller asked more questions about the research. They argued at this point the caller had a clearer idea of what they were consenting to and more time to ask questions without delaying the business of the call. The two-stage consent procedure ensured that no recordings were made without at least verbal consent, but also allowed time for participants to reflect and decide whether they wanted their recording to be used. It also gave the option for relatives to refuse consent when the HCP was not present thereby reducing the chances of the relative feeling obligated to take part. A similar two-stage consent procedure, with options to provide consent for different uses of the data, was used successfully in the VERDIS project for recording conversations between doctors and patients at a hospice (see Pino et al., 2016).

In order to maximise the ease with which relatives could refuse participation, opportunities were provided to opt out of being approached at all. Information letters were put in rooms, posters were put up around the hospice, and doctors were asked to introduce the study when admitting patients. All of this information raised awareness the study was taking place and gave potential participants the option to ask not to be approached for participation.

During the appointment at which written consent was obtained, participants were asked if they would be willing to be contacted about taking part in an interview about communication at the hospice. Those who agreed were called or emailed 3-6 months following the recorded conversation to discuss the potential interview. Those who agreed to take part were given an appointment and sent the interview study PIS in the post or by email. At the appointment, the interview study was discussed again with the opportunity to ask questions, and participants were asked to sign a further consent form.

### ***3.2.3 Consent procedure: Other healthcare staff present during recordings***

The conversations with relatives were led by the participating HCP, but other members of the healthcare team were often present during the conversations (although they rarely contributed audibly). Whilst their communication was not the focus of the analysis, their voices were sometimes present on the recordings and so they were asked to consent to the recording being used. Prior to the start of recruitment, all staff at the hospice were emailed a PIS and a description of the study aims and procedures. When a participating HCP was about to record a conversation, they sought verbal consent from other healthcare staff present to record. I then approached them at least one day later

to obtain full written consent. No further data were collected about the other healthcare staff present.

### **3.3 Study procedures**

#### **3.3.1 *Recording conversations***

Data collection of audio-recordings of conversations took place between September 2017 and November 2018. The initial procedure was for HCPs to carry the digital voice recorder (DVR) with them at all times and record any eligible conversations they had. However it soon became clear that a more structured approach was required and I needed to be present at the hospice in order to remind HCPs to record conversations. I attended daily morning handover meetings during which all inpatients on the ward were discussed. At these meetings, I asked participating HCPs to identify any potentially eligible relatives. If a participating HCP anticipated having a conversation with an eligible relative, they took the DVR with them. Both one-to-one conversations and those involving multiple family members were eligible to be recorded. HCPs followed the consent procedure described in section 3.2.2 and documented who was present during the recording. They checked with relatives if they had a preference about when and where they would prefer to be contacted and passed on this information so I could follow them up for full written consent.

No recordings were listened to until all present during the recorded conversation gave full written consent to the use of the recording for research purposes. When consent was declined or could not be obtained within twelve weeks of a recording being made, the recording was deleted without being listened to.

Audio-recording was chosen instead of video-recording for ethical and pragmatic reasons. The main reason audio-recorders were used was their portability and ease of use. The conversations did not always occur during scheduled appointments and so it could not be predicted in advance when or where these conversations would take place. Video-recorders would therefore have needed to be set up immediately prior to each conversation and this would have been an extra burden for both HCPs and relatives. I also felt the presence of video recording equipment during such a sensitive conversation might feel more intrusive for participants than a small DVR. Whilst the analysis does miss some important non-verbal data such as eye gaze and physical contact, the audio-recordings still provide a rich source of data to meet the research aim. Audio-only data collection has yielded valuable results in recent CA studies in similarly sensitive end-of-life settings (e.g. Pecanac, 2017; Shaw et al., 2016).

### **3.3.2 *Post-bereavement interviews and HCP focus group***

Relative participants were invited to take part in an interview between three and six months following the recorded conversation. Interviews took place between March 2018 and February 2019. The purpose of these interviews was not to provide an account of the recorded conversation, as the recordings are a much more accurate representation of the conversation. Instead, the purpose was to gain relatives' perspectives on communication over their time at the hospice, including their satisfaction and what they felt was important for good communication. The recorded conversations did not occur in a vacuum and so interviews provided information about what communication had occurred leading up to that point. Participants were given the option of where the interview took place.

The semi-structured interviews used a topic guide (see Appendix 11 for full topic guide). This was developed based on the existing literature (as reviewed in Chapter 1), informal observations from time spent on the wards during data collection, and preliminary findings from the analysis of recorded conversations. Patient and public involvement (PPI) representatives were consulted on how appropriate they felt the content and wording of the questions were. The final topic guide covered the following issues:

- Admission to hospice
- Assessment of the quality of families' relationships with staff (roles of different members of staff, whether they had someone with whom to discuss both patient and relative concerns)
- Delivery of information (including level/clarity of information, feeling understood, being told when HCPs felt the patient was likely to die soon)
- Decision making (involvement in decisions, time to discuss decisions, preferences for involvement)

The topic guide was used flexibly to focus on issues considered important to participants. Prompts and probes were used where appropriate to gain a deeper understanding of the participants' perspectives. If participants became visibly upset during the interviews, they were given time and the option to take a break or halt the interview. Information on the bereavement counselling services at the hospice was also available to all participants in the interviews.

Following the end of data collection of recorded conversations, those HCPs who had recorded conversations that were included in the corpus were invited to take part in a focus group to discuss communication in the hospice. The purpose of this focus group was to discuss HCPs' perspectives on

what makes a good end-of-life conversation with relatives and how they see their roles. A topic guide was developed based on findings from the systematic review and initial findings from interviews with relatives and recorded conversations (see Appendix 12 for full topic guide). The topic guide covered the following issues:

- Purpose and content of conversations (what is important to discuss, roles of different members of staff)
- How topics are raised and discussed (prognosis, process of dying, decision making, relative wellbeing)
- Language and checking understanding
- Barriers and facilitators to good communication

A focus group approach was selected over interviews as the preferred approach to encourage discussions between colleagues (Kitzinger, 1994) about the different approaches they may take and how they saw their different roles within the team. All HCP participants were of a high level of seniority, which may have reduced the risk of participants being reluctant to express opinions in front of each other. They had also had regular meetings when working together and so the scenario of discussing working practices together was not new to this group. If a HCP was not able to attend the focus group, they were invited to an individual interview.

### **3.4 Study approvals**

#### ***3.4.1 Ethical approval***

The study received a favourable opinion from the UCL Research Ethics Committee (ref 11519/001) on 18<sup>th</sup> July 2017. The hospice was not an NHS site and so NHS ethical approval was not required. An amendment to allow consent to be collected through the post for those unable to meet in person was accepted on 15<sup>th</sup> November 2017. A further amendment to increase the time allowed to obtain consent from six to twelve weeks was accepted on 13<sup>th</sup> April 2018. Both of these amendments were made to increase the chances of obtaining consent by giving participants more flexibility about when and how they provided written consent.

### **3.4.2 Research governance approval**

The study was designed with input from the clinical team at the hospice. The research was discussed at a hospice Clinical Governance meeting and all present agreed to allow the study to go ahead. This was documented in the minutes of the meeting.

### **3.4.3 The role of patient and public involvement in the study design**

Two patient and public involvement (PPI) representatives were involved in the design of the study. One was a current outpatient at the hospice and another was a member of a group comprising people with first-hand experience of being carers, family members or friends of people at the end of life. The PPI representatives commented on the protocol, all participant-facing documents and provided their general thoughts on the study. Their suggestions led to numerous revisions to the methodology. This included increasing the profile of the study amongst patients and relatives in the hospice prior to consent being sought, ensuring participants were explicitly given the option of where and when to be contacted, and the inclusion of post-bereavement interviews.

A recent paper (Pino, Parry, Feathers, & Faull, 2017) exploring the acceptability of recording palliative care consultations amongst clinicians, patients and companions was also referred to during the design of the study. Safeguarding recommendations from this study, such as briefing staff in advance and giving participants time to reflect and decide whether to give full consent, were followed.

## **3.5 Analysis of recorded conversations: Conversation analysis**

This section outlines how a conversation analytic approach to transcription and data analysis was utilised in this thesis. For an in-depth description of the conversation analytic approach and why it was used in this project, see Chapter 2.

### **3.5.1 Transcription**

Recordings were transcribed using the Jefferson transcription system (Hepburn & Bolden, 2012; Jefferson, 2004), which is widely used in CA research (see Appendix 13 for a full list of transcription symbols used). This system captures interactions in a high level of detail in order to record how talk is done, not just what is said. Temporal features of talk such as pauses and overlap are transcribed, as are the ways words are spoken such as intonation, elongation, volume and pitch. This system is designed to capture the sequential features of talk in particular.

This system is used because standard verbatim transcriptions of conversations do not give a full picture of the interaction. Features such as pauses, intonation and overlapping speech all impact on the ways in which talk is heard by participants and therefore how they respond (Hepburn & Bolden, 2017). For example as discussed in Chapter 2, CA research has found that if a person pauses or says 'um' at the beginning of a response to a proposal, this can signal an upcoming dispreferred response and can result in a reformulation of the proposal (Schegloff, 2007). This sort of interactional detail would not be identified by standard verbatim transcription.

The Jefferson transcription system has been criticised as being open to the interpretations of the person transcribing. The transcriber decides which features to transcribe in the most detail, which can in turn guide the reader towards what the transcriber thinks is important, rather than being a neutral rendering of the interaction (ten Have, 2002). For this reason, in this thesis features that were not necessarily relevant to the presented analysis were left in the transcripts, as this allows readers to assess the evidence for the claims made in the analysis. Additionally, whilst the Jefferson transcription system has been shown to be capable of producing highly reliable transcripts (Roberts & Robinson, 2004), these transcripts are also used alongside the audio-recording during the analysis, as the recording will always be a more authentic representation of the conversation (Heritage & Atkinson, 1984).

I transcribed 21 of the recordings and checked and edited the remaining eight, which were transcribed by MSc Speech and Language Science students, all of whom were trained and assessed in fine grained linguistic and phonetic transcription methods. Identifiable features such as person and place names were changed to ensure confidentiality. Audio software Audacity was used during the transcription process in order to isolate and listen back to parts of the recording to improve accuracy, particularly when transcribing pauses and overlap. The first-stage transcription of full conversations was done to a high level of detail in order to avoid focusing on any particular pre-defined parts of the conversation. As the analysis became more focussed, sections of transcripts were edited as data were played back repeatedly and new or different features were noticed. Transcripts were subject to further scrutiny from a range of researchers during data sessions in which extracts of data were played for group analysis.

### ***3.5.2 Steps of analysis***

Analysis of the recorded conversations began once the first transcription was complete and continued throughout and following the data collection period. As described in Chapter 2, the process of analysis

in CA is data-driven and inductive and so is not approached with any hypothesis or pre-defined framework in mind.

The analysis was approached following the steps described by Hutchby and Wooffitt (2008). The first step is 'unmotivated looking', which involves looking over the transcript and noticing interesting features of the interaction. The identified feature is then examined in its sequential context and defined more clearly. The full dataset is then re-examined to look for other instances of this sequence-type in order to build up a collection. Deviant cases which do not fit the previous analysis are identified and the analysis re-examined to account for this. The key questions to address for each interactional feature are: What action is the feature doing, and how do the participants orient to this (i.e. what does the next turn display about how the participant has understood the action of the previous turn)? (Hutchby & Wooffitt, 2008).

Whilst these standard steps for CA are used for both pure and applied CA, the task-oriented nature of these institutional conversations needed to be considered. Heritage (2004) suggests analysis of institutional talk should attempt to map the phases of the interaction (e.g. opening, problem presentation). He argues these phases are co-constructed by the participants in their pursuit of the goal and sub-goals of the interaction, and looking at the boundaries between these phases can reveal whether the participants are aligned in their perspective on the task at hand. Whilst clear 'phases' of the interaction such as 'problem presentation' were not always evident, Chapter 4 sets out the general content of the conversations and within the analytic chapters there is a focus on how topic-shifting occurs, for example how the conversation moves into and out of prognostic talk and how transitions into closings are made.

At various points over the analysis period, sections of the data were presented at data sessions with other CA researchers. Participants at these data sessions were invited to provide their own observations on the data and to discuss these within the group. These sessions served to provide potential new avenues to explore in the analysis and to ensure all findings were firmly rooted within the data.

The broad research aim for this thesis, as well as the data-driven nature of CA, allowed a wide range of potential analytic topics to be focussed on. In order to complement the other projects in the I-CAN-CARE programme grant, the communication of prognosis was chosen as a key analytic topic. However beyond this, the remaining analytic chapters were not pre-defined. Once numerous potential analytic topics had been identified from the unmotivated looking step of analysis, the secondary research aim

of providing recommendations for communication training was considered. Analytic topics were chosen based on what would be most useful and amenable to modification through training. The three analytic topics presented are: terminal-phase prognostication sequences, closing the business-at-hand (exiting prognostic talk and transitions into closing sequences), and disagreements during talk about prognosis and comfort care.

### **3.6 Analysis of interviews and focus group: Thematic analysis**

Temporary workers employed by UCL transcribed eight interviews verbatim and the remaining five interviews and the focus group were transcribed by a professional transcribing company. The transcripts were then checked for accuracy and entered into NVivo 11 software for analysis. All person and place names were removed and replaced with pseudonyms.

The analytic approach taken was thematic analysis, following the steps described by Braun and Clarke (2006). Thematic analysis is widely used in qualitative research and is flexible but still follows clear steps which allow a transparent, auditable decision trail (Nowell, Norris, White, & Moules, 2017). The purpose of this analysis was not to develop a new theory as in grounded theory (see Glaser, 1992; Strauss & Corbin, 1998) or to tell a chronological story with a focus on how the story is being told as in narrative analysis (see Riessman, 1993). Equally, transcripts were not analysed as accurate accounts of individual conversations. Instead, the analysis was used to identify relatives' and HCPs' perspectives on what is important to them during communication in a hospice environment and what difficulties can arise in this context. A thematic analysis approach allows the analyst to summarise datasets whilst considering the similarities and differences between the perspectives of individual participants (Braun & Clarke, 2006; Nowell et al., 2017). This allowed similar and differing preferences and beliefs to be explored across relatives and HCPs.

The first step set out by Braun and Clarke (2006) is for the researcher to familiarise themselves with the data. This was done by re-reading the transcripts alongside reflexive notes written during data collection, including initial analytic thoughts (Tuckett, 2005). I then conducted initial coding on two interview transcripts and the focus group transcript, alongside a second analyst (Joe Low, supervisor). Following initial coding, we met to discuss the codes and agree on what was relevant to the analysis. For example, it was agreed that whilst not directly describing communication, codes relating to the positives of having a family room or perceptions of good care were still relevant to experiences of communication. I then coded the remaining transcripts to identify further codes and begin to identify



themes. A list of the codes generated from this initial coding process is provided in Appendix 14, with examples of coded extracts.

Once coding was complete, I reviewed the codes from both the relative interviews and the HCP interview and focus group to identify links between them and develop themes and sub-themes. These themes were then further refined and named through returning to the data and discussions with the second analyst. The purpose of the analysis was to report on communication at the hospice in terms of the reported experiences of relatives and HCPs and so themes were developed at a semantic level (i.e. reflecting the explicit content of the data; Braun & Clarke, 2006). These themes are reported in Chapter 8 with evidence from within the transcripts. Writing this chapter was a part of the analytic process as this is involved further interpretation of the themes in order to provide an analytic narrative (Braun & Clarke, 2006).

### **3.7 Ethnographic experience**

This was not an ethnographic study, but I was present at the hospice most days throughout the 14-month recruitment period and so acquired first-hand knowledge about the day-to-day workings of the hospice. Antaki (2011) argues in favour of acquiring ethnographic background knowledge when carrying out applied CA projects in order to understand the context within which the conversation is taking place. In Heath's studies of medical and other workplace interactions for example, he delayed collecting data until he had carried out fieldwork. This allowed him to understand the organisations he was studying and the processes and technologies that arose within his recorded interactions (Heath, 2004).

Being present at the hospice provided information that made the conversations easier to understand during the analysis of both the recorded conversations and the interviews. For example, it was not always obvious from the recordings where the discussion was taking place and whether or not the patient was present. Knowledge of how ward rounds took place and discussions with HCPs made this much clearer. Additionally, references to drugs, symptoms, other named members of staff, and other healthcare facilities were all familiar, reducing the likelihood of misunderstandings during analysis. Familiarity with HCPs' voices and manner of speaking also aided the transcription process.

Further, as described in section 3.3.1, my presence at the hospice aided recruitment to the study. Not only was my presence a reminder to HCPs to consider which relatives may be appropriate to approach, it also allowed me to build trust with staff at the hospice. Clinician gatekeeping can be a major barrier to recruitment, especially in palliative care settings (White & Hardy, 2008). I was requesting that HCPs

record potentially difficult conversations at an extremely sensitive time for relatives, and so creating strong relationships with staff was vital to the success of the study.

## Chapter 4 Overview of recordings

Before presenting the conversation analytic findings in the upcoming chapters, this chapter provides the context for this analysis by giving a descriptive overview of the recorded conversations in the corpus. Details of the recordings and the demographics of the participants are provided. There is then an outline of the setting in which conversations with relatives took place and the topics that regularly arose.

### 4.1 Sample

In total, 34 conversations were recorded between September 2017 and November 2018, with consent obtained for the use of 29 of these. A summary of the recordings can be found in Table 4.1. Of the five recordings that were not used only one participant specifically asked for the recording to be deleted, citing feeling uncomfortable with it being used in research. In the remaining four cases, participants either could not be contacted or verbally agreed to the use of the recording but did not return the consent form.

**Table 4.1** Details of recorded conversations

Recorded conversations (N=29)	
Recording length, mean (range)	18:48 minutes (04:10-40:47 minutes)
Number of staff present, median (range)	2 (1-5)
Number of relatives present, median (range)	2 (1-5)

The 29 included recordings involved five senior healthcare professionals (HCPs) and 51 relatives of patients. Over half of relatives were the adult children of patients and a quarter were the partner or spouse of a patient. The HCP sample included two consultants, two registrars and a clinical nurse specialist (CNS). Table 4.2 provides the full demographic details of the sample. A further five HCPs were recruited but did not make any recordings that were used in the study. Of these five, one worked primarily in the outpatient department and so was rarely on the wards, three were only working at the hospice for a brief time during data collection, and one made a recording for which consent from relatives could not be obtained.

**Table 4.2** Demographics of participants in recordings

	HCPs (N=5)	Relatives (N=51)
Female, N (%)	3 (60)	37 (72.5)
Mean age, years (range)	40.8 (31-53)	50.8 (19-86)
Ethnicity		
White British or Irish, N (%)	2 (40)	34 (66.7)
White Other, N (%)	1 (20)	4 (7.8)
Mixed White/Asian, N (%)	2 (40)	7 (13.7)
Black African, N (%)	0	4 (7.8)
Black Caribbean, N (%)	0	1 (2.0)
Indian, N (%)	0	1 (2.0)
Mean years in palliative care (range)	9.4 (1.7-19)	-
Job title		
Consultant, N (%)	2 (40)	-
Specialist registrar, N (%)	2 (40)	-
Clinical nurse specialist, N (%)	1 (20)	-
Relation to patient		
Adult child, N (%)	-	28 (54.9)
Partner/Spouse, N (%)	-	13 (25.5)
Parent, N (%)	-	1 (2.0)
Friend, N (%)	-	2 (3.9)
Sibling, N (%)	-	1 (2.0)
Adult grandchild, N (%)	-	1 (2.0)
Cousin, N (%)	-	3 (5.9)
Son-in-law, N (%)	-	2 (3.9)

Table 4.3 lists each recorded conversation and the senior HCPs and relatives present. One relative (R09) was involved in two different recorded conversations. Throughout the analytic chapters when extracts of conversations are presented, the extracts are labelled with participants' identification numbers, the HCPs' roles, relatives' relationships with the patient, and the time within the conversation the extracts begin and end in minutes and seconds.

**Table 4.3** List of participants in each recording

Recording number	Healthcare professionals (participant number)	Relatives (participant number)
05_01	Consultant (HCP05)	Daughter (R01)
01_02	Clinical nurse specialist (HCP01)	Partner (R02) Daughter (R03)
01_04	Clinical nurse specialist (HCP01)	Daughter (R04) Daughter (R05)
02_06	Consultant (HCP02)	Partner (R06) Mother (R07)

Recording number	Healthcare professionals (participant number)	Relatives (participant number)
01_08	Clinical nurse specialist (HCP01)	Daughter (R08)
01_09	Clinical nurse specialist (HCP01)	Wife (R09)
02_09	Consultant (HCP02)	Wife (R09)
02_10	Consultant (HCP02)	Daughter (R10)
05_11	Consultant (HCP05)	Husband (R11) Daughter (R12)
09_13	Specialist registrar (HCP09)	Friend (R13)
01_14	Clinical nurse specialist (HCP01)	Daughter (R14) Daughter (R16) Grandson (R15)
07_17	Registrar (HCP07)	Wife (R17) Daughter (R18)
05_19	Consultant (HCP05)	Daughter (R19) Son (R20)
05_21	Consultant (HCP05)	Daughter (R21)
07_27	Registrar (HCP07)	Daughter (R27) Daughter (R28)
02_31	Consultant (HCP02)	Daughter (R31)
09_32	Registrar (HCP09)	Son (R32) Wife (R33)
05_34	Consultant (HCP05)	Daughter (R34) Wife (R35)
05_36	Consultant (HCP05)	Husband (R36) Daughter (R37) Daughter (R39) Daughter (R40) Son (R38)
05_41	Consultant (HCP05)	Wife (R41)
05_42	Consultant (HCP05)	Friend (R42)
05_43	Consultant (HCP05)	Daughter (R43) Sister (R44) Son-in-law (R45)
09_47	Registrar (HCP09) Clinical nurse specialist (HCP01)	Wife (R47) Cousin (R48)
05_49	Consultant (HCP05)	Daughter (R49) Son (R50)
05_51	Consultant (HCP05)	Wife (R51)
02_52	Consultant (HCP02)	Son (R52) Daughter (R53)
05_54	Consultant (HCP05)	Daughter (R54) Son-in-law (R55) Husband (R56)
05_57	Consultant (HCP05)	Wife (R57)
05_61	Consultant (HCP05)	Cousin (R61) Cousin (R62)

## **4.2 Setting of recorded conversations**

The setting of each recorded conversation was not documented, but they generally took place either in the patient's room, in the family room, or in a private meeting room on the ward. Conversations with consultants mostly took place during one of their two ward rounds per week, but they sometimes arranged a specific meeting to speak with relatives or had more spontaneous conversations when relatives sought them out on the ward. On the days when consultants were not at the hospice, registrars would visit those patients highlighted by consultants or nursing staff as needing to be seen, or where relatives had requested to speak to a doctor. The CNS tended to speak with relatives when they were highlighted by the team as needing some more time to talk about psychosocial issues or the patient's care needs or symptoms. Foundation year doctors, GP trainees and registered nurses also regularly had in-depth medical conversations with relatives, but these were not recorded for the study.

## **4.3 Content of recorded conversations**

Previous studies have attempted to describe the structure and content of healthcare interactions. In Byrne and Long's (1976) classic study, they mapped out the structure of primary care consultations in the UK. They identified six phases to the consultation and the order in which they occurred within the roughly ten-minute consultations. These phases were: (1) Establishing a relationship with the patient, (2) Attempting to discover the reason for the visit, (3) Conducting a verbal and/or physical examination, (4) Considering the condition or providing a diagnosis, (5) Agreeing and detailing further treatment or investigation, and (6) Terminating the consultation (Byrne & Long, 1976). Robinson (2003, p.30) has also suggested the following similar phases for primary care consultations where a new medical problem is being presented: (1) Establishing a new medical problem as the reason for the visit, (2) Gathering additional information (history taking, physical examination), (3) Delivery of diagnosis, and (4) Treatment recommendation. Robinson (2003) showed that each of these phases does not always occur, but when they do not, this is oriented to as a deviation from a normal consultation. In conversations with families at the end of life, Barton et al. (2005) identified the following phases of family meetings; (1) Openings, (2) Description of current status, (3) Holistic decision making, and (4) Logistics of Dying.

Despite some similarities with each of these proposed structures, the conversations recorded for this thesis did not have such a clear structure. Whilst other observational studies of communication at the end of life focussed on formal, scheduled family meetings (e.g. Barton et al., 2005; Curtis et al., 2002;

Pecanac, 2017), there was only one recording of this type in the corpus (recording no. 05\_11). As described in section 4.2, most meetings were more informal, taking place during routine visits to patients' rooms. There was therefore rarely one key concern to be addressed, as relatives and HCPs may have had issues that they wanted to discuss or, at other times, the conversation was simply a general catch up. This section does not therefore aim to map out a standard set of phases that all conversations of this type followed. Despite the heterogeneity in the conversations, there were some topics that regularly arose. This section will therefore provide a description of these in order to provide context for the upcoming analytic chapters. They are presented broadly in the order in which they occurred, but there was much variation between conversations and talk on each of these topics was often interrelated.

#### **4.3.1 *Summary/update on current situation***

The first words exchanged by the HCP and relatives were not recorded because the HCP first had to obtain verbal consent for the recording to take place. However the recordings did generally capture the beginning of the 'business' of the conversation. In most cases, this started with a discussion of how the patient was doing. In particular they discussed what changes had occurred since they last spoke. If this was their first conversation, there was some discussion of the patient's story up to admission. This was not a detailed history taking as that tended to have been done by a more junior doctor on admission. The proportional contributions of the HCP and relatives during this talk varied. In some cases, the HCP led the description of the current situation, with relatives inputting either through tokens such as 'yeh', or by adding to the story with their own perspective. In other cases, it was the relatives who updated the HCP on what had been happening. These discussions were therefore a co-construction between the HCPs and relatives as they each provided their own observations about what had been happening to the patient.

#### **4.3.2 *Explanation of symptoms and medications***

Unlike the summaries of the current situation in which relatives often took the lead, explanations of symptoms and medications were mostly information provision from the HCP to the relatives, albeit often in response to relatives' questions or descriptions of symptoms. HCPs often gave assurances that the observed symptoms were a natural part of dying. In particular, they discussed the balance between the relief of pain and distress, and trying to maintain the patient's consciousness. They also explained that drowsiness was often due to the dying process rather than any medications. At this point decisions were sometimes made to alter which medications the patient was taking, to increase

or decrease doses of their medications, and/or to switch them from oral medications to a syringe driver. In addition to these more medical concerns, there were also discussions about whether the patient had any awareness of what was going on around them and whether or not relatives should try to talk to them.

#### **4.3.3 *What to expect***

Linked with explaining current symptoms were HCPs' descriptions of what to expect in the coming days. These could be in terms of potential side effects of medications, or possible future symptoms and how they would be treated, including what they would or would not do to treat the patient. In some cases there was a discussion about what actually happens during the dying process and what signs and symptoms to expect in the final hours of the patient's life. Twenty-three of the 29 conversations included talk on prognosis, which is discussed in detail in Chapter 5.

#### **4.3.4 *Relatives' wellbeing***

Relatives' wellbeing often arose during talk on other subjects, for instance when relatives spoke of the difficulty of an uncertain prognosis or of witnessing distressing symptoms. HCPs would also ask explicitly about relatives' wellbeing, often towards the end of conversations once talk on the patient's care was complete. They asked generally about how the relatives were coping and discussed other relatives who were not present in the conversation. There were sometimes more specific questions about who wanted to be present when the patient dies, although this usually came earlier in the conversation. In addition to asking about the relatives' current situation, HCP sometimes asked about their relationship with the patient and what the patient was like prior to the illness.

#### **4.3.5 *Other topics***

There were other topics that arose in several conversations but were not as common as those described above. For instance, there was sometimes a need to discuss practicalities of what would happen after the patient's death. Jewish and Muslim families in particular discussed this as their religions dictate that people should be buried as soon as possible following death, and so arrangements needed to be made in advance. Other families planned to take the patient's body abroad, requiring documentation from the hospice. HCPs occasionally had to raise post-death practicalities, for example if a referral to a coroner would be required, delaying the issuing of a death certificate.



Section 4.3.2 described how decisions were sometimes made to change medications due to signs and symptoms that had been discussed. This type of on-the-spot decision making in response to concerns about symptoms was common (not dissimilar to problem presentation and diagnosis leading to a treatment recommendation in primary care; Byrne & Long, 1976; Robinson, 2003). However, on occasion HCPs or relatives came to the conversation with a decision in mind that had more significant implications and therefore required a longer discussion. These decisions included issues such as whether or not to treat infections or hypercalcaemia, and whether to use sedative medications.

Conversations with the CNS covered broadly the same topics as those with the doctors, however in general, more time in these conversations was spent talking about the wellbeing of the family and in several cases the signs and symptoms to expect in the final hours and days of the patient's life. Decisions about medication were not made by the CNS, although the purpose of different medications and potential future decisions were discussed. The conversations which the CNS led were an average of 25 minutes 34 seconds long, compared to 17 minutes 18 seconds for those conversations in which she was not involved. Chapters 5 and 6 in the thesis cover prognostication, exiting prognostic, and moving into closing relevant environments, all of which followed similar patterns in conversations with the CNS as in those with doctors. For clarity, the participant labels in the included extracts specify whether the conversation was with a doctor (DOC) the clinical nurse specialist (CNS).

This chapter has demonstrated the rich content of the data in the corpus and the broad range of potential areas of focus for the analysis. The upcoming analytic chapters are not arranged according to the topic headings above, but elements of each of these topics arise across the analysis. These chapters present analysis of: terminal-phase prognostication sequences, closing the business-at-hand, and disagreements during talk about prognosis and comfort care.

## **Chapter 5   Terminal-phase prognostication sequences**

This chapter examines terminal-phase prognostication sequences. The analysis considers how relatives and healthcare professionals (HCPs) accomplish prognostic talk, including requesting and providing prognostic information. Whilst prognosis can refer generally to the likely course of a medical condition, here the term is used more specifically to refer to expected time to death. Prognostic talk occurred in 23 of the 29 recordings in the corpus.

The analysis begins in section 5.1 by describing the sequential environment in which the topic of prognosis is initiated and how this is done; either through stepwise topic transition (Jefferson, 1984; Sacks, 1992) or topic initial elicitors (Button & Casey, 1984). In the majority of cases, HCPs' prognostic estimates were elicited by relatives requesting prognostic information about when a patient was likely to die (referred to as 'time estimate requests'). Section 5.2 explores how these time estimate requests were formulated and how the HCPs responded to these requests, including how different formulations of the time estimate request could lead to different responses from the HCP.

HCPs sometimes made prognostic statements without these being elicited by a relative's time estimate request. Section 5.3 focuses on how HCPs formulated these prognostic statements and how relatives responded, either with a time estimate request for a more specific estimate, or by rejecting the newsworthiness of the statement.

Parts of this chapter have been adapted and accepted for publication in Palliative Medicine. A table of additional examples of features of prognostic talk created for this paper is provided in Appendix 15.

### **5.1   Topicalisation of prognostic talk**

There was no pattern of how early within the conversation prognostic talk was initiated. However, it frequently followed on from a discussion about the patient's deterioration, particularly when this talk was about the patient's awareness or sleepiness. This was often linked to medications, for instance HCPs explaining that patients were now too sleepy to be able to swallow medications or that drowsiness can be caused by medications, but also by the final stages of disease. This is seen in Extract 5.1 below. Prior to this extract, the doctor (DOC) and friend of the patient (FRI) had been discussing the patient's confusion and hallucinations, and the doctor suggested an anti-hallucination medication.

**Extract 5.1 DOC: HCP05 (Consultant), FRI: R42 (Friend of patient),  
04:31-05:08**

01 DOC: Uhhem hh negative side effects he could have (0.3)  
02 it could make him more sleepy. I've picked one that  
03 shouldn't make him too sleepy, .hh that should just  
04 take away those (0.3) overactive (0.5)  
05 [ideas and and] and  
06 FRI: [Yea::h okay. ]  
07 (0.6)  
08 DOC: yes [thou:ghts,] .hhhh Let's try that, (0.5) If it  
09 FRI: [yeah ]  
10 DOC: would make him more sleepy (0.4) I think the way he  
11 DOC: ↑looks now and in comparison to from the weekend,  
12 .hhh I think he'll become (0.3) more sleepy=  
13 FRI: =Yea:h.  
14 (0.2)  
15 DOC: even wh- if (0.2) we gave him [no medicine at all]  
16 FRI: [Yea::h yeah ]  
17 DOC: just from what the (.) what the myeloma and what  
18 the calcium are doing.  
19 FRI: Yea:h.  
20 (0.3)  
21 DOC: °I think° (0.9) °he probably has a limited amount of  
22 time now.°  
23 FRI: You mean like (0.3) ↓days [or,  
24 DOC: [°I think days yes.°

There is a 0.5-second pause at line 8 after the doctor has described the potential sleepiness. Following this is the pivotal utterance (Sacks, 1992), 'if it would make him more sleepy', which begins topic transition towards prognostication. This utterance links the potential sleepiness from the medication, with the sleepiness from his natural deterioration (lines 10-18). The prognostic statements<sup>10</sup> (lines 21 and 24) are marked by slightly quieter speech, which softens the delivery as is often found in bad news deliveries (Freese & Maynard, 1998).

In the corpus, discussions about deterioration established that the patient is unlikely to be awake or alert again. This suggests that the patient is at the very end of their life and this therefore makes prognostic statements or time estimate requests relevant, allowing stepwise topic transition rather than requiring a disjunctive topic shift to introduce prognostication (Jefferson, 1984; Sacks, 1992). In Extract 5.1 this topic transition is led by the doctor who then makes the first explicit prognostic statement, but the same practices were also performed by relatives in other conversations. This is demonstrated in Extract 5.2, prior to which the patient's two daughters (DA1 and DA2) had been describing how difficult they have found their mother's loss of consciousness. DA1's time estimate

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<sup>10</sup> Note the use of 'I think' by the doctor four times within this sequence. Section 5.2.1 discusses the use of uncertain language in detail

request links with this talk by asking how long their mother is likely to remain in this state (lines 9-11). It is clear that this is referring to time to death, rather than an expectation of her waking up because she has already referred to having had her 'last conversation with her' (line 1). It is understood this way by the doctor as she provides a prognostic time estimate in her next turn (lines 14-15).

**Extract 5.2 DOC: HCP07 (Registrar), DA1: R27, DA2: R28 (Daughters of patient), 17:19-17:35**

01 DA1: You know we've had our last conversation with her.  
 02 [ >We're not gonna< ] y'know  
 03 DOC: [ °That's right° ]  
 04 DA2: [ Yea:h ]  
 05 (0.3)  
 06 DA1: So that's quite hard, .hh  
 07 DOC: °Yeah°  
 08 DA1: Um: (0.4) ↑also >just thinking about it< in terms of  
 09 (0.8) how long do we expect this to be: (0.2)  
 10 DOC: °Mm°  
 11 DA1: the ↓case: like wha- wha [ what's realistic cause  
 12 DOC: [ .hhh tch .hhh  
 13 DA1: y'know ]  
 14 DOC: So- [ (.) I mean I think (.) ↓y'know (0.2) I think  
 15 hours to da:ys I think at the moment.

Whilst there are some signs of the difficulty of the topic from the stalled start with an 'um', pauses and repair at lines 8-9, talk about unconsciousness leads to prognosis in an unproblematic way with little work needed from the relatives to topicalise it.

Stepwise transitions into prognostic talk occurred in the majority of cases. However in three conversations in the corpus, prognostic talk arose from a doctor asking if the relatives had any questions or needs. This resembles what Button and Casey (1984) referred to as a 'topic initial elicitor' where the speaker makes an enquiry that opens up a space for the other person to introduce a potential topic. This means that the other person can put forward a possible new topic without having to link this to the previous one. This is seen in Extract 5.3, a conversation between a doctor (DOC) and daughter (DAU) of a patient. It occurs 34 seconds into the conversation following the doctor's brief summing up of recent fluctuations in the patient's condition.

**Extract 5.3 DOC: HCP02 (Consultant) DAU: R31 (Daughter of patient), 00:34-01:46**

01 DOC: Is there anything in particular (0.2) that you feel we  
 02 should be (0.8) doing differently: or (0.3) thinking  
 03 about with you,  
 04 (1.9)  
 05 DAU: ↑I mea:n #I- I don't know cause it's really hard  
 06 cause obviously (.) w:hen he came and he did pick  
 07 (0.4) pick back up (0.2)

08 DOC: °Mm°  
 09 DAU: There's that slight (0.2) confu:sion (.) not just  
 10 with family and friends like ↑↑oo he's gonna get  
 11 ↑better like a ↑miracle's taken [place] kind of  
 12 DOC: [yeah ]  
 13 DAU: thing .hh And then: it's like so .h one day (0.4)  
 14 up (0.4) next day you come in, (0.8) right do::wn  
 15 DOC: Yeh.  
 16 (0.2)  
 17 DAU: And it was like y'know so there was that bit of  
 18 confusion like w: (0.6) <what's rea::lly going on?>  
 19 DOC: Mmm  
 20 DAU: Like (0.6) the medical side of it is a bit  
 21 confusing I guess,  
 22 DOC: Mmm  
 23 DAU: Not (.) understanding cause obviously .h know his  
 24 hear:t (0.2) is: failing >when he had a< heart  
 25 failure,  
 26 DOC: Yes  
 27 DAU: We know the ki- bout the kid↓neys (.) but then it's  
 28 like (0.4) then it's like w:l (0.7) I guess there  
 29 isn't a time? Like how long [does it] (0.5) take  
 30 DOC: [↑Yeh ]  
 31 DAU: for the heart to fail, how long does it take .h for  
 32 the kidneys to fail, so it's a bit (0.3)  
 33 DOC: Mmm  
 34 DAU: it ↑can be a little bit I think confu:sing, a bit  
 35 (1.1) y:[eah.]  
 36 DOC: [Yeh ]  
 37 (0.9)  
 38 DOC: And [the these] conditions (.)  
 39 DAU: [an ↑hmm ]  
 40 DAU: Mmm?  
 41 DOC: that that are kind've all adding up together, (0.3)  
 42 .hhh u[m:: ] to be honest we get a bit (1.1)  
 43 DAU: [m↑hm]  
 44 DOC: confused is probably not the ri(h)ght [word,]  
 45 DAU: [Yeah ]  
 46 (0.3)  
 47 DOC: But we are also: uncertain

Here the doctor employs a topic initial elicitor (lines 1-3), which is common at the opening of conversations (Button & Casey, 1984). Whilst there are institutional limits on what topics can be initiated here, the doctor does not nominate a specific topic for talk. This leaves it open for the daughter to raise prognosis as a possible next topic. Button and Casey (1984) showed that recipients of topic initial elicitors display their utterance as being a result of the prior turn by marking their response as searched for. This is seen in lines 4-5 as the daughter pauses before responding and begins her response with 'I mean I don't know'. Whilst most time estimate requests in the corpus were more direct (see section 5.2 for more detail), here there is more of a requirement to build up the case for the request as it has not yet been topicalised. The daughter does this with a description of her

confusion arising from her father's fluctuation. She receives continuers from the doctor throughout, with particular emphasis on the 'yeh' at line 30 when the daughter begins to reach the topic of prognostication. The doctor then takes up the topic from line 38. The topicalisation has therefore been interactional and mutual (Button & Casey, 1984) emerging through the doctor's topic initial elicitor, the daughter's proffering of the topic of prognostication, and the doctor's uptake of this topic.

## 5.2 Time estimate requests and responses

Twenty of the 23 conversations involving prognostic talk included a time estimate request from the relative at some point<sup>11</sup>. This section describes the ways in which these requests were made by relatives and responded to by HCPs.

### 5.2.1 Epistemic rights and authority in time estimate requests and responses

With the exception of those arising from topic initial elicitors described in section 5.1, time estimate requests were generally direct without relatives providing an account for why they were requesting prognostic information. None of the time estimate requests led to further solicitation from the HCP to confirm what or how much the relative wanted to know. Both relatives and HCPs therefore treated relatives as having a strong entitlement to the information (Curl & Drew, 2008; Heritage & Raymond, 2012). Despite this orientation to the rights of the relatives to make the request, the HCP's access to accurate prognostic information was not as clear and so both parties had to negotiate this uncertainty throughout the interactions. The following extracts exemplify typical time estimate request formulations and responses within the collection, with a focus on HCPs' and relatives' displayed rights and access to prognostic information.

Extract 5.4 took place 10 minutes into a conversation between a doctor (DOC) and daughter (DAU) of a patient. They had previously been discussing the patient's sleepiness when the daughter received a phone call. This extract came immediately after explaining who was on the phone.

**Extract 5.4** DOC: HCP05 (Consultant), DAU: R34 (Daughter of patient),  
10:13-10:47

01 DAU: Er:m (0.3)  
02 DOC: Em, (0.2)  
03 DAU: What d'you think ↓now (.) of the days,  
04 DOC: Of the days.  
05 (0.9)

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<sup>11</sup> Seventeen of these were unprompted by HCPs and three were requests for more specific information following descriptive prognostic statements from HCPs (see section 5.3 for further descriptions of the latter type)

06 DOC: >This has been a,< (0.3) another marked change in  
07 the last twenty four hours. .hhh And we ↑talked last  
08 wee:k hhI said I don't think it's months, hhhI said  
09 weeks or days then, .hh I think we've now changed  
10 from weeks to days.  
11 DAU: To days.  
12 (0.5)  
13 DOC: Just because of this not walking not ↓talking (.)  
14 not eating not drinking. .h This looks like the  
15 last days probably.  
16 DAU: Yea:h.  
17 DOC: We have (0.4) ↑lear:ned that we have no idea [to ]  
18 DAU: [yeh]  
19 DOC: predict how many. .hh But I would expect him to  
20 (1.0) talk much less.

The request at line 3 displays a high entitlement to prognostic information. It is a direct interrogative and the daughter does not account for wanting this information. However the request also displays that the daughter has some awareness of the uncertainty of the situation. By asking 'what do you think', the question is framed as a request for the doctor's opinion, rather than for an objective statement of fact. Therefore whilst the question format suggests that the doctor has a higher epistemic status than the relative (Heritage, 2012), the relative displays her awareness that the doctor cannot answer with certainty. Such displays of awareness of the prognostic uncertainty were seen throughout the collection, with others using more explicit references to the uncertainty (e.g. in 01\_02 the daughter of a patient stated "obviously time scales we know are impossible to predict"). In Extract 5.4, the daughter's reference to 'now' in her time estimate request suggests an awareness that a prognosis is changeable, and 'of the days' also displays her understanding that it is likely to be short. The doctor treats this as a direct request and goes on to answer with a time estimate of days (lines 9-10 and 14-15), therefore aligning with the relative's display of entitlement to this information.

Whilst the doctor provides a prognostic estimate, the uncertainty oriented to in the request is reflected in the doctor's response in three ways:

1. The use of qualifying language
2. Accounting for the estimate
3. Explicit statements of uncertainty

#### *1. Qualifying language*

The daughter's uncertain language in her time estimate request is also seen in the language of the doctor's response. For instance, at the beginning of her prognostic estimate on line 9, the doctor states 'I think' (see also Extract 5.1, lines 10, 12, 21, 24, and Extract 5.2, lines 14-15). In this context 'I

think' is being used tentatively, expressing uncertainty and also softening her assertion (Aijmer, 1997). All prognostic estimates in the corpus were preceded by qualifying language. Pre-positioned epistemic stance markers are suggested to help recipients to align themselves to what is coming (Kärkkäinen, 2003). In this case, the qualifying language indicates to the daughter in advance, that the doctor's prognostic estimate should be understood as a general idea, not a precise forecast. Following the estimate, the clinician uses the qualifier 'probably' (line 15), further downgrading the certainty of the prognostic estimate.

## *2. Accounting for the estimate*

The doctor accounts for her estimate prior to answering in lines 6-7 and then following the estimate in lines 13-14, by describing the recent changes in the patient's functioning. Accounts forecast the upcoming short prognosis and provide evidence for the doctor's claim. When a diagnosis (or in this case prognosis) is uncertain, doctors have been shown to be more likely to provide explicit evidence for their claims. In such cases the doctor cannot rely solely on their authority or expertise because this has been weakened by the uncertainty, and therefore they must provide evidence of how they reached their diagnosis (Peräkylä, 1998, 2006). In the examples in this collection, the evidence presented was based on changes that were accessible to both the HCP and relative. In Extract 5.4, these changes in walking, talking, eating and drinking had already been established by both the doctor and daughter earlier in the conversation. The relative's epistemic access is therefore increased (Heritage, 2012) and the prognostic estimate is presented as somewhat collaborative. This collaboration is seen more explicitly in Extract 5.10 (section 5.3) as, following a prognostic estimate, the clinical nurse specialist (CNS) states 'and it's actually hearing it from some of the members of your family' and the daughters then give further insights into the changes they have observed.

## *3. Explicit statements of uncertainty*

In lines 17-19, the doctor makes an explicit statement of the difficulty of predicting time to death (also see Extract 5.3, lines 42-47). Whilst suggesting they had 'no idea' could potentially undermine the doctor's authority, it is framed as being based upon the medical team as a whole ('we', line 17) and the result of experience (something that had been 'learned') rather than a lack of expertise (lines 17-19). It implies that a less experienced clinician may attempt to give a more specific answer, but that she is experienced enough to know that this cannot be accurately predicted. Such statements occurred regularly throughout the corpus and often included self-deprecating statements which suggested that HCPs are bad at predicting prognosis (see Extract 5.7 line 204 and Extract 5.8 line 11). Self-deprecation (linked with face-saving and relational rapport; Walkinshaw, Mitchell, & Subhan,



2019) further emphasises the uncertainty and counters any potential suggestions from relatives that the HCP should be able to give a more specific answer. It also protects against future complaints from the relatives if the estimate turns out to be incorrect.

Extract 5.5 is another example of this same type of time estimate request design and HCP response. This extract took place seven minutes into a conversation between doctor (DOC) and the husband (HUS) and daughter (DAU) of a patient. The conversation was arranged to discuss that the patient would now be staying at the hospice to die rather than being discharged to a nursing home. Immediately before the extract, they had been discussing reducing her medications because she was no longer alert enough to swallow them.

**Extract 5.5 DOC: HCP05 (Consultant), HUS: R11 (Husband of patient),  
DAU: R12 (Daughter of patient), 07:13-08:29**

01 DOC: If she becomes so sleepy as she [is now] she will eat  
02 DAU: [mmhm ]  
03 DOC: less,  
04 DAU: Mmhm=  
05 DOC: =drink less and then [we don't need] the:  
06 DAU: [so she'd m ]  
07 DAU: Mmhm  
08 DOC: blood sugar control [medicine medicines] ↑anymore  
09 DAU: [Mmhm mmhm ]  
10 DOC: .h So we just stop those. .hh  
11 HUS: As far as you can give it (.) what is your prognosis  
12 then: as f- er:m erw h:ow now you can see her  
13 condition [wor- ]  
14 DOC: [°Yeh°] .hhh (0.3) I'll try and answer it  
15 as well as I can.  
16 HUS: [m I know  
17 DOC: .h I can't give you anyth- any precise: time.  
18 (0.2)  
19 DAU: Mhmm  
20 (0.2)  
21 DOC: Er:m °e° (.) the way I would a↑ssess it is, (.)  
22 th- (0.2) how quickly has she ↑changed, (0.6) And  
23 she changed over (0.2) short weeks, .h (0.5) had  
24 she become (0.4) more sleepy, (0.3) so I would  
25 expect .hh (0.5) the timing to be in weeks, (0.5)  
26 [rather than] ↑months  
27 HUS: [In week ]  
28 DAU: °Y:eh°  
29 (0.9)  
30 DOC: [But]  
31 HUS: [Mmm]  
32 (0.3)  
33 DOC: probably not (.) days.  
34 (0.2)  
35 DOC: So- I would [be s]urprised if it was as sh- as short  
36 HUS: [m↓mm]

37 DOC: as days.

*30 lines omitted where HUS asks it will be peaceful and DOC explains what to expect to happen to the patient*

67 DOC: Then I would expect her to stop ↑waking up at one  
68 point,  
69 DAU: Mhm  
70 DOC: And how long that is (0.5) it's (0.9) I- I've been  
71 surprised so many times that I've just learnt to say  
72 we don't really know.

Like in Extract 5.4, the formulation of the time estimate request (lines 11-12) is direct and in fact more explicit as the husband refers to 'prognosis', displaying that he is ready to hear a direct answer. Uncertainty is also built in to the question (it is qualified with 'as far as you can give it') and the use of 'your' prognosis suggests a request for an opinion. The doctor begins her response with two statements of the uncertainty of prognosis, which are acknowledged by the relatives (lines 14-19). In the collection, when HCPs led with such explicit statements of uncertainty, they often signalled that they would answer the question despite this uncertainty, seen in lines 14-15 ('I'll try and answer it as well as I can'). This allowed HCPs to answer promptly and show the relative that they have been heard and are entitled to the information, whilst still downgrading their own access to the information. As in Extract 5.4, the doctor uses qualifiers such as 'I would expect' (lines 24-25) and 'probably not' (line 33) but gives an answer of 'weeks' (line 25). She accounts for this with a description of the changes in alertness (lines 21-24), which had been discussed earlier in the conversation. The doctor makes a further explicit statement about the uncertainty following the estimate in lines 70-72, once again highlighting that her experience means that she knows that it is unpredictable.

### **5.2.2 Declarative time estimate request formats and responses**

In the above extracts, time estimate requests took the form of interrogatives (i.e. they were formatted as questions). This was the most common form, but there were four cases in which declarative forms were used (i.e. they were formatted as statements). In these cases, the relatives made statements about not knowing, or wishing they could know or have some control over how long it would be until the patient died. Declarative statements were commonly used by patients in Pino and Parry's (2018) study of hospice consultations. Doctors in that study treated such statements as requests for life expectancy estimates. The same is seen in the four cases in this corpus. Extract 5.6 is an example of this declarative format being treated as a time estimate request. Prior to this extract, the daughter of the patient (DAU) had explained that because her mother had deteriorated so quickly, her daughter (pseudonym Ellen) had not arrived home from abroad yet. She explained that she was now due to arrive the following day.

**Extract 5.6 DOC: HCP05 (Consultant), DAU: R54 (Daughter of patient),  
05:47-06:42**

01 DAU: So she's (.) she'll be here tomorrow, .hhh  
 02 (0.5) ~↑↑but I'm just really hoping that she'll~  
 03 (0.3) ~°↑↑be able to ↑↑see° °°her°°~  
 04 (0.7)  
 05 DOC: tch  
 06 (0.5)  
 07 DAU: .hhh ~↑And I told hhher [last ] night that Ellen's  
 08 DOC: [↑°yeh°]  
 09 DAU: ↑coming,~  
 10 (0.7)  
 11 DAU: ~↑↑and she had °↑↑just tears° °°coming to her°°~  
 12 (0.8)  
 13 DAU: .hh hhh >.HHH °°So I just that's ↑↑~my one wish  
 14 that~ she just holds on until then°°  
 15 (0.6)  
 16 DAU: °°but°° (0.3) °°obviously we don't°° (2.0)  
 17 DOC: °°You know what, (.) I think your mother° ↓knows  
 18 (0.3) from what you what you what you've just told  
 19 me.  
 20 (1.7)  
 21 DOC: °°There's nothing I can do°° (.) nothing I can do to  
 22 make it longer or shorter I wouldn't  
 23 [of course do anything to make it shorter]  
 24 DAU: [~Anything yeh hh of course~ ]  
 25 DOC: .hhh  
 26 (1.3)  
 27 DOC: It's (0.7) tch (0.5) it's (0.5) i- no way I can  
 28 predict it [from the] way she's ↑looking at the  
 29 DAU: [okay, ]  
 30 DOC: moment, (1.6) time could be short could °just be  
 31 hours. Because of the (0.5) pauses in her  
 32 breathing, (.) [that's us]ually a sign that time is°  
 33 DAU: [°°Okay°° ]  
 34 DOC: °°getting very short.°°  
 35 DAU: =°°Really,°° (0.3) °°okay.°° hh

Here, over lines 1-16 the daughter tearfully explains why she hopes that her mother will live until the following day. Throughout, she displays her awareness of the uncertainty and lack of control over how much longer her mother is likely to live, as well as the likely shortness, by referring to 'hoping' and 'wishing' (lines 2 and 13) that she 'holds on until then' (line 14). At line 16 she begins 'obviously we don't' before cutting off. It could be speculated that she was going to say 'we don't know', or potentially that 'we don't have control over it'. Using declarative statements, she has performed the same actions as the previous extracts; she has displayed her awareness of the uncertainty and likely shortness of the prognosis as well as her desire to know the likely time until the patient will die. Declarative requests display less entitlement than interrogatives (Curl & Drew, 2008) and so this same action is done over a more elaborated sequence of turns and with more of an account for wanting to know.

When the doctor responds, she mirrors the daughter's quiet speech. Before responding to the time estimate request, she first responds to the daughter's wish for her mother to live longer. She does this by suggesting that her mother is aware that the granddaughter is coming and stressing that she cannot do anything to control how long the patient will live (lines 17-23). She then goes on to respond to the time estimate request in the same ways as were seen in the earlier interrogative-formatted requests. The doctor highlights the uncertainty through an explicit statement (lines 27-28) and qualifiers (e.g. 'could', line 30); gives a time estimate ('hours', line 31); and accounts for this estimate by referring to physical changes accessible to the relative (line 31-34). This demonstrates that despite its declarative format, the doctor understood the daughter's talk as a performing the same actions as those time estimate requests in an interrogative format, and responded accordingly.

### **5.2.3 *References to time in prognostic estimates***

In the extracts presented in the previous sections, it is notable that despite time estimates being direct, neither HCPs nor relatives refer explicitly to death or dying. In fact, across the 23 prognostic conversations, only one relative used the word 'death' and none used 'die' or 'dying'. Instead they all referenced time in some way. However, this did not cause any interactional difficulty and references to time were treated by HCPs as referring to time to death. For example in Extract 5.4, the relative asks about 'the days' (line 3), and the doctor uses the same type of language in her response, referring to 'days', 'weeks' and 'months' (lines 4, 8, 9, 10, 15). The context of when and where the conversation is taking place (within a hospice when the patient is no longer awake) as well as the interactional context (following talk about deterioration), has provided enough mutual understanding for there to be no need to explicitly name death. There were just two conversations in which HCPs used the terms death or dying within their prognostic statements; one is shown in Extract 5.11, and one is examined in more detail in Chapter 7, alongside examples of references to death outside of prognostic talk.

Across the corpus, HCPs provided time estimates in terms of 'hours', 'days' or 'weeks'. Raymond and White (2017) describe such time references as 'absolute' as they are shared concepts that anyone has access to (as opposed to event-related e.g. 'on my birthday'). They specify that 'absolute counted' references are those that are unitised and calculate the distance between now and the event being discussed (e.g. in an hour, in two days). The references in the data to 'hours', 'days' or 'weeks' do this but are not as specific as those which Raymond and White refer to, as they do not specify the number of hours, days or weeks. Instead they resemble the categories used in some prognostic tools such as the PiPS-A and PiPS-B (Gwilliam et al., 2011). Therefore these types of references will hereafter be referred to as 'absolute categorical' prognostic estimates. In contrast, the remainder of this section

describes HCPs' uses of less specific estimates, which are referred to as 'descriptive' prognostic estimates.

An absolute categorical estimate was given by HCPs in response to 16/20 time estimate requests in the collection, with little delay or checking what the relative wanted to know. There were however, four discussions in which the HCP did not give one of these clear time-based estimates (or confirmation of a candidate time estimate), instead using descriptive prognostic estimates. In these discussions, the request from the relative did not project a time-based response as strongly as in the other conversations. Extract 5.7 is an example of such a case. This extract continues from line 27 of Extract 5.3.

**Extract 5.7** DOC: HCP02 (Consultant), DAU: R31 (Daughter of patient),  
01:17-05:11

27 DAU: We know the ki- bout the kidneys (.) but then it's  
28 like (0.4) then it's like w:l (0.7) I guess there  
29 isn't a time? Like how long [does it] (0.5) take  
30 DOC: [↑yeh ]  
31 DAU: for the heart to fail, how long does it take .h for  
32 the kidneys to fail, so it's a bit (0.3)  
33 DOC: Mmm  
34 DAU: it ↑can be a little bit I think confu:sing, a bit  
35 (1.1) y:[eah.]  
36 DOC: [Yeh ]  
37 (0.9)  
38 DOC: And [the these] conditions (.)  
39 DAU: [an ↑hmm ]  
40 DAU: Mmm?  
41 DOC: that that are kind've all adding up together, (0.3)  
42 .hhh u[m:: ] to be honest we get a bit (1.1)  
43 DAU: [m↑hm]  
44 DOC: confused is probably not the ri(h)ght [word,]  
45 DAU: [Yeah ]  
46 (0.3)  
47 DOC: But we are also: uncertain  
48 DAU: Yeh  
49 DOC: about how: and when (0.3)  
50 DAU: Mmm [mmm  
51 DOC: [things will change. .hh um (1.5) We know about  
52 (0.7) y'know the statistics from thousands of  
53 people,  
54 DAU: M[hmm?  
55 DOC: [but that doesn't help when you're looking after  
56 one individual person.  
57 DAU: Yeah yeah  
58 DOC: And he will follow a different (0.2) well his own  
59 course

*116 lines omitted where discuss reasons for fluctuations and what is happening to patient physically*

176 DOC: .hhh Um it- (0.5) I thi:nk (0.7) we feel very  
 177 strongly: (0.5) that he's in the right place.  
 178 (0.2)  
 179 DAU: Yeh.  
 180 (0.4)  
 181 DOC: Um:: (0.7) and (2.0) I am worried (0.7) [that] (0.4)  
 182 DAU: [°mm°]  
 183 DOC: perhaps .hhhhh (0.8) in the last couple of days  
 184 things have changed  
 185 (0.7)  
 186 DAU: Mhm[m  
 187 DOC: [and he might not (0.7) pick up.  
 188 (1.1)  
 189 DOC: uhh from this point, .hhh  
 190 DAU: I mean he had quite a dip. That was when they  
 191 called me at the four A M,  
 192 DOC: Right,  
 193 DAU: That was like, (0.2)  
 194 DOC: Mmm  
 195 (0.2)  
 196 DAU: I mean that's the worse I've seen him.  
 197 DOC: Okay.  
 198 (0.7)  
 199 DAU: But the:n it was like by that (.) evening, (0.6)  
 200 a ↑changed ↑man again [it was] li:ke (0.4)  
 201 DOC: [Yeh ]  
 202 DOC: So what I'd [say ] now might com- (0.3) be  
 203 DAU: [↑yeah]  
 204 DOC: completely rubbish, h(h)em,  
 205 DAU: ↑huh ↑hehe↑he  
 206 DOC: He ↑might [prove me] wrong that ed  
 207 DAU: [↑yeah, ]  
 208 DAU: mmm  
 209 DOC: y'↓know an and I- (0.2) #a- in my line of work  
 210 that's a good thing really  
 211 DAU: Y:eah  
 212 DOC: .hh Em but I am (0.2) I am concerned.

The daughter's time estimate request is formatted in a way that does not project an absolute categorical estimate as strongly as in previous extracts. Whilst her request is formatted as a question, it is constructed in a less direct way than Extract 5.4 and Extract 5.5, and over several turns. The daughter describes her confusion about the patient's fluctuation and then asks how long it takes for the heart and kidneys to fail (line 29-32). The request is more 'unknowing' than the previous extracts as the daughter states her general confusion and in the lead up discusses improvements in her father's condition. This is also seen later in the extract when she describes another occasion where she was told her father was likely to die but then suddenly improved (lines 190-200). There is therefore a steeper epistemic gradient requiring an extended sequence in response (Heritage, 2012).

Her use of ‘the’ heart and ‘the’ kidneys (lines 31-32) also depersonalises her questions and so does not directly ask for her father’s prognosis. This depersonalisation is reflected in the doctor’s statement in lines 52-53 about looking at ‘statistics from thousands of people’. Following an omitted sequence discussing how people usually deteriorate, the doctor comes back to the individual patient and states that he is ‘worried’ (line 181), forecasting the negative valence of his upcoming statement, that ‘he might not pick up’ (line 187). There is some resistance from the daughter as she describes a previous occasion when the patient had got better. The doctor once again highlights the uncertainty but then reiterates that he is ‘concerned’ (line 212), whilst not giving an absolute categorical estimate of how long he thinks it may be until the patient dies.

Whilst the initial question ‘how long does it take for the heart to fail’, could have been interpreted as a question specifically about the patient’s own prognosis, the relative does not pursue a more specific time estimate at any point in the extract. There is a silence at line 185 after the doctor has stated that things have changed and again at 188 after he has said that ‘he might not pick up’. These were opportunities where the daughter could have taken a turn to ask about timing, but instead her focus was on understanding the fluctuations in her father’s condition. Rather than pushing to give an absolute categorical estimate when it has not been directly requested, the doctor emphasises the general downward trajectory that he would expect the patient to take. All four conversations in which an absolute categorical time estimate was not given followed this same pattern of less explicit references to time in the request (e.g. in recording no. 01\_09 wife asked the CNS ‘how do you see the progression with him now?’) and no pursuit of a more specific prognosis by the relative. HCPs provided descriptive prognostic estimates only, matching the specificity of their response to the specificity of the relative’s time estimate request.

#### ***5.2.4 When time estimates are not accounted for***

There was some variation in whether and how prognostic estimates were justified by HCPs. In 17/20 cases, estimates were accounted for by referring to changes in the patient’s functioning. In the three cases where the HCP did not account for their estimate, the relative had put forward a candidate time estimate within their request, which had been provided by a HCP. This is demonstrated in Extract 5.8, a conversation between a doctor (DOC) and the wife (WIF) and daughter (DAU) of a patient. This extract came around four minutes into the conversation following a discussion about medications and the patient’s deterioration.

**Extract 5.8 DOC: HCP07 (Registrar), WIF: R17 (Wife of patient) DAU:  
R18 (Daughter of patient), 03:51-04:26**

01 WIF: You know an- a:nd so it's been downhill.=  
 02 DOC: =°Mmm°  
 03 (0.2)  
 04 WIF: ↑↑>I have to ask< the most horrible ques[tion,]  
 05 DOC: [↑e Th]at's  
 06 fine.=  
 07 WIF: =How long (0.3) time do you think he could go on  
 08 like this before, (0.4) death.  
 09 DOC: t.h[hhh ] .hh ↑I would say at the moment  
 10 WIF: [comes.]  
 11 DOC: so doctors and nurses are very bad about predicting  
 12 progno:sis, you know it's really difficult [to do  
 13 DAU: [I mean we  
 14 were already told [yesterday that it was] days  
 15 DOC: [But em °yeh° ]  
 16 DAU: [not ] ↑hours >so that's a good< [point is it]  
 17 DOC: [s'yeh] [yea:h. ]  
 18 DAU: days or [one day ]  
 19 DOC: [I would say] days at the ↓mo[ment] and he,  
 20 DAU: [Yeh ]  
 21 WIF: [(Okay)]  
 22 DOC: [.hhh ] I mean equally, y'know (0.2) one wouldn't  
 23 be sur↑prised if Simon had a sudden(.) deteriora[tion  
 24 DAU: [mm  
 25 DOC: .hh an[:d] er::m you know and (.) [it we]re to↑day  
 26 DAU: [Mm]  
 27 WIF: [yeh ]  
 28 DOC: .h[hh ] But equally at the moment I'd be thinking of  
 29 DAU: [Yeh]  
 30 DOC: say we'd say days rather than weeks or something

In line 7 the wife produces the time estimate request. The doctor then begins to answer by highlighting the uncertainty, but is interrupted by the daughter in line 13 who reformulates the request, pointing out that another HCP had already given them an estimate of 'days not hours'. This invites the doctor to either affiliate with or challenge the estimate, rather than to formulate her own independent estimate. Disagreement is generally a dispreferred response which requires an account, whereas agreement does not (Pomerantz, 1984). Therefore, in agreeing with candidate time estimates, HCPs did not account for the estimate. Indeed in this extract the doctor is not personally accountable for this estimate and so does not need to provide evidence for it. In Extract 5.8, the doctor does however suggest that the estimate could turn out to be wrong without actually challenging her colleague. She does this by highlighting the uncertainty of the situation in lines 22-25. Here she uses 'one' rather than 'I' when suggesting that it could be hours not days, then in lines 28 and 30 repairs from 'I'd' to 'we'd' when affiliating again with the previous estimate. This all serves to distance herself from disagreement with the other HCP and present that estimate of days as a team viewpoint. In all



three cases in which a candidate time estimate from a HCP was put forward, the response from the HCP was to agree with this estimate whilst highlighting the uncertainty.

### 5.3 Healthcare professionals' unelicited prognostic statements

In the majority of cases (17/23), HCPs' first prognostic statements were elicited by time estimate requests from relatives. There were however, six cases in which the HCP made an initial prognostic statement without a prior time estimate request. This section describes how these statements were formulated and responded to. Extract 5.1 was an example of this, with the prognostic statement being made by the doctor at lines 21-22, and further examples, Extract 5.9 and Extract 5.10 are seen below. Prior to Extract 5.9, the doctor (DOC) explained to the friend of the patient (FRI) that the patient was now sleeping more so unable to eat and drink.

**Extract 5.9** DOC: HCP09 (Registrar), FRI: R13 (Friend of patient),  
07:18-07:50

01 DOC: And I guess a:ll of this means  
02 FRI: ((coughs))  
03 (0.6)  
04 DOC: that we're anticipating that time might be quite  
05 short now.  
06 (3.5)  
07 FRI: Very short,  
08 DOC: Mmm  
09 (1.0)  
10 DOC: °Yeh°  
11 (2.2)  
12 FRI: Kay.  
13 (1.2)  
14 DOC: None of us know exactly,  
15 (4.8)  
16 ( ) hhh  
17 (0.4)  
18 DOC: but I think we need to be prepared that it i-it  
19 °could be as short as days.°  
20 (0.6)  
21 FRI: °°Days°°  
22 (0.4)  
23 DOC: °°Could be.°°  
24 (2.4)  
25 FRI: ↑Okay.

The six cases of prognostic statements without prior time estimate requests all included the same sort of qualifiers that were seen in response to time estimate requests (see 'think' and 'probably' in Extract 5.1, line 21, 'might' in Extract 5.9, line 4, and 'feel' in Extract 5.10, line 5). In these discussions, the HCPs' first statements were descriptive prognostic estimates, describing shortness of prognosis

generally. Much like the majority of time estimate requests described in section 5.2, these statements did not explicitly mention death or dying. Instead, they referred to time being short or having limited time (see Extract 5.1, lines 21-22 and Extract 5.9 lines 4-5) and in Extract 5.10 that ‘it does feel very imminent’ (lines 1-2). Relatives oriented to this as referring to death, demonstrated in Extract 5.1 (line 23), Extract 5.9 (line 7), and Extract 5.10 (line 3), in which the next turn from the relative is a time estimate request where they request a more specific estimate from the HCP. As described in section 5.2, responses to these time estimate requests gave an absolute categorical estimate with qualifying language emphasising the uncertainty (Extract 5.1, line 24; Extract 5.9, line 19; Extract 5.10, line 5).

Such unelicited prognostic statements were not limited to conversations in which there were limited signs of prognostic awareness from families. For instance one such statement was seen in a conversation which occurred following the hospice calling the wife of a patient and advising she come in immediately because of her husband’s rapid deterioration (recording no. 05\_57). In another example, Extract 5.10 below, the daughters had shown numerous signs of prognostic awareness throughout the conversation. Prior to the extract, the CNS and daughters had discussed deciding who wanted to be there when the person died (although as with the prognostic talk seen throughout the chapter, they did not use the word ‘die’).

**Extract 5.10 CNS: HCP01 (Clinical Nurse Specialist), DA1: R04 (Daughter of patient), DA2: R05 (Daughter of patient), 11:44-11:52**

01 CNS: .hh I mean it d- it does feel it does feel very  
02 imminent. It (0.3) e:m tch [but it’s ]  
03 DA2: [an an as in] today?  
04 Or:  
05 CNS: It feels like days, (0.2) It does feel like days.  
06 DA2: Mmm  
07 CNS: Because her colour’s completely ↓changed  
08 DA1: M[mmm=  
09 DA2: [Mmm=  
10 CNS: =and it’s actually hearing it from: some of the  
11 members of your [family it ] [y’↓know]  
12 DA1: [Changed just] this [morning] even  
13 DA2: [Mmm ]  
14 DA1: just (0.2) being away for [an hour and a half] I’m  
15 CNS: [Exactly. ]  
16 DA1: quite sur[prised. mm]  
17 CNS: [Yeah and ] the: (.) the rapidness of her  
18 breathing.

At lines 1-2, the CNS states that ‘it does feel very imminent’. Her use of ‘it’ to reference the patient’s death, despite the family not having made a time estimate request, suggests that this was already ‘on the table’ at this point in the conversation (and indeed they had discussed ‘progression’, ‘end-of-life care’, and staying overnight with the patient). At line 3, in overlap with the CNS, one of the daughters

makes a time estimate request. This results in the CNS providing an absolute categorical time estimate of days (line 5), an account for this estimate (lines 7-11 and 17-18), and following this extract, an explicit statement of uncertainty.

Time estimate requests from relatives followed the unelicited HCP descriptive prognostic statements in Extract 5.1, Extract 5.9 and Extract 5.10, resulting in HCPs upgrading to absolute categorical estimates. In the remaining three cases, the relatives did not respond with a time estimate request or even a news receipt. The HCPs then gave another prognostic statement, this time upgrading to an absolute categorical time estimate. Prior to Extract 5.11, the doctor (DOC), partner (PAR; pseudonym Michael) and mother (MOT) of a patient had been discussing her deterioration and the doctor had suggested using sedative medications with little uptake from the family.

**Extract 5.11** DOC: HCP02 (Consultant), PAR: R06 (Partner of patient),  
MOT: R07 (Mother of patient), 05:04-06:01

01 DOC: I think (1.3) [as] you alluded to (0.4) [Michael]  
02 PAR: [mm] [mmm ]  
03 DOC: her time is really short.  
04 PAR: Mm (0.2) yeh  
05 DOC: I I (0.3) when I saw he:r  
06 MOT: Yeah y'said=  
07 DOC: =even on wedn[esday I'd ]  
08 MOT: [Mmm that's] ri::ght  
09 (0.4)  
10 PAR: Mm  
11 DOC: I would not've been surprised (0.8) if today she  
12 was no longer with us,  
13 PAR: Yeh yeh [yeh]  
14 MOT: [Mm ] [mm ]  
15 DOC: [Em:] but I feel (1.4) °w::°-with as  
16 much certainty as I ca:n cause (0.3) I've been  
17 wrong so many [times] (.) I [do] feel over the  
18 MOT: [mmm ] [m ]  
19 DOC: weekend (0.6)  
20 PAR: Mm  
21 DOC: it is likely (0.8) that [that she] will ↑die  
22 MOT: [Right ]  
23 (0.4)  
24 MOT: ↑Right  
25 (0.5)  
26 PAR: >I mean I< °ehereh° [I was r]acing to get here  
27 MOT: [Mmm ]  
28 PAR: today p-to get her [last] breath  
29 MOT: [Mmm ]  
30 DOC: Kay  
31 (0.2)  
32 MOT: [Mmm ]  
33 PAR: [Because] I knew that (0.5) there not might be too  
34 many ↑more of them.  
35 (0.3)

36 MOT: [Mmm]  
 37 DOC: [Yes]  
 38 PAR: And I'm not counting the days I'm counting the  
 39 breaths that's how it fee:ls.  
 40 DOC: Yes  
 41 MOT: Mmm  
 42 PAR: .hh But from my from my point of vie::w u- u- from  
 43 a ↑spiritual point of view (0.2)  
 44 DOC: Mm  
 45 PAR: e:m (0.4) being a practice Buddha- a- practising  
 46 Buddhist  
 47 DOC: Yes  
 48 (0.4)  
 49 PAR: e::m:: .h (0.5) what we feel is that this is the  
 50 most important time of the li:fe  
 51 DOC: >Okay<  
 52 (0.3)  
 53 MOT: [Mm ]  
 54 PAR: [A:nd] .h (0.2) to have you:r (0.3) um: (. )  
 55 consciousness

Here the initial prognostic statement on lines 1-3 references the partner's previous speech, which implies that this is not new information. This is reflected in the relatives' agreeing responses at lines 4 and 6, which display their existing knowledge of the short prognosis. The doctor then ups his prognostic statement in lines 7-12, again receiving a display of agreement from the partner (line 13). In lines 15-19 the doctor begins a further prognostic statement, pauses and then explicitly states the uncertainty, and finally in line 21 delivers his prognostic estimate. This statement is formatted as an announcement, as unlike the statement in lines 1-3 which suggested shared knowledge, 'I do feel' suggests the doctor is providing knowledge that the relatives do not have access to. The mother's response (line 24) gives a news receipt which acknowledges the statement as news but does not encourage elaboration (Maynard, 2003). In lines 26-39 however, the partner rejects the newsworthiness of the statement by displaying his own pre-existing knowledge of the likely short prognosis (Maynard, 2003). He talks with more certainty and urgency than the doctor had, describing knowing (in contrast to the doctor's feeling) and 'racing' to see the patient. He also refers to counting breaths rather than days, which suggests a potentially shorter prognosis than the doctor had provided. This all displays to the doctor that his prognostic statement is not news to him and suggests that prognostication is not a topic for further discussion. This is further evidenced by his next turn at line 42 where he begins to change the topic back to the doctor's previous suggestion of using sedative medications.

In all six cases of unelicited prognostic statements from HCPs, the HCP began with a descriptive statement of the shortness of time, but went on to upgrade to an absolute categorical prognostic

estimate. This suggests that unelicited prognostic statements are used to introduce the topic prognosis and to forecast the upcoming short prognosis. These statements are therefore more cautious than those elicited by time estimate requests. In the first three cases, the descriptive prognostic statement was treated as newsworthy by the relatives as they requested more specific information in the form of time estimate requests. In contrast, in Extract 5.11 above and a further case not presented here (recording no. 05\_57), the relatives rejected the newsworthiness of the statement by describing the actions they were already taking due to their knowledge of the short prognosis. In a final case, the unelicited prognostic statement was strongly challenged by the relatives. This was the only case in the corpus in which this happened, and so will be presented in detail in Chapter 7.

## **5.4 Discussion**

This chapter has explored terminal-phase prognostication sequences, covering how prognostic talk is initiated and how prognostic information is requested and provided. The first section showed how talk of deterioration, especially alertness, allowed an unproblematic, stepwise topic transition (Jefferson, 1984; Sacks, 1992) into prognostic talk. Sleepiness or going to sleep are terms commonly used as euphemisms for both unconsciousness and death, and can be used to link these two topics. Sleepiness was also used to link medication (which can cause drowsiness) and the impact of disease leading to unconsciousness and eventually death. The analysis showed that in the majority of cases prognostication arose in this stepwise fashion, but that in some cases there was more of a bounded topic shift to prognostic talk via doctors' topic initial elicitors (Button & Casey, 1984). In these cases, the doctors left the topic open to relatives. It is not possible to tell from their statements whether doctors intended these to lead to prognostic talk, and so the relatives did work to topicalise this. Whether through stepwise topic transition or topic initial elicitors, the cases in this collection showed that prognostic talk could be initiated by the relatives, the HCP, or more often mutually.

The next section of analysis described the formulation of time estimate requests and how HCPs responded to these. Neither relatives nor HCPs tended to refer directly to death or dying, but in the interactional and institutional context of the conversation, references to time were understood by both parties to be referencing time to death. Both relatives and HCPs oriented to the relatives having a strong entitlement to this prognostic knowledge. The majority of time estimate requests were formatted as interrogatives, a request format which displays stronger entitlement than declarative statements (Curl & Drew, 2008). Additionally, relatives did not account for requesting prognostic information and HCPs answered without checking their readiness to hear the prognosis. This

highlights a key difference between this corpus and the conversations recorded as part of Pino and Parry's (2018) study of hospice consultations with patients. In their study the authors found that before requesting or providing prognostic estimates, doctors, patients and companions worked to 'prepare the conversational environment' to address the patient's existing knowledge and their readiness to hear their prognosis. Patients in that study were also more cautious in their life expectancy estimate requests, with the majority using declarative statements not interrogatives (Pino & Parry, 2018). These differences may reflect the increased urgency to be informed of prognosis when patients are at the very end of life.

Despite the relatively direct time estimate requests and the willingness of HCPs to provide prognostic estimates, these estimates were uncertain. The analysis in this chapter showed that relatives orient to this uncertainty within their time estimate requests and so give HCPs permission to be uncertain in their responses. This demonstrates the collaborative nature of these conversations. The relatives format their requests in ways that are sensitive to the difficult job the HCP has to do (also seen in Pino & Parry, 2018) and minimise apparent burden of the request by projecting a response that is an opinion rather than a fact (Clayman & Heritage, 2014). The analysis demonstrated how HCPs emphasise this uncertainty whilst still maintaining their high epistemic status. One way in which they did this was by providing evidence for their prognostic estimate. Uncertainty can undermine a HCP's authority, and so highlighting the evidence provides grounds for their claim to knowledge (Peräkylä, 1998, 2006). Stivers and Timmermans (2016) found similar practices in genomic test results consultations, as physicians accounted for their interpretations of uncertain test results. In the cases presented in this chapter, the evidence being cited was accessible to the relatives, therefore building a clearer, more collaborative case for their estimate.

HCPs also explicitly named the uncertainty and difficulty of predicting time to death. Rather than reducing the HCP's epistemic status, here their awareness that they cannot accurately predict prognosis was presented as the result of years of experience. HCPs displayed that they were confident enough in their expertise to state that they were uncertain and some doctors even used self-deprecating comments. Self-deprecation has been shown to build rapport and reduce the other person's responsibility for interactional trouble in sensitive discussions such as police interviews with children (Childs & Walsh, 2017). Where self-deprecation occurred in the corpus (see Extract 5.7 line 204 and Extract 5.8 line 11), it came as part of a repair (i.e. the doctor began giving a prognostic estimate, stopped to express the uncertainty, and then continued). The use of self-deprecation here put the responsibility of not being able to decisively predict prognosis on the doctor, rather than suggesting it was the relative's fault for asking an unanswerable question. This echoes Robinson's

finding that initiators of repair often use formats that imply that they, not their addressee, are responsible for the trouble source (Robinson, 2006).

It is also worth highlighting that statements of uncertainty came alongside the provision of time estimates. HCPs therefore were not telling relatives that they did not know what the prognosis was, rather they were suggesting caution towards the precision of these estimates. The analysis showed that uncertainty does not cause HCPs to avoid prognostic talk and provided examples of HCPs making unelicited prognostic statements. These were more cautious than elicited statements, using more general statements about time being short. However following these initial broader statements, HCPs went on to provide absolute categorical time estimates, whether or not this was requested by relatives. The cautiousness displayed in HCPs' unelicited prognostic statements, as well as the majority of prognostic talk being initiated by relatives, reveals a preference for relatives to request prognostic information rather than HCP providing it without a request from relatives.

This chapter has examined how HCPs and relatives initiated prognostic talk, how time estimate requests were made by relatives and responded to by HCPs, and described the more cautious prognostic statements made by HCPs when not elicited by requests from relatives. Throughout it was demonstrated that HCPs and relatives worked collaboratively to negotiate uncertainty and establish a prognostic estimate.

## Chapter 6 Closing the business-at-hand: exiting prognostic talk and transitions into closing sequences

The previous chapter described the terminal-phase prognostication sequence in which healthcare professionals (HCPs) gave either absolute categorical, or descriptive prognostic time estimates and explained the related uncertainty to relatives. This chapter begins in section 6.1 by describing how relatives and HCPs exit this prognostic talk by transitioning into talk on more certain, controllable and action-oriented topics. A deviant case is presented, in which this transition does not occur and the doctor moves straight towards closing, causing interactional trouble. More typical moves into closings are then presented, however there are some difficulties associated with recording and analysing closings in conversations at the terminal phase in a hospice which impacted the analysis. These issues are discussed in section 6.2, before moving on to discuss practices used by HCPs to transition into closing relevant environments in sections 6.3.1 and 6.3.2. Closing sections were not straightforward and often participants moved out of closing sections to introduce new topics or recycle previous topics. Section 6.3.3 presents a case in which prognostic talk was recycled by the relative during closing and how the doctor responded to this and moved back into closing. Finally, section 6.3.4 discusses how relatives made transitions into closing relevant environments.

### 6.1 Exiting prognostic talk

Once a prognostic time estimate was provided and the uncertainty explained, HCPs and relatives moved the conversation on in various ways. The most common practice within the corpus was for HCPs to transition into talk about how the patient's comfort would be ensured. Extract 6.1 is an example of this practice (the extract is four lines on from Extract 5.1 in Chapter 5, following the doctor asking if the estimate was what the friend expected).

**Extract 6.1** DOC: HCP05 (Consultant), FRI: R42 (Friend of patient),  
05:13-05:44

01 FRI: ~Yeah.~ hhh (0.3) ↑jus:t from (.) my own like (.)  
02 seeing how he is and how quickly he's going (0.4)  
03 downhill.  
04 (0.4)  
05 DOC: °That's what you see as well°  
06 (0.3)  
07 FRI: [°Yeah°]  
08 DOC: [°Yeah°] °yeh°  
09 (0.4)  
10 DOC: .hhh So we'll (.) we won't do anything (.) to  
11 prolong his life, .hh So we won't do >anything<



12 (0.3) °as° (.) we already said no blood  
13 [tests no other treatment of the] calcium, .h but  
14 FRI: [Yea:h yea:h yeah ]  
15 DOC: what we'll be really (0.2) really careful about is  
16 °that he° .hh to (0.9) avoid any (0.2) unnecessarily  
17 (0.4) u unnecessary dis↑tress and definitely avoid  
18 any pain.  
19 FRI: .hhh Yeh (.) that would be great.  
20 DOC: °Yeh°  
21 FRI: ↑Thanks

Here the friend of the patient displays acceptance of the prognosis, providing her own account of the changes she has seen in the patient (lines 1-3). The doctor affiliates with this on line 5, displaying their shared perspective on the patient's prognosis. The 'so' on line 10 is a marker of topic change (Bolden, 2009) away from prognostic talk. Prior to the extracts presented here, the doctor and friend had discussed the patient's wish for no further treatment and their priority of avoiding pain. The multiple references to 'we' when describing not prolonging life on lines 10-13 therefore not only invoke the medical team as a whole, but also the collaboration between the medical team and the friend. The doctor stresses the avoidance of pain and invokes certainty with the emphasis on the word 'definitely' (line 17) when referring to this. There is a self-initiated self-repair at line 16 where the doctor begins saying 'that he' but then changes her wording to say they will 'avoid any' 'unnecessary' distress and pain. She cannot say that he will not be in pain as it could be speculated she was beginning to. Instead, she can only comment on what is within their control, which is to do what they can to avoid distress and pain where possible. The friend displays her approval of this plan (line 19) and orients to her perspective being acknowledged by thanking the doctor at line 21. Following this extract the doctor goes into more detail about how they would treat any anxiety or pain.

Talk about maintaining comfort at the end of life is inherently linked with prognosis and so can be transitioned to from prognostic talk in an unproblematic stepwise fashion (Jefferson, 1984). It moves talk from an uncertain and uncontrollable topic, to one firmly within the doctor's expertise and where they can demonstrate what can be done. When this happens, the doctor's language changes to reflect this. In Extract 6.1, the doctor changes from the qualifying language seen in examples of prognostic talk in Chapter 5, to more certain, action-oriented language such as 'definitely' and clearly listing what will be done (lines 10-18).

A similar practice for exiting prognostic talk is seen in Extract 6.2, a conversation between the clinical nurse specialist (CNS) and the daughter of a patient (DAU). The extract begins as the CNS is explaining the uncertainty of prognosis (line 1-9). At line 10, the CNS then transitions towards the focus on future care for the patient. The CNS and daughter had already spoken at length about which medications

could be used to treat any discomfort, and this is alluded to in lines 14 and 15 as she refers to paying attention to what the patient needs. She then moves to focus instead on the daughter's role in providing 'company' (line 17) and to the patient as a person and what she would want (lines 20-23). The CNS has therefore highlighted what the medical team can do, what the family can do and also moved from the general talk on the unpredictability of death to more personalised talk about the patient.

**Extract 6.2 CNS: HCP01 (Clinical Nurse Specialist), DAU: R08  
(Daughter of patient), 10:18-10:52**

01 CNS: My mentor when I first started training em  
02 compare (0.3) uh she kept mm er telling me to  
03 compare life to death. So it's sort of when you're  
04 waiting for the baby to be due, (0.3)  
05 DAU: Mmm  
06 (0.3)  
07 CNS: And you're waiting for that date (.) [but it's (0.8)  
08 DAU: [Mm  
09 CNS: s s it's not usually that date.  
10 DAU: Mmmm  
11 CNS: And it's em (0.7) it's just working around mum.  
12 (0.2)  
13 DAU: Mmm  
14 CNS: Anything where we feel like she needs we we (0.2)  
15 [pay] attention to it but otherwise it's just [gonna]  
16 DAU: [Mmm] [mmm ]  
17 CNS: be about .hhh your company, (0.3)  
18 DAU: Mmm  
19 (0.3)  
20 CNS: If she was (0.5) awake sat here with us right now  
21 what would she be telling you to do?=  
22 DAU: Mmmm  
23 CNS: R re remind yourself of [what she'd be saying to you]  
24 DAU: [Yea:h yeh yeh yeah. ]

In most cases, moving talk towards things that can be controlled was done by talking about monitoring and treating pain and ensuring comfort, but Extract 6.3 demonstrates a different example of this. Much earlier in this conversation the daughters of the patient (DA1 and DA2) had explained how they had been called in the previous night as staff had thought it was likely their mother would die. There was then prognostic talk, during which they discussed how difficult the uncertainty could be for the family members.

**Extract 6.3 DOC: HCP07 (Registrar), DA1: R27, DA2: R28 (Daughters of patient), 19:30-20:17**

01 DA1: Em:: hh but (0.7) it's hard to kind of know how to  
 02 balance this really because obviously at some point I  
 03 need to see my chi:ld  
 04 DOC: Mmm  
 05 DA1: but I don't want to leave my mum. [So: ] you know I'm  
 06 DOC: [°N:o°]  
 07 DA1: not really sure (0.6) in that sense how to deal  
 08 with it cause I had a you know a crying daughter  
 09 this morning,  
 10 DOC: tch °Yea[h°  
 11 DA1: [who wanted me, (0.5) but I didn't want to  
 12 leave here [ be]cause I want to see [my mum.]  
 13 DOC: [Yeh] [°ye:s° ]  
 14 DA1: You know so:  
 15 DOC: .hh It's (.) it is really really [hard.]  
 16 DA1: [Yeh ]  
 17 DOC: And we will support you .hh you know kind of however  
 18 we can- .hh ↑Have you been seeing anyone from our  
 19 family support team,  
 20 DA2: No=  
 21 DA1: =No:  
 22 DOC: .h Would that be ↑helpful to you,  
 23 DA1: It [might be. yeah ]  
 24 DOC: [°Y'know and°< they're trained] counsellors,  
 25 [u:m as ↑we:ll ]  
 26 DA1: [°Okay.° .h I think that s-] I think someone mentioned  
 27 it last week (.) but I think cause of the bank  
 28 holiday and stuff  
 29 DA2: >Kind of got a bit< lost in the  
 30 [system maybe yeh ]  
 31 DOC: [>Course that's the trouble isn't< it then like]  
 32 DA1: [Yeh ]  
 33 DOC: thursday- y'know [>cause of erm< ]  
 34 DA1: [BUT yeah we had] we'd agreed to it  
 35 be[forehand] so: [yeah.]  
 36 DOC: [Yea:h. ] [Okay ] I'll see if I can get hold of  
 37 someone today. .hh And we ↑do also have a  
 38 ↑children's counsellor

At line 15, the doctor provides an upgraded assessment of the daughter's comments that 'it's hard' not knowing how long it will be until her mother dies, by stating 'it is really really hard' (Pomerantz, 1984). In non-institutional talk this affiliation could encourage elaboration, but in institutional encounters, such proposals of affiliation are associated with closing troubles-telling and moving into problem solving (Ruusuvuori, 2007). This practice is seen here as the doctor does not leave a gap for the family to take a turn, and moves talk from the uncertainty of prognosis towards what can be done by signposting the support available to them (lines 17-19). The daughters respond positively to this and then once again the doctor's talk is action-oriented as she tells them she will set this up (line 36-

37). As was seen in the previous extracts, the doctor has exited prognostic talk by taking a concern expressed by the relatives and offering something that can be done about it.

These extracts demonstrate HCPs moving from uncertainty to certainty by highlighting what can be done to help the patient and their relatives. In other cases, relatives also made moves towards certainty. Having received an uncertain prognosis, they would often ask instead about what was actually happening to the patient's body. Extract 6.4 occurs nine lines on from the prognostic talk Extract 5.8 in Chapter 5.

**Extract 6.4 DOC: HCP07 (Registrar), WIF: R17 (Wife of patient) DAU: R18 (Daughter of patient), 04:33-05:10**

01 DOC: [↑It's difficult to] be more [precise]  
 02 WIF: [because I find ] [I know ]  
 03 DOC: [than that ]  
 04 WIF: [I know ]  
 05 DAU: [Is it more] a [question not merely a question of]  
 06 WIF: [It's fine it's fine. ]  
 07 DAU: his hear[t or is that the wrong thing.]  
 08 DOC: [tch .hh ↑Well it's often the ] cancer making  
 09 the body so weak,  
 10 DAU: Yes  
 11 DOC: Y'know kind of as well [because it's often that .hh]  
 12 DAU: [That's what I thought yeh ]  
 13 DOC: and then obviously with that then th- the body  
 14 being able cope with (0.2) er:m (.) things and  
 15 then [.hh] essentially, (0.2) er::m the cancer's  
 16 DAU: [Mmm]  
 17 DOC: sort've overwhelming the body [and the] hear:t and  
 18 WIF: [yeh mm ]  
 19 DOC: [other] vital or[gans] can't cope anymore. .hh  
 20 DAU: [Mmm ] [mm ]  
 21 DOC: And then our focus now is ↑very much on keeping  
 22 Simon as comfortable as pos[sible, .hh]  
 23 WIF: [Yes yes ]  
 24 DOC: and not doing things unneces[sari]=now the nurses  
 25 DAU: [yes ]  
 26 DOC: will have to position,  
 27 DAU: Yeh  
 28 DOC: and help him, (.) to be comfortable, .hh If  
 29 necessary they will give extra injections prior  
 30 WIF: Y:eh  
 31 DOC: to move[ment and things] too.  
 32 DAU: [Y:eh yeh ]

In Extract 6.4, following the doctor's statement of uncertainty in line 1, the daughter adjusts her prognostic question to ask about what is actually happening to the patient's body (lines 5-7). This is a question well within the doctor's expertise and so moves the conversation away from the uncertainty of prognosis. The language in doctor's description of what is happening inside the body is more

equivocal than the previous talk on prognosis, but still uses terms such as ‘kind of’, ‘sort’ve’ and ‘essentially’ (lines 11-17). This, and the doctor’s pauses and ‘erm’s, demonstrate that there is still some difficulty for the doctor in responding to the daughter’s question. Whilst the physical, bodily process of dying is more objective than predicting time to death, it remains difficult to know exactly what is happening to a person’s body at this time. At line 21, the doctor therefore once again transitions into talk about comfort care, using ‘and then’ to link it with the previous talk. This allows more certainty in her language as she sets out comfort as a priority (lines 21-22) and points to actions the medical team will take to ensure this (lines 24-31).

When talking about the impact of the cancer on the body, the doctor uses depersonalised terms such as ‘the body’, ‘the heart’ (lines 9, 13, and 17). In contrast, when she talks about what they can do to keep the patient comfortable she re-personalises her language, using the patient’s name (line 22). This was often seen throughout the collection and the personalised talk on comfort also contrasts with depersonalised references to time in prognostic talk seen in Chapter 5 (e.g. in Extract 5.4 the doctor refers to ‘the last days’ not ‘his last days’). Depersonalisation to separate the person and their body when discussing potentially sensitive topics has been found in various medical settings including discussing sexuality in gynaecological consultations (Weijts, Houtkoop, & Mullen, 1993), and physiotherapists using depersonalisation for negative assessments and personalised language for positive assessments (Parry, 2005). In this example, the doctor deals with a distressing situation for the relative by portraying a situation in which the body is dying, but the person is comfortable.

This section has demonstrated how HCPs change their language from uncertain, depersonalised talk when discussing prognosis, to more certain, personalised language when transitioning into talk on future actions. Moving to talk about what can be done for the family and patient, particularly focusing on comfort care, allows this shift and orients towards action and certainty.

### **6.1.1 *Deviant case: exiting prognostic talk into closing***

There was one deviant case in which the doctor moved to close the conversation immediately following prognostic talk. This was a conversation between a registrar (DOC) and close family friend of a patient (FRI), with a consultant (CON) also present. Extract 6.5 occurs 7 minutes 40 seconds into a conversation in which they had discussed sedative medications, not giving food and fluids, and then moved onto the terminal-phase prognostication sequence. Throughout, whilst the friend did explicitly agree to the registrar’s plan (e.g. stating “I think he would say medication to keep him calm because

thinking of Amanda... he wouldn't want Amanda to see him like how is right now")<sup>12</sup>, most of her turns at talk were minimal responses such as 'yeh' and 'okay'.

**Extract 6.5** DOC: HCP09 (Registrar), FRI: R13 (Friend of patient),  
CON: HCP05 (Consultant), 07:41-08:51

01 DOC: but I think we need to be prepared that it i-it  
02 °could be as short as days.°  
03 (0.6)  
04 FRI: °°Days°°  
05 (0.4)  
06 DOC: °°Could be.°°  
07 (2.4)  
08 FRI: ↑Okay.  
09 (7.0)  
10 DOC: Okay.  
11 (3.2)  
12 DOC: D'you wanna a minute just to stay here: I can make  
13 you a cup of tea,  
14 (0.8)  
15 FRI: °I'm al<sup>l</sup>right.°  
16 DOC: [You can just (0.7) use this room to m (0.6)  
17 just re<sup>l</sup>ax for a moment?  
18 (3.9)  
19 DOC: Yeah?  
20 (1.2)  
21 DOC: If you wanna ask me any ↑questions?  
22 (0.6)  
23 DOC: you know you can just grab me any time.  
24 (0.6)  
25 DOC: Just see me in the corridor or I'll be in the office  
26 at the end. Just come get me.  
27 (0.5)  
28 FRI: Okay thank you.=  
29 DOC: =Yeh,  
30 (1.3)  
31 DOC: And now shall I give Amanda a call,  
32 (1.1)  
33 FRI: Yeh.  
34 (2.5)  
35 DOC: Kay.  
36 (2.5)  
37 DOC: Kay.  
38 ((noise of packing stuff away for 3.8))  
39 FRI: ↑Thank you  
40 (0.7)  
41 DOC: °°It's [okay°°]  
42 CON: [°Okay ] Maggie°  
43 ( ) (take care)  
44 CON: W- (.) we promise we'll do ((noise of DVR being  
45 moved)) (1.1) we'll see that (0.5) he just settles  
46 down.

<sup>12</sup> 'Amanda' referenced in this statement and in line 31, is the patient's daughter, and at line 50 the doctor is referring to putting the participant information sheet in the patient's room

47 ((noise of DVR being moved))  
 48 FRI: Thanks  
 49 (0.4)  
 50 DOC: I'll pop this in the: (.) [in his] room okay,  
 51 FRI: [°mm° ]  
 52 [ ((noise of DVR being moved))  
 53 FRI: [°Okay°)  
 54 DOC: Are you sure I can't get you a drink?  
 55 ((FRI's response can't be heard over the noise of  
 56 packing away))

At lines 4 and 8, the friend provides displays of acknowledgement by repeating 'days' and saying 'okay'. The account for the prognosis had come prior to the prognostic statement, but if this sequence was following the pattern on exiting prognostic talk seen in other cases, we could expect to see a move from the doctor towards talk on comfort care. Instead, when neither party takes a turn to introduce a new topic (see 'okay's and long silences in lines 8-11), on line 12 the doctor makes a move towards closing (see section 6.3 for a description of offers being used to transition into closings). It could be argued that the majority of the prior discussion was about comfort care for the patient and so it was not necessary to raise it here. However further evidence that this is a problematic exit from prognostic talk comes in line 44. At this point, the closing section is well underway and in fact lines 35-43 are a possible pre-closing and terminal exchange (Schegloff & Sacks, 1973). The consultant, who had been merely an observer for most of the conversation, moves out of the closing section to 'promise' they will make sure the patient 'settles down'. That the consultant intervenes here when the conversation was all but complete suggests she is treating the registrar's move straight from prognostic talk into closings as problematic. She uses 'we' to promise on behalf of both herself and the registrar, suggesting that this is something the registrar should have been communicating. This intervention highlights that references to comfort care following prognostic talk are the norm. Following this, the registrar moves back into closing by making a further offer of a drink to the friend.

A final observation to make about this extract is that on returning the recorder, the registrar stated that it was not a good example of communication with relatives. Whilst this was just a casual comment and was not explored in detail, it does suggest that the interaction felt problematic to the registrar and this was reflected in the analysis.

## 6.2 Studying closings in conversations with relatives in a hospice

The upcoming sections analyse more typical transitions into closing sequences, but first the difficulties of studying closings in this setting are discussed.

Much of the initial key CA work on closings came from recordings of phone calls (see Button, 1987; Schegloff & Sacks, 1973) in which there is a clear end to the conversation when both participants hang up the phone. In healthcare settings such as primary care and outpatient consultations with patients, closings are more complex than phone calls as closing utterances may be made, but the doctor and patient must still break co-presence and so the interaction continues (Heath, 1986). In the corpus of conversations recorded in the hospice setting, this becomes even more complex for several reasons. The conversations took place in a range of settings including in the patient's room, in a private room and in the ward's family room. In all of these cases (but particularly for conversations outside of the patient's room), there are several potential ways for the conversation to end. Either the relative or HCP may be the one to exit the room, or they may leave the room together, meaning there is no standard way across recordings in which co-presence is broken.

Primary care and outpatient consultations also have a clear end-point. They have been arranged to be a certain length of time and whilst this is not always stuck to, both patient and HCP are aware that there are limits to how long the consultation can continue. At the end of this time the patient will not only break co-presence with the doctor, they will leave the building. In the inpatient hospice setting, there were rarely set timings for consultations with relatives, and at the end of the conversation, both parties often remained on the ward and so did not necessarily fully break co-presence. Finally, the HCP chose when to end the recording. This meant that they decided when they believed the interaction was over, which was not always after co-presence had been broken. For these reasons, we cannot be confident that the 'terminal exchange' was always captured, as further talk may have occurred following the end of the recording. However the terminal exchange is just the final part of the closing section (Schegloff & Sacks, 1973). As discussed in Chapter 2, there are practices which can shut down a topic and "mark that topic as a possibly last one" (Schegloff & Sacks, 1973, pp., p.306), leading to pre-closings and then to the terminal exchange. The conversations in the corpus involved discussions of difficult topics such as patients' short prognosis, physical and psychological distress, and relatives' own distress. How HCPs and relatives negotiate the move from these topics (i.e. the main business of the conversation) to reaching a point where the conversation can be closed, is the focus of this analysis.

### **6.3 Transitions into closing relevant environments**

As described in Chapter 4, there was no one clear course that the conversations in this corpus took. However what was clear, was that the conversation could not move straight from the 'business' of the conversation (i.e. the patient's current symptoms and prognosis, and the relative's wellbeing) into



closings, and that HCPs used a variety of practices to transition into ‘closing relevant environments’ (Robinson, 2001; Schegloff & Sacks, 1973). In the majority of cases, this move was made either by the relatives expressing gratitude to the HCP, or by the HCP soliciting final-concerns, making offers or providing advice. Final-concern solicitations and statements of gratitude did not generally lead straight to the closing of conversations, but did close the main business of the conversation. Making offers and giving advice for the coming days could both close the main business of the conversation and lead directly into closings. None of these practices guaranteed a move into closings, but they allowed the possibility of this by moving out of the main business of the conversation.

### **6.3.1 HCP transitions into closing relevant environments: final-concern solicitation**

The first HCP practice to transition into closings, final-concern solicitation, was discussed in detail by Robinson (2001) who used the term ‘final-concern business pre-closing sequence’ to describe the practice where HCPs solicit any last concerns from patients in a primary care setting. In the current corpus, final-concern solicitations were made following the resolution of a topic relating to patient care. Extract 6.6 is a conversation between a doctor (DOC) and the son (SON) and daughter (DAU) of a patient. Immediately prior to the extract they had been discussing an anti-anxiety medication that the patient had been given (this is what is being referenced in lines 1-7). The doctor sums up talk on this medication with a positive assessment that it ‘seems to be doing the trick nicely’, which receives agreement from the family. With this topic closed and no one introducing a new topic at line 8, the doctor moves from the business of the conversation and towards closing with a final-concern solicitation (line 9-10).

**Extract 6.6** DOC: HCP05 (Consultant), DAU: R49 (Daughter of patient),  
SON: R50 (Son of patient), 03:40-03:51

```

01  DOC:    That seems to be doing [the]
02  SON:                                [yeh]
03  DAU:    Yeah
04  SON:    [sh- sh- ↓yeh ]
05  DOC:    [doing the trick] nicely
06  SON:    [It has] actually yeh
07  DAU:    [yeh ]
08          (0.7)
09  DOC:    Fantastic. .hh Do you have any questions? (.) any
10          [concerns? ]
11  SON:    [No everything's] fine everything's everyone's
12          brilliant [actually]
13  DAU:    [Mhm yeh ] [they're] fantastic [yeh ]
14  DOC:    [°Good° ]
15  SON:    [yeh ]
16  DOC:    [Good] good

```

The final-concern solicitation was designed with a preference for a 'no-type' response due to the negative polarity of 'any' questions or concerns (see Heritage et al., 2007; Robinson, 2001), as was the case in all final-concern solicitations in the corpus. Despite this preference, when giving no-type responses relatives still provided an account for their no. In their accounts relatives expressed that all of their previous concerns had been answered during the conversation or, as in this example, that they were grateful and happy with the care their relative was receiving. It may be that accounts are required here to display that their lack of questions is not due to a lack of concern about their family member's care, but rather that they are satisfied with the answers they have been given and with the care that is being provided.

Final-concern solicitations do of course provide the opportunity for families to introduce new topics with a yes-type response. Extract 6.7 below begins 7 minutes on from Extract 6.3. At lines 1-3 the doctor is summing up a plan of dealing with a complaint from the family about something a nurse had said to them the previous night. At line 5, the doctor moves out of that topic and towards closing by using a final-concern solicitation.

**Extract 6.7** DOC: HCP07 (Registrar), DA1: R27 (Daughter of patient),  
DA2: R28 (Daughter of patient), 27:29-34:43

01 DOC: We can just look into that (.) [and ] see but I'm sorry that  
02 DA2: [°yeah°]  
03 DOC: was sort of obviously going to be distressing [for you.] .hh  
04 DA2: [Yea:h. ]  
05 DOC: [Was there ] ↑anything else you wanted to talk about at all,  
06 DA2: [Thank you.]  
07 (0.4)  
08 (DA1/2) .hh  
09 (0.8)  
10 DA1: I think that's probably i:t.  
11 (0.3)  
12 DA1: U::m: (0.2) okay. I think you've probably answered every  
13 question.=  
14 DOC: =[°mmhm°]  
15 DA2: =[.HHH ] I MEAN MY only other concern I'm just  
16 [gonna be kind of] honest, you know.]  
17 DA1: [ >mm mm mm< yeh ]  
18 DOC: [↑Fine that's- ] I'd rather  
19 [you were that] and then you went away and >I always say< to  
20 DA2: [Um:: yeah ]  
21 the medical studen[ts the only stup]id question is one you  
22 DA2: [yeah and I- ]  
23 DOC: [didn't ask.]  
24 DA2: [And I kn- ] and I kn- its not so much a sht- a question  
25 it's more of a comment .hh  
26 DOC: Yeah,  
27 DA2: Like on that (.) on: not last night but the night before  
28 when [my mum was in a lot of] pa:in=

29 DA1: [A::h yeah okay ]  
 30 DOC: =°Mmm°  
 31 DA2: .hhh erm: like my brother was up [here and st]uff, an:d he  
 32 DOC: [Yea:h ]  
 33 DA2: described it to us and it sounded very very distressing,  
 34 DOC: Mmm  
 35 DA2: .hh and the pain was not under control

*6.5 minutes omitted where the daughters make a complaint about pain medication not being increased, they talk through what happened and check the chart, a nurse (NUR, pseudonym Steven) enters and joins the discussion, the doctor and nurse suggest a plan for pain medication for the coming days*

36 DOC: I'll just check the: I'll check the P R Ns now then.  
 37 DOC: [Is that okay?]  
 38 NUR: [Okay lovely ] that's absolutely fine.=  
 39 DA2: =Thank you Steven  
 40 DOC: °Lovely°  
 41 (0.4)  
 42 DOC: °Mmm°  
 43 DA1: Okay  
 44 DOC: °Can I get° anything else I can do for you at all  
 45 DA1: I think that's it um  
 46 DA2: Mmm  
 47 DA1: Thank you you've been really helpful=  
 48 DA2: =Yeah  
 49 DOC: No problem at all.  
 50 DA1: Okay thank you. .hh (Um) thank you  
 51 (0.5)  
 52 DA2: Thank youhh

Once again, the final-concern solicitation is formatted with a preference for a no-type answer, which DA1 begins to provide in lines 10-13, again with an account that all of their questions had been answered. At this point, DA2 raises a final concern. Her speech is latched to her sister's and slightly louder, appearing to rush to take a turn in order to get her concern heard before the conversation is closed. She begins her statement with 'I mean' (line 15), which can signal upcoming adjustments (Fox Tree & Schrock, 2002; Schiffrin, 1987), in this case to her sister's no-type response. She then forecasts the potentially troublesome nature of her upcoming issue by stating that it is a 'concern' and that 'I'm just going to be kind of honest' (lines 15-16). She also later corrects the doctor's reference to it as a 'question' to state 'it's more of a comment' (lines 24-25), further projecting upcoming troubles talk. She then begins her complaint from line 27. Extract 6.7 demonstrates that final-concern solicitations allow for relatives to introduce new topics, but that there is work required from the relatives to do so. The negative polarity of 'any' makes it interactively difficult to raise further topics, and in this extract, the problematic nature of the final concern requires forecasting.

Following 6.5 minutes of talk about the complaint, the formulation of a plan to avoid further issues in the coming days and an acceptance of this from the relatives, the doctor recycles her final-concern solicitation in line 44. This repeat of the final-concern solicitation at the end of the conversation is further evidence that the initial one was designed to move towards closing (Robinson, 2001). This time it receives no-type responses from the daughters and DA1 then provides a gratitude statement that allows the conversation to close (see section 6.3.4 for a discussion of different uses of gratitude statements).

### **6.3.2 HCP transitions into closing relevant environments: advice and offers**

The recycled final-concern solicitation in Extract 6.7 is the only example of a final-concern solicitation moving straight into closing. Generally in the corpus, final-concern solicitations did not create closing relevant environments themselves, but instead were often followed by offers and advice relating to the coming days. Section 6.1 demonstrated how, when exiting prognostic talk, HCPs moved from the uncertain and uncontrollable to the more certain and controllable by describing what could be done. Making offers and providing advice performed a similar role in that they focused on what the HCP and relatives could do in the coming days. These future-oriented practices resemble the second of Robinson's (2001) business pre-closing practices, the 'arrangement-related business pre-closing sequence'. Arrangement making has been shown to be understood by participants in talk as a possible last topic before closing, and in conversations with patients is used by HCPs to close the business of the consultation and transition into closings (Heath, 1986; Robinson, 2001; Schegloff & Sacks, 1973; West, 2006). In the terminal phase in a hospice however, arrangement making can be difficult, as meetings with HCPs were rarely pre-arranged, usually happening on an ad hoc basis during the ward round, and the HCPs could not be sure that the patient would still be alive by their next ward round. There were therefore no cases in which HCPs gave a specific time at which they would see the relatives again. Instead, making offers and providing advice appeared to perform similar actions; offers and advice moved out of the business of the conversation, and highlighted the HCP's ongoing relationship with the family, and what actions would or could be taken. Both of these practices could be used instead of final-concern solicitations to move out of the business of the conversation, but more often a combination of these different practices was used.

Extract 6.8 below, a conversation between a doctor (DOC) and the son (SON) and daughter (DAU) of a patient, is an example of providing advice following transitions into closing.

**Extract 6.8** DOC: HCP02 (Consultant), SON: R52 (Son of patient), DAU: R53 (Daughter of patient), 17:33-17:42

01 SON: Thank you for [every ]thing.  
 02 DOC: [We::ll]  
 03 DOC: it's a team effort.  
 04 DAU: Mmm  
 05 DOC: U:m  
 06 DAU: Mm  
 07 DOC: Mutual  
 08 (2.3)  
 09 DOC: A::nd >yeh< look after each other.  
 10 SON: Thank you very much.  
 11 (0.3)  
 12 SON: Okay.

Following gratitude statements (see section 6.3.4) from the family, on line 9 the doctor tells them to 'look after each other'. Other examples of advice included HCPs recommending families 'eat drink and sleep' (recording no. 02\_09), 'look after each other' (recording no. 05\_43) and 'keep talking' (recording no. 01\_09 and 02\_06). These advice statements resemble solicitudes described by Button (1987) such as 'take care' as they were short statements rather than lengthy recommendation sequences that required explanation or checking from relatives. As Button (1987) demonstrated, whilst they provide the option of allowing further, non-closing talk, they remain closing implicative. Additionally, whilst questions about relative wellbeing often led to lengthy sequences about how the relative was doing (e.g. see Extract 6.16 in section 6.3.4), advice statements displayed concern for the relative's wellbeing but did not project an extended telling of the relatives' experiences.

The final HCP practice to transition into closings was to make offers to relatives for the coming days. These included offers such as their own and other staff members' availability for further contact, hospice facilities and services, and more immediate offers to give them time in a private room or to make them a drink. Making offers more closely resembled arrangement making, particularly when the offers made related to the HCP's availability. An example of this is in Extract 6.9, (19 lines on from Extract 6.6, during which the doctor and relatives mutually praised each other).

**Extract 6.9** DOC: HCP05 (Consultant), DAU: R49 (Daughter of patient), SON: R50 (Son of patient), 04:00-04:09

01 DOC: Great that you can be here.  
 02 (0.6)  
 03 DAU: °°yeh°°  
 04 DOC: ↑Good .hh nice to see you, and we're around (.)  
 05 [if you have any other questions. ]  
 06 SON: [Yeh no problem at all. Yeh that's] great  
 07 (DOC) Yeh?  
 08 SON: Thank [you]  
 09 DAU: [Mm=]  
 10 DOC: =Fine [FINE ]  
 11 DAU: [Thank] you

At lines 4-5 the doctor makes her availability offer, 'we're around if you have any other questions'. The doctor uses 'we're' around rather than 'I'm' around, which was common in the corpus as HCPs made offers on behalf of the team as a whole. As discussed, due to the short prognosis, the doctor cannot state when they will next see the family, but by offering her and her team's availability she highlights their ongoing relationship and orients to the future. The offer is followed by acknowledgement from the son (line 6) and statements of gratitude from the family, which form the pre-closing of the conversation (lines 8-11).

The contrast between Extract 6.6 and Extract 6.9 from the same conversation demonstrates how making offers of availability were more closing implicative than final-concern solicitations. In contrast to final-concern solicitations, the offer of availability for further questions in Extract 6.9 is formatted as a statement rather than an interrogative. This means that, whilst the relatives provide an account for their no-type response to the final-concern solicitation (Extract 6.6, lines 11-13), they only need to acknowledge the offer to create a closing implicative environment (Extract 6.9, line 6).

Offers and advice did not however always lead so smoothly into closings and Extract 6.10 demonstrates that when relatives do not acknowledge or accept offers, this can cause interactional difficulties. This extract occurs 25 minutes into a conversation in which there has been some disagreement between a doctor (DOC) and the daughter (DAU) and son (SON) of a patient (see Chapter 7 for a detailed analysis of this conversation).

**Extract 6.10** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
SON: R20 (Son of patient), 25:05-25:47

01 DOC: .hh [You can be           ] around here (0.3) all the  
02 DAU:        [(Think that's it)]  
03 DOC: time that you (0.5) ↑want to you can stay  
04 overnight if you want to as well. .hh But you can  
05 also (0.3) take some rest.  
06        (0.5)  
07 DOC: Go [home.  
08 DAU:        [Yeh someone'll be °staying with her°  
09        (0.5)  
10 DAU: °every ↓night yeh.°  
11        (0.2)  
12 DOC: °Okay.°  
13        (0.2)  
14 DAU: °Y:eh.°  
15        (0.2)  
16 DOC: °↑Lovely°  
17        (0.2)  
18 DAU: Thank you though.  
19 DOC: .hhh Is there anything else that you need .hhh  
20 DAU: °mmm°  
21        (1.5)

22 DOC: (Well I assume you're) Muslim, hh .hh do if you want  
 23 any time, eh um for prayers, (.) that (0.2) y- we  
 24 can put a sign on the (.) on the door: .hh that  
 25 you're not disturbed, .h=  
 26 DAU: [m ]  
 27 DAU: =↑N:o: that's fine. [No  
 28 DOC: [Would y- (0.2) [would] you want  
 29 DAU: [Mm ]  
 30 DOC: to see an imam?  
 31 (0.6)  
 32 SON: N:::o [we've] got a: er our own imam so I think  
 33 DAU: [°Mm° ]  
 34 SON: (.) they'[re gon]na come in [on fridays ] and  
 35 DAU: [Y:eh ]  
 36 DOC: [Come in yeh]  
 37 SON: [things like] [that ] yeah  
 38 DAU: [Y:eah ]  
 39 DOC: [°Fine°]  
 40 DOC: °That's good°  
 41 SON: hhh  
 42 DOC: (°That's°)  
 43 SON: So:  
 44 DAU: ↑Thanks: for the information  
 45 (0.6)  
 46 DOC: °Okay°  
 47 SON: Mmhm  
 48 DOC: °Thank [you.°  
 49 SON: [Thank you very much.  
 50 DOC: °Okay.°

The extract begins in lines 1-7 with the doctor offering for the family to stay overnight and advising they 'take some rest'. In response, at lines 8 and 10 the daughter treats the offer as not being necessary by stating 'someone'll be staying with her every night'. Whilst the upshot is that people will be staying overnight as offered, she is not accepting the offer as this is presented as an already established arrangement, negating the relevance of the doctor's offer. At line 18, the daughter does thank the doctor for the offer, however her 'though' tagged on the end of the thanks further presents the offer as not having been accepted or necessary.

The doctor then makes a further offer in line 19. This resembles a final-concern solicitation, but also provides an offer as it asks if there is anything else they 'need' rather than any further questions or concerns. The daughter's quiet 'mmm' followed by 1.5 seconds of silence provides neither a yes- or no-type response, leading to the doctor introducing a candidate final concern relating to religious needs (lines 22-25). She makes an offer to put a sign on the door to prevent them being disturbed during prayers, which the daughter declines. The doctor then comes back in overlap with the daughter to make a related offer of arranging for an imam to visit. This time the son declines the offer with an account (lines 32-37). Up to this point, all potential future actions from the doctor have been declined,

but at line 44 the daughter thanks the doctor 'for the information'. Whilst there has still been no agreement on future action, this does at least display that a service has been provided by the doctor and therefore the conversation can be brought to a close.

A final point to make about the offers made by HCPs is that there were often limits to what was being offered, and this was more common in the doctor's conversations than in those with the CNS. Whilst all the offers related to the relatives' wellbeing in some way, they did not directly offer emotional support, instead focussing on more practical elements. For instance when doctors offered their availability, there were often limits and conditions put on this as they offered their availability for 'doctorable' issues (issues for which the HCP can provide a solution; Heritage & Robinson, 2006). In Extract 6.9 the doctor stated that she and the team were around 'if you have any questions'. This sets out an institutional scenario for the two to meet again as a 'client' with a question and a professional with an answer. In Extract 6.15 in section 6.3.4 below, the doctor also refers to being 'available for questions' (lines 17-18). He then uses the more open 'talk' (line 21) but this is preceded by 'if anything changes', suggesting there are conditions to the circumstances in which this would occur and what the topic of this 'talk' would be. In contrast, although during closings the CNS made similar offers and statements of advice for the coming days, her offers of availability were designed more openly, such as offers to 'chat' (recording 01\_02). In Extract 6.11 below, the CNS highlights the ease with which the family could speak with her suggesting she was 'only' in the office next to the patient's room (lines 1-2). She uses the casual term 'pop in' (line 7) and jokes that she gets 'bored otherwise' (lines 10-11). This all serves to reduce the formality and potential barriers to future conversations between the family and the CNS.

**Extract 6.11 CNS: HCP01 (Clinical Nurse Specialist), DA1: R14  
(Daughter of patient), DA2: R16 (Daughter of patient) 40:22-40:28**

01 CNS: I'm only in the office: sort of next to your dad's  
02 room  
03 (0.3)  
04 CNS: [so ]  
05 DA1: [Mmm ]  
06 DA2: [↑Oh right] okay.  
07 CNS: you're [welcome] to pop in,  
08 DA1: [mmm ]  
09 (0.6)  
10 CNS: I [get bored & otherwise] hh  
11 DA1: [Thank you very much.]



Where relatives did bring up emotional issues, doctors often engaged in talk about this, but their responses highlighted the institutional-setting as they gave practical advice or used signposting<sup>13</sup>. This was seen earlier in the transition out of prognostic talk in Extract 6.3 where the doctor affiliated with the relatives' troubles talk and then moved to offer the hospice's counselling services. Similar practices were seen as they transitioned towards closings. Prior to Extract 6.12 below, the doctor had asked how the daughter was doing and she spoke about looking after her children.

**Extract 6.12** DOC: HCP05 (Consultant), DAU: R21 (Daughter of patient),  
07:09-07:31

01 DAU: But I've my: I've got my husband but h-h he needs me  
02 as we:ll, hhe neehds mhy supporhht .hh I'm supporting  
03 everyone  
04 DOC: heh  
05 DAU: and my uncle. .hhh erm .hhhh Yeah but I'm alright. I'm  
06 doing I'm doing alright. I have my ups and downs.  
07 (0.3)  
08 DAU: As everyone does but,  
09 (0.6)  
10 DOC: You've got the so you've (0.5) use ↑us=  
11 DAU: =Yeh I [know yeh ]  
12 DOC: [but we also have] (.) a counselling team, a (.)  
13 even a (.) a children's counsellor.  
14 DAU: Ye:ah [yeh. ]  
15 DOC: [If you] wanted

The doctor allows the daughter to give a full account about how she is coping and then her immediate response is to make offers of support from the team and signpost the counselling service (lines 10-13). Once again, this closes down the troubles talk and moves the conversation towards closure (although as we see in the next section, the daughter then moves out of the closing to recycle prognostic talk).

### 6.3.3 Recycling prognostic talk during closing

As we have seen in the previous sections, new or recycled topics were sometimes introduced during closings. This section describes the only case in which prognostic talk was recycled during closing and how the doctor responded to this and moved back to typical transitions into closing. Extract 6.13 occurred 16 lines on from Extract 6.12. Approximately six and a half minutes earlier, the doctor had stated that the prognosis was not months 'but whether it's weeks or days that's hard to say'. They had then gone on to discuss that they would keep medications to a minimum and would not prolong the patient's life, and the doctor explained what changes to expect. In Extract 6.12, reflecting the use

<sup>13</sup> There were in fact some examples of HCPs affiliating with relatives' troubles-tellings and not moving straight to problem solving, but these did not occur at topic boundaries or during closing.

of offers to transition into closing relevant environments described in section 6.3.2, the doctor had offered to arrange for her children to see the children's counsellor at the hospice. At the beginning of Extract 6.13 the doctor is describing what would happen next.

**Extract 6.13** DOC: HCP05 (Consultant), DAU: R21 (Daughter of patient),  
07:47-08:21

01 DOC: We'll get them to phone they would (.) phone you  
02 and make an appointment.  
03 DAU: Okay  
04 (0.2)  
05 DOC: So of course for your kids it would all go through  
06 you  
07 DAU: Yeh (.) okay [that's fine.]  
08 DOC: [if they want]ed anything,  
09 DAU: Okay.  
10 (0.3)  
11 DAU: .hhh  
12 DOC: °°Yeh°°  
13 DAU: Yeh  
14 (0.2)  
15 DAU: .hhh Okeydoke. .hhh  
16 (1.0)  
17 DAU: It's just the not knowing that's all it's like am I  
18 gonna be sitting here in a ↑weeks ti:me? ↑two w-.hhh  
19 (0.6)  
20 DAU: It's just yeah it's har:d.  
21 (0.8)  
22 DAU: °But (.) it is what it is°  
23 (1.0)  
24 DOC: I can't imagine it's going to be (0.3) long weeks.  
25 (0.3)  
26 DAU: You don't think.  
27 (0.4)  
28 DOC: °I can't imagine it°  
29 (0.5)  
30 DAU: °Okay.°  
31 (0.7)  
32 DAU: I hope for her: I ho- this: (0.4) I know it sounds  
33 aw:ful, .hhh bu::t dy'know she's got nothing to,

The offer is initially accepted in lines 7 and 9, and lines 12-16 are possible pre-closings as at each turn both the doctor and daughter pass on the opportunity to introduce a new topic (Schegloff & Sacks, 1973). It would be sequentially relevant at this point for a terminal exchange of 'bye' 'bye', or 'thank you' 'you're welcome', to occur. However instead, at lines 17-18 the daughter reintroduces prognostic talk, stating that 'it's hard' in line 20. Recycling prognostic talk at this point and as part of a troubles-telling, suggests that the doctor's offer had not solved the trouble that the daughter described prior to and during Extract 6.12. The offer of a children's counsellor may have been accepted but it does not address the daughter's own difficulties relating to the uncertainty of her mother's prognosis.

At lines 19 and 21, the doctor does not take a turn following the daughter's statements. There are no obvious second pair parts for the doctor here. Due to the institutional nature of the conversation, consoling the daughter is less relevant than in a non-institutional environment (Jefferson & Lee, 1981, 1992). She has also already given the daughter a prognostic estimate earlier in the conversation and so it is not clear whether this is an implicit time estimate request or a troubles-telling. Following the lack of response from the doctor, the daughter states 'it is what it is' in line 22, which minimises the daughter's troubles. This is a figure of speech, which has been shown to be regularly used to close a topic, particularly by tellers of troubles or complaints (Drew & Holt, 1988, 1998).

Despite the daughter's figure of speech removing the expectation that the doctor should respond to the troubles-telling, at line 24 the doctor gives another prognostic estimate, suggesting it was unlikely to be 'long weeks'. Terms such as 'long weeks' or 'short days' were regularly used in conversations about prognosis between HCPs. For instance suggesting a patient had 'short days' generally meant the HCP expected the patient to live for around one to two days, not six to seven. However, these terms were rarely used in the recorded conversations with relatives in the corpus. Her use of 'long weeks' provides slightly more specificity than her previous absolute categorical time estimate. A further difference between this and other prognostic talk earlier in this conversation and in other conversations in the corpus, is the use of the word 'imagine'. HCPs regularly used the word 'think' as a qualifier when discussing prognosis, but here, even when the daughter reformulates the doctor's statement to 'you don't think' (line 26), the doctor persists with 'imagine' (line 28). The use of 'imagine' seems more informal and less certain as it moves away from the cognitive processes associated with 'thinking'.

The doctor's prognostic statement provides an answer of sorts to the daughter, but it also goes some way towards addressing the emotional element of the daughter's troubles-telling as it reduces 'the not knowing' referenced in line 17. Stating 'I can't imagine it's going to be long weeks' seems to treat long weeks as a bad outcome to be avoided and therefore the doctor's statement as positive news. Evidence that this is how it is taken by the daughter comes in lines 31-32 where the daughter appears to be beginning to say that she hopes this is the case before cutting herself off. She states this explicitly in line 47 and 49 in Extract 6.14 below. The doctor has therefore addressed the daughter's emotional troubles whilst remaining firmly in her institutional role.

In 14 omitted lines, the daughter goes on to describe a situation in which she would wish for a longer prognosis (if there were a chance her mother could recover)<sup>14</sup>. The prognostic talk sequence then ends with a further figure of speech (line 49, Extract 6.14). This time the doctor does take the opportunity of the possible topic closure to introduce a new topic by making an offer for the daughter to bring in music or pictures (lines 51-54). Whilst this has changed the topic, it does link with the daughter's previous statement 'for her sake' (line 47) as it is focussed on making things better for her mother. It also frames the daughter as being the one who knows what is best for her mother, thereby neutralising the previous threat to the daughter's morality arising from hoping for her mother to die sooner rather than later.

**Extract 6.14** DOC: HCP05 (Consultant), DAU: R21 (Daughter of patient),  
08:36-09:12

47 DAU: Just for her: sake I'd (0.3) .hh  
 48 DOC: °Yeh°=  
 49 DAU: =I'd rather °it be sooner than later  
 50 (0.5)  
 51 DOC: .hhh So if there's anything you could think of that  
 52 (0.7) uhm:: would make it (.) feel more like her  
 53 place. .hhh Whether pictures, or: whether (.)  
 54 there's certain music that she li:kes, [(in that case)]  
 55 DAU: [Nn she likes ]  
 56 she likes the quiet.=  
 57 DOC: =↑Oh really, okay good.  
 58 DAU: Yea:h if I used [to go] to her house put telly on she'd  
 59 DOC: [Good ]  
 60 DAU: t(h)ell me tohh tuhhrn it [o(h)ff.h] .hh  
 61 DOC: [Oh right]  
 62 DOC: [>good to ↓know< ]  
 63 DAU: [and she actually] likes quiet?  
 64 DOC: Perfect  
 65 DAU: So [that's] fi::ne yeh  
 66 DOC: [Okay ]  
 67 DOC: We'll do that.=  
 68 DAU: =Cause when I've had the telly on I've had it ↓really  
 69 really low?  
 70 (0.2)  
 71 DAU: u↑huh [huh hu:h hah]  
 72 DOC: [hhh kay ]  
 73 DAU: Y'know she likes .hh pea::ce like, .hh °she'd be happy  
 74 in there in peace.°  
 75 (0.3)  
 76 DAU: °huh huh [hhh° ]  
 77 DOC: [°°Alright°°]  
 78 (0.2)  
 79 DAU: Okay, thank you (.) appreciate it,  
 80 DOC: (°°That's [okay.°°])  
 81 DAU: [Thanks. ]

<sup>14</sup> Omitted lines are presented in Extract 7.iii in Chapter 7 alongside a discussion of moral stance in hypothetical scenarios

The doctor's offer and the lines following create the more typical closing relevant environment seen in other conversations. Although this has moved from prognostic talk towards closings, unlike the deviant case presented in section 6.1.1, this is not out of place as it restarts the transition into closing initiated in Extract 6.12 and Extract 6.13. Whilst the daughter declined the offer to bring in music, saying her mother prefers the quiet, the doctor treats this as a request, stating 'we'll do that' in line 67. This allows the doctor to present her offer of personalising the space as having been accepted and to suggest action from the team. These standard features of closings create the closing relevant environment to allow for the pre-closings and probable terminal exchange at lines 77-81.

#### **6.3.4 Relative transitions into closing relevant environments: gratitude statements**

When families closed the business of the conversations, this was generally done through expressions of gratitude. Like final-concern solicitations, these did not transition directly to closings, but moved out of the business of the conversation. Extract 6.15 occurs 20 and a half minutes into a conversation between a doctor (DOC), and the son (SON) and wife (WIF) of a patient. The son had been describing how his father (the patient) had worried about how his mother was coping.

**Extract 6.15 DOC: HCP09 (Registrar), WIF: R33 (Wife of patient),  
SON: R32 (Son of patient), 20:32-21:11**

01 SON: Um: m m if you'd been arguing it's (0.2) about whether  
02 or not you're going to get any sup[ort in]to the house  
03 WIF: [Y:eh ]  
04 SON: when he [was] (0.5) uh immobile.  
05 WIF: [m ]  
06 WIF: Yeh.  
07 (0.8)  
08 WIF: Okay.  
09 SON: Cause he was wanting you to.  
10 WIF: Yeh I know.  
11 (0.9)  
12 WIF: °Um°  
13 (1.8)  
14 WIF: Okay,  
15 (0.5)  
16 WIF: Well >thank you very much.<  
17 DOC: Pleasur:e and eh a- always (.) available for  
18 question:s  
19 (0.5)  
20 DOC: throughout the day if something (0.2)  
21 [↑changes] or you want to talk (0.5) just come and  
22 SON: [Thanks ]  
23 DOC: find  
24 (0.6)  
25 WIF: °Thank you°  
26 (0.5)  
27 DOC: Okay?

28 (0.4)  
 29 DOC: tch.hhh (0.6) °°Good.°° And take breaks as well I mean  
 30 its hard being in the room (.) which is why I wanted  
 31 to offer you the opportunity to talk outside as well  
 32 (0.2) [erm]  
 33 WIF: [Yes]  
 34 (0.7)  
 35 DOC And theres the family roo::m: theres the garden  
 36 downstairs,

The wife closes down the son's talk with 'yeh I know' (line 10), following which no one else takes a turn. With this topic closed, the wife makes her statement of gratitude on line 16. She begins her statement with 'well', which is associated with topic closure (Heritage, 2015). There is evidence that the doctor treats this statement as transitioning towards conversational closure, as he uses practices demonstrated in section 6.3.2 to be closing implicative; making offers of availability (lines 17-23), advice for the coming days (lines 29-31) and further offers of facilities (lines 35-36).

Gratitude statements moved the conversation out of the business of the conversation, but did not always mean that no further topics were raised. For instance, in Extract 6.16, the daughter makes her statement of gratitude (lines 1-5) to which the doctor responds 's'a pleasure'. However rather than using any practices to progress further towards closing, he introduces a new topic by enquiring about her work.

**Extract 6.16 DOC: HCP02 (Consultant), DAU: R10 (Daughter of patient),  
 21:04-24:51**

01 DAU: Can I just say I think you guys are just doing  
 02 (.) the most incredible job .HHHH #I don't know  
 03 how you guys do this#  
 04 (1.4)  
 05 DAU: but (0.4) ~I'm extremely gratefuhl that you °do°.hh~  
 06 .shihhh  
 07 DOC: °Mmm°  
 08 (1.0)  
 09 DOC: S'a pleasure  
 10 (1.0)  
 11 DOC: ↑Can I say? um (0.3)  
 12 DAU: hhh  
 13 DOC: you (0.4) and work  
 14 (0.3)  
 15 DAU: Mhm  
 16 DOC: What's the story,

*229 lines omitted where daughter discusses own situation at work and tells jokey stories of others having to go into work immediately following major medical events*

246 DOC: .hhh[hhh  
 247 DAU: [.hhhh Well (.) thank you Andrew.  
 248 DOC: Oh [gosh that's alright,]

249 DAU: [Appreciate it. ]  
 250 (0.3)  
 251 DAU: Right. [Appreciate it ]  
 252 DOC: [Look after yourself] today,

In line 11 when he introduces this topic, he begins his turn with ‘can I say’. This ‘misplacement marker’ (Schegloff & Sacks, 1973) resembles patients’ uses of ‘by the way’ as a way to introduce a ‘doorknob’ additional concern in consultations (White, Levinson, & Roter, 1994). The doctor is therefore orienting to this additional topic being out of place in this closing relevant environment. Further evidence that the gratitude statement in lines 1-3 was a closing move, is that in lines 247-252, following an expanded sequence of talk on work, the daughter recycles her gratitude statement and the doctor moves to advice for the coming days, creating a closing relevant environment.

As the extracts throughout this chapter have demonstrated, gratitude statements are seen at the end of closing sections, not just as a transition into closings, and the interactional context in which they occur determines the action they perform. Where they occur at the end of the main business of the conversation (as in Extract 6.15 and Extract 6.16) they perform the action of transitioning into closings. In contrast, when they follow offers and advice within the closing section (e.g. Extract 6.8 lines 1 and 10; Extract 6.9, lines 6, 8 and 11; Extract 6.10, line 49; Extract 6.14, lines 79 and 81) they form part of the pre-closing or terminal exchange, as described by Clark and French (2008).

## 6.4 Discussion

The chapter explored how the business-at-hand in these potentially difficult conversations was closed, by first looking at how prognostic talk was exited and then how the conversation as a whole was closed. When exiting prognostic talk, both HCPs and relatives moved talk on in a stepwise fashion (Jefferson, 1984) from the uncertain and uncontrollable topic of prognosis, to discuss what could be predicted and what could be done to help the patient and their relatives. In institutional or ‘service’ encounters, troubles-tellings are organised in a way to close down talk on troubles and move to solutions (Ekström et al., 2013; Jefferson & Lee, 1981). However, whilst in most medical settings there is a clear link between the trouble and the solution (e.g. problem presentation can lead to treatment advice; Heritage & Lindstrom, 1998; Ruusuvuori, 2007), here there is no clear solution for either the short prognosis or the inability to accurately predict prognosis. The HCPs therefore moved the conversation to more ‘doctorable’ issues (Heritage & Robinson, 2006). Talk became more action-oriented as HCPs could describe clear steps they would take to ensure patient comfort. Where relatives raised a problem that the HCPs could not directly deal with themselves (e.g. relatives’ emotional distress), they used signposting to other services. The use of signposting to provide a

practical response to a problem beyond the HCP's immediate capacity has previously been found in calls to a Parkinson's helpline where nurses were not permitted to give direct medical advice and so offered leaflets and made suggestions to speak to a doctor (Bloch & Antaki, 2019). As well as being action-oriented, transitioning to the topic of comfort care is a kind of 'bright-siding' (Holt, 1993). Here the HCPs moved from prognostic estimates to give a more bright-side perspective, demonstrating there is much that can be done to prevent the patient being in pain. The deviant case presented in section 6.1.1 in which the doctor moved straight into closings, causing interactional difficulties, further demonstrated the norm for this 'bright-side' type practice focusing on patient and relative wellbeing following prognostic talk.

Practices for transitioning from the business of the conversation and moving towards closings showed a similar orientation to action. Those practices identified as being used by HCPs (final-concern solicitation, providing advice and making offers) resembled the 'final-concern business-preclosing' and 'arrangement-related business-preclosing' sequences described by Robinson (2001) for negotiating closings in primary care. The analysis revealed that these practices performed similar actions, but were used in ways to fit a setting where arrangement making and problem presentation are more complex.

Like arrangement making, advice and offers propose future actions. They resemble action formulation, which has been shown to be used to close the business-at-hand in primary care settings and outside of healthcare settings in meetings (Barnes, 2007; Gafaranga & Britten, 2004). However formulations are a gloss for previous talk, much like the re-invocation of previously made arrangements used to close primary care consultations (Robinson, 2001; West, 2006). In the data presented in this chapter, formulations of offers and advice were sometimes used in this way, but more often new offers or plans were presented. This suggests that rather than summarising the previous talk, advice and offers were moves to end the conversation with an emphasis on action and the HCP's ongoing relationship with the family.

The other HCP practice for transitions from the business of the conversation, final-concern solicitations, did not lead directly into closings. Whilst advice and offers allow a proposal of a future action, if relatives responded to final-concern solicitations with no-type answers, this was not possible. No-type answers to final-concern solicitations were therefore always followed by offers and/or advice, allowing the HCP to emphasise action. A further reason for final-concern solicitations not leading as directly into closings as advice and offers is the obligation for an answer. Robinson (2001) highlighted that whilst the negative polarisation of 'anything else' meant yes-type responses



to final-concern solicitations were rare, they still provided a formal opportunity to do so, whereas arrangement sequences did not. In the data presented in this chapter, offers and advice merely required acknowledgement. Final-concern solicitations in contrast required an account, even when giving a preferred no-type response. Generally an account is only required for a dispreferred response (Pomerantz, 1984), but as discussed in section 6.3.1, this appears to be different in this setting where families are advocating for the patient. Families displayed that they were fulfilling their role as advocates by highlighting that they did in fact have questions but that these had been answered during the conversation. This finding, along with the focus on action, reflects the results from the systematic review that HCPs and families of patients at the end of life made statements to justify their decisions as 'right' and highlighted their ongoing care for the patient (Anderson et al., 2019).

The final practice for transitioning into the closing section was when relatives made statements of gratitude. Woods, Drew, and Leydon (2015) found that appreciation tokens were used by callers to a cancer helpline to initiate closings in 68% of calls, fitting with the preference in mundane conversations for the caller rather than the called to make the first move to close a conversation (Sacks, 1992). In contrast, previous studies of face-to-face healthcare settings have shown that it is usually the doctor who moves the conversation towards closing (Heath, 1986; Robinson, 2001; West, 2006). This norm, alongside the emphasis on action and ongoing relationships already discussed, may explain why gratitude statements tended to be followed by advice or offers rather than moving directly into closings. By providing closing-implicative offers and advice, HCPs accept the relatives' proposals to close the conversation but also take the opportunity to stress their ongoing relationship with them.

A further finding was that when exiting prognostic talk or closing the conversation as a whole, HCPs sometimes needed to address emotional concerns raised in relatives' troubles-tellings, and they did this once again by moving towards problem solving. Similar cases have been presented elsewhere in the literature, in which empathetic statements or extended affiliations with patients' troubles-tellings were used to facilitate treatment recommendations (Ford, 2017; Ruusuvuori, 2007). In these studies the authors demonstrated how empathetic statements can be used to serve the mostly biomedical institutional agenda. However in the current corpus, discussing relative wellbeing was a core part of the institutional agenda, not a departure from it. The institutional norm to respond to troubles-telling with advice (Jefferson & Lee, 1981, 1992) was still maintained though, as HCPs addressed relatives' distress with practical advice and offers.

This chapter has demonstrated that both exiting prognostic talk and transitioning into the closing of conversations were done by emphasising future action. By highlighting what can be done to help patients and relatives, HCPs closed down the business-at-hand whilst emphasising their ongoing care for and relationship with patients and their families.

## **Chapter 7    Disagreement during talk about prognosis and comfort care**

Chapters 5 and 6 demonstrated how talk on prognostication, including initiation, provision of a prognostic estimate, and exiting prognostic talk, were collaborative ventures between healthcare professionals (HCPs) and relatives. Both parties treated prognostic talk as relevant and when HCPs provided a prognostic estimate, relatives displayed recognition of this. In contrast, this chapter presents a single conversation in which a doctor attempts to discuss prognosis but meets with relatives' resistance to the topic of prognosis and disagreement with the doctor's stance that there is no viable curative treatment for their mother, and that she is imminently dying. It demonstrates the different ways in which the family members challenge the doctor and how the doctor in this interaction pursues the topic until there is at least some display of acknowledgment. The single conversation is presented chronologically and in depth, but the practices identified are not unique to this conversation. Throughout the analysis, similar and contrastive extracts from other conversations are therefore presented. Extracts from the main conversation are numbered in the standard format (i.e. 7.1, 7.2 etc.), whereas those from other recordings are numbered with Roman numerals (7.i, 7.ii etc.).

The single conversation presented here was between a consultant (DOC), and the daughter (DAU) and son (SON) of a patient who had been admitted to the hospice that day following the diagnosis of a brain tumour approximately two to three months earlier. The family had already spoken to a more junior doctor, but this was their first meeting with the consultant. Prior to the extracts presented in this chapter, they discussed the patient's ability to speak and eat, and briefly discussed steroids and laxatives. The sequence in which an absolute categorical prognostic time estimate is provided and subsequently challenged occurs around 18 and a half minutes into the conversation. However in order to analyse this sequence, the references to prognosis and related challenges earlier in the conversation must first be examined.

### **7.1    Passive resistance to talk about prognosis and comfort care**

The first move to engage in prognostic talk occurs in Extract 7.1, three minutes into the conversation. Immediately prior to this, the relatives were explaining that their mother cannot eat because she is always either sleeping or in too much pain to eat.

**Extract 7.1** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
SON: R20 (Son of patient), 02:53-03:30

136 DAU: So when can she eat  
137 (0.5)  
138 DAU: u(h)[hh ↑Yea:h hh .hh]  
139 DOC: [Yeh true true. ] So- (0.4) we'll have to ↑see  
140 how things go. (0.2) An:d .hh just seeing your mum  
141 when she came ↑in hh so (0.5) [the first time]  
142 DAU: [Mmhmm ]  
143 DOC: round, but also now in a relaxed way, .hhhh °I I°  
144 just need to tell you that I'm concerned. I'm  
145 concerned (0.5) °about° hhow long her body can .hh  
146 can carry on living like this.  
147 SON: Mmhmm  
148 DOC: .hhhh  
149 (1.0)  
150 DOC: Em the fir:st (.) impression was when she was in  
151 pai:n °eh I-° (0.5) it was very un (0.2) very  
152 uncomfortable for her, .hh uhm but also then she is  
153 not she was not (0.3)  
154 DAU °Mhm°  
155 (0.6)  
156 DOC: alert enough and and .h clear enough to (0.5) to  
157 explain to me what was happening

The doctor's utterance 'we'll have to see how things go' (lines 139-40) could be understood as referring to the previous topic of the patient's appetite, but is then used as a pivotal utterance (Sacks, 1992) to segue into prognostic talk. The preface 'I just need to tell you that I'm concerned' (lines 143-4) forecasts bad news (Maynard, 2003).

Up to this point, the sequence has followed the same pattern as HCPs' unelicited prognostic statements seen in Chapter 5, as the doctor has used stepwise moves to transition from talk on deterioration towards a descriptive statement about the patient's potentially short prognosis (lines 144-6). However this receives only minimal uptake from the family (see lines 147 and 149), suggesting potential passive resistance (Heritage & Sefi, 1992; Stivers, 2005). In response, in 19 omitted lines she accounts for her concern with descriptions of the patient's deterioration. This practice of accounting, which had produced agreement in other conversations, once again only received minimal acknowledgement (silences and 'mm's).

This type of minimal uptake from family members is also seen in Extract 7.i, a conversation between a different doctor and family, where the doctor suggested using sedative medications. In Extract 7.i there are once again silences and unmarked acknowledgements (Heritage & Sefi, 1992) in lines 3, 7 and 8, followed by continued explanation from the doctor that does not result in uptake from relatives (see lines 9-25).

**Extract 7.i** DOC: HCP02 (Consultant), PAR: R06 (Partner of patient),  
MOT: R07 (Mother of patient), 04:27-05:10

01 DOC: I would (0.6) advocate giving her something .hh  
02 (1.1) (1.1) to help her to relax both mind and body.  
03 (0.7)  
04 DOC: Em: (0.6) and by that I mean (0.4) really using  
05 (0.4) medication that's a sedative? (0.9) And a  
06 muscle relaxant.  
07 (0.8)  
08 PAR: Mm=  
09 DOC: =So it does two things.  
10 (0.7)  
11 DOC: Em (0.3) it will make her sleepier, (1.4) and it  
12 will make her less aware, (0.4) therefore (0.5)  
13 PAR: mm[m ]  
14 DOC: [of] what's happening,  
15 (0.4)  
16 MOT: Ri::ght  
17 DOC: And her (0.3) muscles (0.6) will become more  
18 relaxed. Which will allow us (0.5) hopefully (0.9)  
19 to keep her more comfortable (0.6) and in-a (0.4)  
20 [maybe]  
21 PAR: [Mmhm ]  
22 (0.8)  
23 DOC: different pos[itions]  
24 MOT: [Mmm ] mm  
25 (0.7)  
26 DOC: I think (1.3) [as] you alluded to (0.4) [Michael]  
27 PAR: [Mm] [mmm ]  
28 DOC: her time is really short.

Such unmarked acknowledgements and silences have been described in settings including community nurse visits to new mothers and paediatrician-parent interactions, as displaying passive resistance to advice (Heritage & Sefi, 1992; Stivers, 2005). The norm in these situations is to display acceptance of recommendations, and therefore where this does not occur, clinicians treat this as problematic and pursue this acceptance (Stivers, 2005). This occurs following the doctor's treatment recommendation in Extract 7.i, as in lines 26-28 the doctor responds to the relatives' passive resistance by using the patient's short prognosis to begin to strengthen the argument for sedative medication. Extract 7.1 does not contain a treatment recommendation, but prognostication is treated as requiring acknowledgement in the same way. That displays of acknowledgment are the norm following prognostic statements was demonstrated in Chapter 5, as relatives responded either with marked acknowledgements (e.g. okay, right); with partial repetition of the HCP's statement; or with questions that displayed their understanding of the short prognosis. For example in the omitted lines from Extract 5.5, having been told his wife's prognosis was likely to be 'weeks', the husband asked 'and will she go out peacefully with er when she goes?'.

Following Extract 7.1, in absence of any signs of acceptance from the relatives, the doctor provides another descriptive prognostic statement (lines 181-2 Extract 7.2):

**Extract 7.2** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
SON: R20 (Son of patient), 04:14-04:31

177 DOC: .hhh  
178 (0.5)  
179 DOC: >↑And I just want,< (0.3) t- (0.4) want to [tell you]  
180 SON: [Mmm ]  
181 DOC: because for me it's a warning sign, (.) it's a  
182 warning sign that time could be getting short.  
183 SON: Mhm  
184 (0.3)  
185 DAU: So you just noticed that by (.) touching her:  
186 DOC: °By s:: f [ countling her breath. [Very easily°]  
187 DAU: [(Right)] [Oka:y ]  
188 DOC: But to be: [>absolutely sure<]  
189 DAU: [Oh so you can: ] you can: assess that  
190 by (0.2) er, (0.7) how you did it

This statement uses more explicit terms, but maintains cautious, qualifying language ('could' and 'for me') and does not provide an absolute categorical estimate. Rather than acknowledging the suggestion of a short prognosis, the daughter focusses on the doctor's account, seeking confirmation that this assessment was reached 'by touching her' (line 185). Her use of 'just' in line 185 minimises the work done by the doctor to reach her assessment, to which the doctor responds with description of what she did beyond 'touching her' (line 186). In lines 189-90, the daughter's questioning of whether prognosis can be assessed this way expresses scepticism. Whilst accounting for an assessment in the context of uncertainty can lead to statements from relatives that support the assessment, as was seen in Chapter 5, it also leaves HCPs open to have their logic challenged and their certainty questioned (Stivers & Timmermans, 2016). This is not a direct challenge to the doctor's assessment of prognosis<sup>15</sup>, but it does delay the progressivity of the prognostic talk and the lack of acknowledgment of the actual prognostic statement is a similar move to the previous passive resistance.

In 28 omitted lines the doctor further explains what she has observed to reach her assessment and that the problems cannot be fixed, again receiving only minimal acknowledgement tokens from the relatives.

<sup>15</sup> See section 7.6 for a more direct challenge to how the doctor reached her prognostic estimate

## 7.2 Resistance to talk about prognosis and comfort care: topic change

In Extract 7.3, the doctor begins to explain that the priority is to make the patient comfortable. However the son uses the doctor's reference to medication to shift the topic to medication more generally (line 227, Extract 7.3), thereby shutting down the topic and resisting further prognostic talk. Once again this is not an active rejection of the doctor's stance, but instead resists the topic of prognosis.

**Extract 7.3** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
SON: R20 (Son of patient), 05:14-05:38

219 DOC: So the only thing (.) I can ↑do is watch from the  
220 outside that we're not doing anything .hhhh u:m  
221 (0.2) tch (0.2) that (0.4) yeh. (0.3) Not doing  
222 anything that would (0.2) hinder her, her breathing  
223 obviously, .hhh (0.6) but (1.1) if she's so but make  
224 sure that if she's awake (0.2) and uncomfortable  
225 that we can treat that and treat that with the  
226 smallest doses of medicine we c-  
227 SON: Mm [that's what I was gonna say] about the steroids  
228 DOC: [possibly can use, ]  
229 SON: is like (0.8) [if she's overdosing on ]  
230 DOC: [Shall we rather take them down?]

Following Extract 7.3, there were four minutes where the doctor explained how they could reduce medications. Throughout this talk, in contrast to the passive resistance seen during the doctor's attempts to discuss prognosis, there were signs of agreement from the relatives (e.g. 'yeh yeh' and 'right'). This is seen at line 379 (Extract 7.4a) where the daughter agrees with doing 'everything natural'. However at line 382 the daughter makes a disjunctive topic change from the doctor's talk on planning minimal intervention to ask if the doctor is an oncologist. Oncologists would generally be associated with active treatment of cancer, which is at odds with the doctor's earlier talk about not being able to treat the cancer. The doctor's response claiming oncological experience (line 385) may therefore be understood as orienting to a possible upcoming challenge to her knowledge from the daughter.

**Extract 7.4 (a)** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 09:15-10:01

378 DOC: >I'd< rather do everything natural without=  
379 DAU: =↑Yea:h [cause yeah yeh ]  
380 DOC: [without drips and] (0.4) °°things°°  
381 (0.2)  
382 DAU: Um are you an onco- oncologis:t? o:r,  
383 DOC: I'm a palliative [↑care doctor? .hh Which means I've]  
384 DAU: [Palliative care s I was gon- ]  
385 DOC: worked a long time in on[cology,] but .hhh my

386 DAU: [Yea:h ]  
 387 DOC: [speciality's ]  
 388 DAU: [Yeah I was gonna ask] about the::: so this:: uh  
 389 pai:n and .hh her being in so much pain does it  
 390 <affect the tumou:r> or like (0.4) cause more  
 391 pressure,  
 392 (0.8)  
 393 DAU: cause [of the] amount of pain that (0.1)  
 394 DOC: [°Y:eh°]  
 395 DAU: [<the body's:> ]  
 396 DOC: [That's pushing around] .h ↓No it (0.2) not  
 397 [that way] around. So it doesn't (0.2) doesn't .h  
 398 DAU: [No: ]  
 399 DOC: do any further harm to [her brai:n,]  
 400 DAU: [Mmm ]  
 401 (0.3)  
 402 DOC: The pain, [.hhh ]  
 403 DAU: [Mmhmm]  
 404 DOC: But it probably (.) does harm to her hhh tch  
 405 DAU: [Of course yeah]  
 406 DOC: [(°sort've her°)] her p-person. [.hhhhh ] Um:  
 407 DAU: [yeah yeah yeh]  
 408 DOC: .hh so we'll (0.5) a- (0.4) as I said we'll [use]  
 409 DAU: [mm ]  
 410 DOC: (0.2) small doses of painkiller for that. .h But  
 411 I've got no worries that it (0.2) it (0.2) it  
 412 [wors]ens the tu[mour.]  
 413 DAU: [Mm ] [mhm ]  
 414 (2.9)

The doctor's response is interrupted by the daughter raising the topic of the impact of pain on the tumour (line 388). This is an interruption rather than an overlap, as the doctor's turn constructional unit (TCU) was still in progress and the daughter's turn halts the progress of the doctor's action of explaining her role (Sidnell, 2010). However the daughter in fact treats the doctor's utterance in line 385 as an interruption, as her turn in line 388 ('I was gonna ask') is a delayed completion of her utterance in line 384 ('I was gon-'). Delayed completion provides a warrant for overlap with the prior turn and regains the speaking turn (Lerner, 1989). 'I was gonna ask' presents the daughter's upcoming talk as 'business-at-hand' therefore providing a warrant for introducing the topic here without making any links with the previous talk (Button & Casey, 1988).

Lines 388-393 provide further evidence that the daughter is not affiliated with the doctor's stance that her mother's prognosis is short, as she asks about whether the pain will make her mother's tumour worse (therefore focusing on preventing disease progression, which is no longer relevant when a person is imminently dying). In response, the doctor acknowledges the daughter's point of view by showing her understanding of how the daughter might think that ('that's pushing around', line 396). In a counter move that shifts the topic back towards comfort care, the doctor suggests that



the pain harms her 'person'. This response from the doctor resembles 'supportive disagreement' (Weiste, 2015), as the doctor finds congruence in their perspectives and validates the daughter's concerns, but ultimately dismisses them. This elicits agreement from the daughter (line 407), immediately after which the doctor provides the upshot that they would treat pain (lines 408-10). The doctor has used the daughter's worries about pain worsening the tumour to return to the topic of reducing pain for comfort care.

Extract 7.ii from the conversation about sedative medication (4 minutes 20 on from Extract 7.i) shows a similar use of linking relatives' concerns with the doctor's topic. Following an initial objection from the partner, the doctor and family members had reached a compromise about increasing the patient's (pseudonym Alexa) pain medication. Prior to this extract, as the doctor was summing up the plan, the partner started talking about the patient's pressure sores and whether the dressings should be changed.

**Extract 7.ii** DOC: HCP02 (Consultant), PAR: R06 (Partner of patient),  
MOT: R07 (Mother of patient), 08:46-09:23

01 PAR: [We ] both agreed that maybe it was best to just .hh (0.2)  
02 DOC: [Yeh]  
03 PAR: let her be at peace because to start (0.3)  
04 DOC: Yes  
05 (0.4)  
06 PAR: peeling them off an- [and it's] it's gonna be ↑so  
07 MOT: [°Mmm° ]  
08 PAR: ↑traumatic for her  
09 DOC: I actually feel the same way.  
10 MOT: Mm[m]  
11 PAR: [M]mm  
12 MOT: mmm  
13 DOC: An:d (0.7) t (.) definitely the approach should  
14 be minimal disturbances. [That] clearly [if ]  
15 MOT: [Mmm ]  
16 PAR: [Yeh ] [yeh]  
17 DOC: .hhh (0.2) if the if the dressings (0.5) ar:e  
18 soaked, (0.4)  
19 PAR: Mm  
20 (0.2)  
21 DOC: er:m (1.2) I think (1.4) with the best will in the  
22 world w- (0.7) we probably should (0.5) change them  
23 MOT: [Yeh]  
24 PAR: [Yeh] ((3 syllables mumbled))  
25 DOC: Er[m ]  
26 MOT: [And] as you've just said [give] Alexa that  
27 DOC: [Yeh ]  
28 (0.2)  
29 MOT: [extra little boost ]  
30 DOC: [Give her an extra boost]  
31 (0.2)  
32 PAR: .hh Yeh

33 MOT: to c- to: be able [to] cope [with] (0.2)  
 34 PAR: [Mm]  
 35 DOC: [Yeh ]  
 36 MOT: [Yeh ] [yeh]  
 37 DOC: [That's] what I think we should [do.]

In this extract, the doctor uses the partner's concerns about changing the dressings to consolidate his plan to use extra pain medication before movement. He begins by agreeing with the partner (lines 9 and 13-14), but presents a scenario in which the dressings should be changed (lines 17-22). He is then supported by the mother in suggesting that, in these circumstances, extra pain medication should be used (lines 26, 29-30 and 33). The partner had changed the topic to pressure sores and by supporting his point of view, the doctor and mother moved the topic back towards agreeing on the use of pain medication.

Returning to the main analysis, at line 414 (Extract 7.4b) there are 2.9 seconds where no one takes the next turn. This pause may indicate some hesitancy from the doctor towards what is coming next (Freese & Maynard, 1998). At this point the doctor could move into a discussion of comfort care, but instead opts to state that the tumour cannot be treated. This is the only case in the corpus in which curative treatment is discussed in this way. In contrast to Pino et al's (2016) finding that doctors provided invitations and opportunities for patients to ask about illness progression, here the doctor initiates this talk directly, without having been asked about it by the relatives. This all indicates that something different is happening here compared to the other conversations in the corpus, and leads to the question of why the doctor moves to explicitly rule out curative treatment here. Examining the prior talk in Extract 7.4a provides some insight into this. The daughter's question about the pain making the tumour worse and her reference to oncology both hint at the possibility of influencing the course of the disease, which is in clear contrast to the doctor's earlier statement that the prognosis is short and her suggestions of minimal intervention. This focus on the tumour is a challenge to the doctor's talk on prioritising pain relief. Therefore before she can move on with this, the lack of curative options must be established.

**Extract 7.4 (b) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 09:58-10:14**

414 (2.9)  
 415 DOC: Just to say again about the tumour, (0.6) I feel  
 416 that there is no way (0.5) that we can: (0.6) so  
 417 the way your mum looks now, (.) I can see no way  
 418 that she would be fit enough to have any  
 419 [treat]ment,° [.hhhh]  
 420 DAU: [°Mmm° ] [°↑mhm°]  
 421 (0.5)

In line 415, the doctor signals that her upcoming statement is not new information as she uses minimising language ('just to say'), and highlights that she is pursuing a previous point ('again'). She once again uses the daughter's previous talk to pursue her own topic of treatment ('about the tumour'). In contrast with the qualifying language seen in Extract 7.1 and Extract 7.2, she uses more unequivocal language, saying 'no way' twice. She begins to make a statement that there is no way they can treat her, but self-repairs at line 416. Here she repairs her account for why treatment is not an option by explaining it is due to their mother's condition. This removes the responsibility for the decision away from herself and other doctors; the lack of treatment options is not about what they can or cannot do, but due to the patient's current circumstances. This reference to the patient's current state also positions this assessment as overriding any previous conversations the family may have had about treatment.

These extracts demonstrate that relatives can utilise the features of topic change to resist talk about prognosis and comfort care, but that doctors can also use relative's talk to return to these topics. The next section continues from the same point in the conversation.

### 7.3 Disagreement about treatment: hypothetical scenarios

In Extract 7.4c, the doctor further accounts for her stance on the lack of treatment options. This language is more authoritative than was seen in the earlier prognostic statements. The use of 'we know' in line 438 invokes the wider medical profession and displays more certainty, particularly as there is an emphasis on the word 'know'. There is a clear statement of what would be needed for treatment to be possible and that their mother does not meet these criteria (lines 422-40). In response, the daughter resists this explanation by suggesting a hypothetical scenario of her mother not being in pain and asks if this would allow her to have treatment (lines 441-8). The use of 'so' at the beginning of this turn suggests that this is an upshot of what the doctor has said (see Bolden, 2009). However, in fact she suggests a hypothetical scenario for treatment at odds with what the doctor has just explained (by suggesting her mother could be treated even if not mobile). She bases this scenario on her mother not being in pain (the one thing the doctor has said can be treated) and repairs from 'if the person' to 'if she', pointing much more strongly towards it applying to her mother.

**Extract 7.4** (c) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 10:14-11:46

422 DOC: Umm (.) if you think about what the treatment would  
 423 be: (0.3) would be radiotherapy she [would be] (0.3)  
 424 SON: [Mhm ]  
 425 DOC: °she would be° have to be (0.2) aware enough (.) to  
 426 [be ly]ing on a:: .h (0.2) treatment radiotherapy

427 DAU: [°Mhm° ]  
 428 DOC: scanner. (0.4) For several times. .h (0.3) With a  
 429 mask o:n,  
 430 DAU: Mh[m  
 431 DOC: [So to have the p (0.2) have the (0.4) head in a  
 432 certain position, .hh .hhh .h (0.3) at the moment  
 433 she wouldn't be able to understand that.  
 434 (0.3)  
 435 DOC: [We c]an't- we ca:n't do that (0.2) in full  
 436 SON: [Mm ]  
 437 DOC: sedation so we can't put patie patients aslee:p to  
 438 give (0.2) treatment, .hhh therefore and we know  
 439 it doesn't help if patients are already quite  
 440 unwell with a with a tumour. .hhh  
 441 DAU: So um: (0.2) if the person: (0.2) if she's not going  
 442 through: (.) that much pain:, (0.3) e::m (0.2) but  
 443 she's still not (.) mobile (0.9) would you be  
 444 (0.8) erm (0.5) fit enough for the treatment,  
 445 (0.8)  
 446 DAU: So obviously if she's not walking, [talking,] but  
 447 DOC: [°↑Mm° ]  
 448 DAU: she's just (0.2) stable no pain,  
 449 (0.9)  
 450 DOC: tch °↓No even without pain° (.) if she's [not] (0.2)  
 451 DAU: [mm ]  
 452 DOC: .h ↑if she's not (0.2) alert enough to understa:nd  
 453 what's happening,  
 454 DAU: °Mm°  
 455 DOC: and if she's not mobile .h (0.3) °°#e e e#°° (0.4)  
 456 there is no (.) it °°#w-w-w#°° .hhhh (0.4) it's not  
 457 only not [f:: not <↑f::it for h> ]  
 458 DAU: [Cause they were basing it a <on her]  
 459 m:obili[ty>  
 460 DOC: [Ya:h  
 461 (0.3)  
 462 DOC: She's not only not [fit] but it would be (0.2) it would  
 463 DAU: [Yeh]  
 464 DOC: be (0.4) cruel to [put her-] so it's some it's a  
 465 DAU: [y:eh ]  
 466 DOC: treatment that's already quite .hhh tricky for  
 467 someone who's fully alert and aware, but if you  
 468 don't know what's happening to you (0.8) fully (0.2)  
 469 then it's it seems cruel  
 470 DAU: Mhmm  
 471 DOC: .hh And we know that the (0.5) that the benefit of  
 472 it (1.0) °°isn't that great.°° So if we knew that it  
 473 would .hhh if we knew that it could ↑cure the cancer  
 474 SON: Mmm  
 475 DOC: then (0.2) we would do everything of course we  
 476 DOC: would [think of ways]  
 477 DAU: [I I ] surely [you can't be a hundred]  
 478 DOC: [°°But it can't°° ]

The doctor begins to explain that this hypothetical scenario would not allow treatment but is again interrupted by the daughter (line 458). However the doctor employs a delayed completion of her

utterance (line 462) to delete the sequential implicativeness of the daughter's interruption and therefore does not address this (Lerner, 1989). She uses stronger language, describing the use of radiotherapy in this situation as 'cruel', a term she uses twice (lines 464 and 469). This reference to cruelty suggests a strong moral stance that would be difficult to challenge; similar to references to a baby's 'best interests' seen in neonatal critical-care decision making (Shaw et al., 2016). The doctor then further accounts for the inappropriateness of treatment, once again using language associated with certainty (e.g. 'we know' lines 471), but using a litotes<sup>16</sup> ('isn't that great') which is associated with cautiousness in dealing with delicate matters (Bergmann, 1992; Lutfey & Maynard, 1998). Her reference to 'we' suggests this is the view of the whole medical profession, and is not just her decision.

The doctor refers to a different hypothetical situation in which treatment would be appropriate but rules this out (lines 472-478). This hypothetical situation where treatment would be appropriate is in contrast to the daughter's earlier hypothetical question (in lines 441-4). Whilst the daughter described a circumstance that could possibly apply to her mother in the future (being pain free but immobile), the doctor is clear that the circumstances in which treatment would be appropriate do not apply to their mother. The use of this this hypothetical scenario also demonstrates a willingness to provide treatment if only circumstances were different. She self-repairs from 'if we knew that it would' to 'if we knew that it could', which suggests that they would treat if there were any chance it could cure the cancer. The doctor uses an extreme case formulation (that they would 'of course' do 'everything' to treat her); a practice used to legitimise claims and often found in adversarial or defensive statements (Pomerantz, 1986).

The use of a hypothetical situation as a moral account was seen in other conversations within the corpus, but used by relatives not HCPs. The daughter of one patient had agreed with the doctor not to use antibiotics to treat a potential infection and used this practice to account for her decision, explaining that she would have opted to treat if it meant getting her mother back to the person she used to be (recording no. 05\_01). In another conversation, a daughter used this to explain why she hoped her mother would die sooner, suggesting that if she had a stroke and could possibly recover she would have a different point of view:

**Extract 7.iii** DOC: HCP05 (Consultant), DAU: R21 (Daughter of patient),  
08:16-08:40

01 DAU: I hope for her: I ho- this: (0.4) I know it sounds  
02 aw:ful, .hhh bu::t dy' know she's got nothing to,  
03 [.hhhh ]

<sup>16</sup> "Litotes describes the object to which it refers not directly, but through the negation of the opposite" (Bergmann, 1992: p.148)

04 DOC: [°It doesn't sound°]  
 05 DAU: nothing to ke- y' kno:w  
 06 (0.5)  
 07 DAU: When people have stro:k'es, it's slightly different you  
 08 can: (0.6) you can get better you [don't] know the:  
 09 DOC: [Yeh ]  
 10 DAU: (0.2) prognos like .hhh but, (0.2) she's got nothing  
 11 to: (0.5) y'know it's not gonna [get better, n:o ]  
 12 DOC: [Not going to get better]  
 13 (0.3)  
 14 DAU: So:  
 15 (0.4)  
 16 DOC: °Yeh°  
 17 DAU: Just for her: sake I'd (0.3) .hh  
 18 DOC: °Yeh°=  
 19 DAU: =I'd rather °it be sooner than later

All of these uses of hypothetical situations display a moral stance. They imply desire for the person to recover, and that it is only the specific circumstances preventing this happening, not an unwillingness to treat or a wish for the person to die.

#### 7.4 Disagreement about treatment: questioning certainty

As was seen with references to 'best interests' in neonatal critical care, there was minimal acknowledgement of the reference to cruelty from the family (Shaw et al., 2016). Instead, at lines 477-9 (Extract 7.4d) the daughter gives her most explicit challenge yet to the doctor. Whilst it would be difficult to challenge not treating on the basis of cruelty, the daughter ignores this and instead questions the certainty with which the doctor has stated that radiotherapy would be of little benefit (line 477-82). She challenges the doctor's extreme case formulation (lines 477-486), but the doctor responds with further certainty, softening this with 'I think' and a quieter voice (line 483). This is upgraded from 'I' to 'we can be sure' in lines 485 and 487, again making the position more difficult to challenge. This medical experience is further invoked by naming 'glioblastoma stage four' (line 490), which highlights that this is not about an individual case, but that it is medical fact that a stage four glioblastoma cannot be cured. The certainty expressed by the doctor across Extract 7.4a-d is in contrast to the qualifying language seen in Extract 7.1 and Extract 7.2 in this chapter and the prognostic statements in Chapter 5. Discussing the viability of treatment allows the doctor to speak with more certainty than giving a prognostic estimate, as the doctor can be sure that treatment cannot be provided.

**Extract 7.4** (d) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 11:44-12:04

476 DOC: would [think of ways]  
 477 DAU: [I I ] surely [you can't be a hundred]

478 DOC: [°But it can't° ]  
 479 DAU: percent (0.2) sure,  
 480 (0.3)  
 481 DAU: they can't (0.2) cure or not (.) statistically it  
 482 can't [but]  
 483 DOC: [°I ] think I can be° (0.2) °sure.°=  
 484 DAU: =Yeah I=  
 485 DOC: =°Think we [can be sure.°]  
 486 DAU: [Nobody know]s::  
 487 DOC: °I think we can be sure that we couldn't [cure the°]  
 488 DAU: [Mmm ]  
 489 (0.7)  
 490 DOC: °glioblastoma [stage four°]  
 491 DAU: [Um::: ]  
 492 (0.5)  
 493 DAU: also like (0.2) is there alternative (0.5)  
 494 medications that are not radiotherapy chemotherapy  
 495 (0.2) that you would suggest,

## 7.5 Disagreement about treatment: conversational disalignment

In Extract 7.4d above, rather than challenging the doctor's assessment, which would be difficult given the certainty displayed, the daughter simply does not acknowledge it and instead pursues the topic of treatment (line 493). The preface 'also' here presents this as a continuation of the daughter's previous utterances, effectively ignoring the doctor's assessment. By specifying 'not radiotherapy chemotherapy' in line 494, she treats the doctor's previous speech about treatment not being possible as only referring to these treatments, leaving open the possibility that there could be other options. Whilst the doctor's initial explanation for not being able to treat the patient referred specifically to radiotherapy (Extract 7.4c, line 423), the doctor had since stated that the tumour cannot be cured (Extract 7.4d, lines 487 and 489). The daughter has only picked up on the part of the doctor's talk that fits with her action of pursuing treatment options, ignoring the parts that do not.

There are then a further 176 lines of talk in which the daughter lists several different treatment options and the doctor explains why each of them is not appropriate. Below are three extracts exemplifying this:

**Extract 7.5** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
 SON: R20 (Son of patient), 12:11-12:42

501 DOC: What we use is (.) symptomatic treatment, that  
 502 means (0.3) s:teroids to reduce any ↑swelling [if  
 503 DAU: [Mm  
 504 DOC: that ↑happens, .hhh painkiller to u- do reduce any  
 505 pain, .hh and anti seizure medicines to (.) avoid it  
 506 causing seizures. .hhh (0.7) But to make your mum

507 (0.6) ↑well again, (0.7) °we don't have any  
 508 treat[ment] unfortunately.°  
 509 DAU: [Mm ]  
 510 (0.5)  
 511 DAU: Is the chemo stronger than: the radiotherapy?  
 512 DOC: (0.4) .hhhtch (0.4) a-hhh ↑It's it's just a  
 513 [different mode, ] of using it, hh um: (0.2) but  
 514 DAU: [°Or is it the same°]  
 515 DOC: neither chemotherapy nor radiotherapy can (0.6) get  
 516 rid of the can[cer.]  
 517 DAU: [Mmm ]  
 518 SON: [Mhm ]

**Extract 7.6** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
 SON: R20 (Son of patient), 13:57-14:10

564 DOC: There is noth (.) there is unfortunately there is  
 565 DAU: Mm  
 566 DOC: nothing we can do to: (0.8) to stop that cancer.  
 567 (0.7)  
 568 DAU: >Have you heard of< (.) immunotherapy?  
 569 DOC: Yeah [°I have°]  
 570 DAU: [Yeah ]  
 571 (0.4)  
 572 DOC: °Yeh°  
 573 DAU: Would you suggest (that) that?  
 574 DOC: (0.7) °It's again it's the same problem.°

**Extract 7.7** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
 SON: R20 (Son of patient), 15:29-15:41

638 DOC: .hhhh It's not proven that it works for (0.5) your  
 639 mum's type of cancer, and it's so it's not a not a  
 640 (0.4) [general] treatment,  
 641 DAU: [°Mhm° ]  
 642 DAU: °Mm°  
 643 DOC: °for- for glioblastoma°  
 644 (0.6)  
 645 DOC: .hh  
 646 DAU: Or the Optune the helmet thin:g

In each of these extracts, the doctor's summing up that treatment is not viable is followed by silence (Extract 7.5, line 510; Extract 7.6, line 567; and Extract 7.7, line 644), and then the daughter posing a question about another possible treatment option. These examples show both disalignment and disaffiliation, as the daughter's response does not accept the doctor's assessment and also does not fit with the doctor's previous talk (Stivers, Mondada, & Steensig, 2011). By asking the doctor questions, she derails the doctor's moves to establish the lack of treatment options, as a question obligates the doctor to either answer or account for not answering (Schegloff, 1968), rather than complete her talk on this.



A range of practices to respond to the daughter's questions are present across these extracts. In Extract 7.5, the doctor responds to the daughter's question in line 511 with a transformative answer (Stivers & Hayashi, 2010). The daughter's question about the relative strength of chemotherapy and radiotherapy is a yes-no polar question, but the doctor responds to say they are the same and that neither can 'get rid of the cancer'. This anticipates and blocks a potential question from the daughter about treating her mother with chemotherapy. In contrast, in Extract 7.6 the doctor aligns with the polar design of the question by answering 'yeah I have' (line 569), which leads to several more lines of talk and the daughter asking if she would suggest immunotherapy for her mother (line 573). The transformative answer was therefore a more efficient way to rule out treatment.

The doctor also displays her negative stance towards not being able to treat the patient. She does this in Extract 7.5 (line 508; 'unfortunately') and Extract 7.6 (line 564; self-repair from 'there is noth-' to 'there is unfortunately nothing'). This displays empathy, and as was seen with the doctor's hypothetical statement in Extract 7.4b, suggests a desire to treat the patient in different circumstances. A similar practice was seen in Extract 7.ii where the doctor states 'with the best will in the world'. Here he was affiliating himself with the family's stance of not changing the patient's dressings, whilst explaining to them that this approach may not be possible.

The doctor's statements do not receive any uptake from the daughter, instead each time she suggests another treatment option for consideration. After six minutes of this, the doctor invokes the highest authority of a national centre for brain tumours (see Extract 7.8), using strong, emotive language such as 'I promise' (line 676). In previous extracts, she had upgraded her authority from 'I' to 'we' and here this becomes 'they', presenting her position not as her personal opinion, or the opinion of her local colleagues or team, but that of the top experts in the field. She uses extreme case formulations (Pomerantz, 1986) to block the possibility of further questions about different individual treatments, referring to 'all options' (line 678) and 'everything that she could possibly have' (line 689). This effectively closes the topic of anti-cancer treatments as it would be difficult to suggest any further treatment following such an explicit ruling out of all treatment options.

**Extract 7.8** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
SON: R20 (Son of patient), 16:08-16:46

672 DOC: .hhhh It's nothing that (0.3) so (.) North Park  
673 is one of the s- that national centres [for:] (.) for  
674 SON: [Mm ]  
675 DOC: brain tumours. .hhh (0.6) °e° (0.4) I (.) I  
676 promise you that (0.3) that (0.8) your mum will've  
677 been seen by (0.2) by specialists wh:o really know  
678 (.) of all [opt]ions .hhh being it on a trial basis

679     DAU:                   [Mm ]  
680     DOC:     or on the N H S. .hhh So the (.) uh treatments  
681               that are not available on the on the N H S but  
682               are promising, (.) they will be run as trials  
683               .hh and (0.5) and (0.4) if your mum was eligible  
684               for (.) for one of those .hh the doctors they're  
685               very vehhry keen to get patients into those  
686               [trials so they] wouldn't (0.2) they wouldn't let  
687     SON:     [Mm yeh I know ]  
688     DOC:     your mum slip through it without (.) without (0.5)  
689               °everything that she could possibly° (0.8) have.

## 7.6 Disagreement with a prognostic estimate: questioning the account for the estimate

Following the closing of the topic of treatment in Extract 7.8, over 77 omitted lines the son complains that the tumour was not caught earlier and the doctor explains that even with early diagnosis, this sort of tumour has a poor outlook. At this point, the doctor has made two statements of the patient's short prognosis (Extract 7.1 and Extract 7.2) and has stated explicitly that the cancer cannot be treated. The doctor could therefore be considered to have 'done her job' of informing the family of the short prognosis. However, unlike the cases in Chapter 5, she has not received any displays of recognition of this short view of prognosis from the family members. Beginning at line 767 (Extract 7.9a), approximately 15 minutes 30 after first raising prognosis, the doctor embarks on the most direct provision of a prognosis yet by initiating talk about a time estimate.

**Extract 7.9   (a) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 18:36-19:21**

767     DOC:     You (.) >probably just< hheard me say that (0.7)  
768               a-hhh (0.3) °I° (0.6) something about hh (0.2)  
769               outlook  
770               (0.2)  
771     DOC:     .hh  
772               (0.8)  
773     DOC:     in terms of time.  
774               (1.4)  
775     DOC:     tsh (0.4) Do you want me to say something about  
776               that now?  
777               (1.0)  
778     DAU:     We'll: the:: diag (0.2) when they diagnosed her  
779               they said (0.8) um: without treatment it's li:ke  
780               (0.2) up to I don't know (0.4) three to six  
781               months,  
782     DOC:     °Mmm°  
783     DAU:     But with treatment it'll give e- (0.3) f:ourte- er  
784               fifteen mo:nths or something,  
785               (1.0)

786 DOC: .hh  
 787 DAU: U:m  
 788 (0.8)  
 789 DOC: So I'm (.) afraid the way I'm seeing you mum now,  
 790 (0.6) I don't th:ink (.) that (0.6) I would be  
 791 even thinking about months [anymore.]  
 792 SON: [Mhm ]  
 793 (0.2)  
 794 SON: Mhm  
 795 (1.1)  
 796 DOC: The way I'm seeing your mum now, (1.1) it could be  
 797 shorter than weeks it could just be days.  
 798 (0.3)  
 799 DOC: °(The way) [the way she looks° °right now.°]  
 800 DAU: [What are you basing that on? ]

The doctor begins 'you probably just heard me say', which topicalises prognostication by referring to previous speech about outlook (in an omitted line the doctor explained that tumours of this grade have a 'poor outlook'). Lines 767-773 are a partial news announcement, which Button and Casey (1985) showed can be used to project that there is more to tell and invite the co-participant to topicalise this using go ahead responses. However, there is a significant silence in line 774, with no uptake from the family. The doctor then explicitly asks the family if they want to be provided with a prognosis (lines 775-6). The way in which the doctor has initiated prognostic talk in this extract makes no reference to her previous attempts to do so. This suggests that rather than building on previous prognostic talk, she is taking a new approach to discussing prognosis in response to the previous resistance. This new approach is the only example in the corpus of a HCP checking willingness to hear a prognosis, and it does not follow any kind of initiation of the topic from the relatives. That the doctor asks this question therefore reflects the interactional troubles that have occurred up to this point in the conversation, as well as providing a contrast with previous conversations in which prognosis was often treated as 'known business-at-hand' (Button and Casey, 1988) with little need for further solicitation from HCPs.

The daughter begins her response with 'well' (line 778) which can function as an alert that the upcoming TCU will be non-straightforward and will be expanded upon to give the full response (Heritage, 2015; Schegloff & Lerner, 2009). The doctor orients to this using a continuer in her next turn ('mmm', line 782) and then not taking a turn following the daughters' suggestion of fifteen months survival time. This appears to treat the response as unfinished, possibly anticipating further expansion to bring it in more in line with the doctor's shorter prognosis. No such adjustment comes however, making the previous signs of disaffiliation on prognosis in little doubt.

The doctor moves to counter the daughter's optimistic prognosis and inform the family of her own time estimate. She forecasts the news with 'I'm afraid' (line 789) and emphasises the current view as superseding the prognosis stated by the daughter by using 'now' several times (lines 789, 796 and 799). The doctor again employs a litotes (by negating the likelihood of their mother living months or weeks; lines 790-1) suggesting cautiousness. Following no uptake of this statement (lines 792-795) she then provides an absolute categorical time estimate by suggesting that 'it could just be days' (line 797). This gradual stepping down from months to weeks to days resembles delaying or shrouding often seen in bad news delivery (Maynard, 2003).

This is the only case in the corpus where a HCP's prognostic time estimate is met with a challenge, as at line 800, in overlap with the doctor, the daughter questions how this prognosis was reached. Whereas in the examples in Chapter 5, the account for the prognosis was positioned next to the prognostic estimate, here it was given 15 minutes earlier in Extract 7.2. This long inferential distance means that the link between the evidence and the prognostic estimate is weakened, opening the doctor up to the daughter's challenge (Peräkylä, 1998, 2006).

**Extract 7.9** (b) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 19:21-20:15

801 (0.3)  
802 DOC: .hhh From what I said about the breathing,  
803 DAU: Mmm  
804 (0.4)  
805 DOC: tch.hh It seems to be affecting (.) really important  
806 centres of her brain.  
807 (1.1)  
808 DOC: °The cancer°  
809 (0.7)  
810 DOC: .hh  
811 (0.8)  
812 DOC: (>So-you-eh<) (1.6) we'll see, (0.3) tch.hh  
813 SON: Mm  
814 DOC: I can- the I've got no way of (.) properly  
815 [pred]icting it,  
816 DAU: [Mmm ]  
817 (0.4)  
818 DOC: And often patients .hh manage to (0.3) .hhhhhhh just  
819 be stro(h)ng des[pite] this for: for quite a while,  
820 DAU: [Mm ]  
821 SON: Mhm  
822 (1.0)  
823 DOC: All I can say is (.) if she [became more un]well we  
824 SON: [( )]  
825 DOC: have nothing (0.6) we have nothing that we can s  
826 (.) do to stop her body from (0.5) closing down  
827 and dying. (.) .hhh I would expect it to be peaceful,  
828 I don't expect that as a (0.2) crisis or anything,

829 (0.2) painful or (0.6) dramatic,  
830 DAU: Is there anything that you can test her breathing  
831 in a longer duration? Or time?  
832 (0.5)  
833 DOC: [.hhh ]  
834 DAU: [Like measure it (0.2) longer: than (0.5) just  
835 touching her:  
836 DOC: .hhh (0.7) [It's n it's no- ]  
837 DAU: [I know you probably did]  
838 (0.5)  
839 DAU: the right procedure [but I'm] just saying  
840 DOC: [°Y:eah° ]  
841 (0.4)  
842 DAU: to be sure.  
843 (0.3)

In response to this challenge, the doctor highlights that she has already explained the prognosis earlier in the conversation (Extract 7.9b, line 802). She receives no uptake of this account (see silences at lines 807, 809 and 811). Further evidence of interactional trouble is the doctor's self-initiated self-repair and 1.6 second pause at line 812. She acknowledges that the way of assessing prognosis is imprecise, but does then use an explicit reference to their mother 'dying' (line 827). Whilst the reference to her 'body' separates the person from the body somewhat, the direct reference to 'dying' is notable.

There are several examples of the use of explicit terms such as 'die' or 'dying' throughout the corpus, but this is only one of two examples where a doctor uses these terms to directly refer to a patient's prognosis (the other example was in Extract 5.11 in Chapter 5). In all other cases, these terms were used either when describing 'the dying process' in a general depersonalised way, or in the context of discussions of practicalities following death. For example in Extract 7.iv, the doctor, daughter (DAU) and son (SON) of the patient have been discussing the arrangements for taking the patient's body abroad. The doctor uses the word 'die' in line 7:

**Extract 7.iv** DOC: HCP02 (Consultant), DAU: R53 (Daughter of patient),  
SON: R52 (Son of patient), 11:14–11:23

01 DOC: So there there is a registration process.  
02 DAU: Mh:m,  
03 DOC: Um which we'll give you the information for.  
04 DAU: °Okay.°  
05 SON: Yeh.  
06 (0.2)  
07 DOC: If he does die over the weekend, (0.3)  
08 SON: °Okay,°  
09 DOC: you can't do anything till Monday.

This reflects Ekberg et al's (2019) finding that death was only made explicit when not referring to the specific individual or where the death itself was ancillary to the focus of the discussion.

In contrast, in Extract 7.9b, ‘dying’ is used as part of a turn that reinforces her earlier statements about a lack of treatment options and her prognostic statements. Whilst previously she had stated that ‘there is nothing we can do to stop that cancer’ (see Extract 7.6), here this is strengthened to ‘nothing we can do to stop her body closing down and dying’. The doctor has stated the uncertainty of the exact timing (see lines 814-9), but here she expresses certainty that ultimately their mother will die. Following this there is a micropause, but the doctor quickly moves on to talk about comfort care. This transitions to a more ‘bright side’ (Holt, 1993) view and is a strategy which was successful for exiting prognostic talk in previous conversations (see Chapter 6). That she moves onto this practice, seen throughout the corpus as a means of exiting prognostic talk, suggests that her statement about their mother dying was part of a summing up and topic closing move. However here this is met with another question from the daughter (lines 830-831). As in the daughter’s challenges in section 7.5, this question once again is not fitted to the doctor’s previous talk creating a challenge to her prognostic talk.

The daughter’s first question about how a prognosis was reached occurred early in the conversation in Extract 7.2. This became more of an explicit challenge in Extract 7.9a, and here in Extract 7.9b, the daughter further upgrades previous challenges to question whether the correct procedure has been used. She refers to the doctor as ‘just touching her’ (lines 834-5), which implies that touching is not a scientific measure and the ‘just’ suggests that not enough has been done. This is further alluded to in the daughter’s suggestion that the doctor ‘probably’ did the right procedure (lines 837 and 839). Whilst this may appear to be a concession that downgrades the challenge slightly, it also questions the doctor’s judgement.

In Extract 7.9c, the doctor begins to respond, but is interrupted by the son clarifying the daughter’s question (lines 850-2). At this point, the doctor modifies her response to say that they will check the breathing regularly (line 855). This is not an objective medical examination and would simply mean staff generally monitoring for signs of deterioration. However the terms ‘check’ and ‘regularly’ sound formal and echo the family members’ references to testing (line 830, Extract 7.9b), confirming and verifying (line 851, Extract 7.9c). This is presented as a compromise with the family; prognosis cannot be scientifically measured, but this offer emphasises that their mother will continue to be monitored for changes in her condition and given medical care.

**Extract 7.9** (c) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 20:16-20:38

844 DOC: .hhh ↑I don’t (0.3) so (.) there’s no need to do it  
845 because it’s [not] causing her any h: any (0.8)  
846 DAU: [m ]

847 DOC: distress? .hhh (0.3) It's just a sign for me that  
848 I'm (0.2) makes me alert? (0.8) If you notice it  
849 more, (.) [°then it means that the time is getting shorter°]  
850 SON: [No I think she means like the the s ]  
851 >the the< .hhhh just to confirm (.) or verify that  
852 [the the sign yeah ] yeah mm  
853 DOC: [Whether I'm sure about it?]  
854 SON: [I think that's what sh]  
855 DOC: [I think we can see ] it over the next few days  
856 regularly. We can just [check it reg]ularly.  
857 DAU: [mMmm ]

In this extract, the doctor used more formal, technical language in order to provide a compromise with the family. A similar strategy was used by the doctor in the conversation about sedative medication, although in that case the doctor downgraded rather than upgraded the references to medical interventions. The family had shown signs of becoming more open to pain medications and so the doctor makes a suggestion for a compromise:

**Extract 7.v** DOC: HCP02 (Consultant), PAR: R06 (Partner of patient),  
MOT: R07 (Mother of patient), 07:52-08:18

01 DOC: So how about (0.2) ((claps)) um: (0.3) t (0.9)  
02 if ↑I suggest that we give he:r (.)  
03 PAR: Mm  
04 DOC: a bit more pain kille:r  
05 PAR: [Mmm ]  
06 DOC: [in the] form of increasing the patch,  
07 PAR: yes [yes]  
08 MOT: [Mmm]  
09 (0.3)  
10 DOC: and [there]fore no needles  
11 MOT: [Yeh ]  
12 PAR: Mm (0.2) [yeah]  
13 DOC: [And ] hopefully that's acceptable for her,  
14 (0.2)  
15 PAR: Mm  
16 (0.5)  
17 DOC: And then (1.1) if: (0.4) if there's a nee:d (0.5)  
18 [for] instance to wash and change her (0.7) we can  
19 PAR: [Mm ]  
20 DOC: give her an extra boost (0.7) [in the form of a]  
21 PAR: [Yeh okay ]  
22 DOC: small injection  
23 PAR: Yeah ok

Whilst in the conversation leading up to Extract 7.9c the family were pushing for more medical intervention, in this conversation the family had shown a preference for less intervention. Therefore the doctor uses minimising language (line 4, 'a bit'; line 10, 'no needles'; line 22, 'small injection'). Stivers (2005) showed that parental resistance to treatment recommendations led to concessions from physicians (either possible future concessions or changes to the treatment recommendation).

Similarly, offers of compromise are seen following resistance in Extract 7.9c and Extract 7.v, but the doctors have designed these offers in ways that upgrade the level of compromise being put forward.

In the prognostic conversation, the doctor does then make clear what these ‘checks’ would involve (Extract 7.9d, lines 859-60). She invites the family to observe the changes for themselves, providing further evidence for her prognosis that they have access to:

**Extract 7.9** (d) DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 20:38-20:59

858 (1.0)  
 859 DOC: And it's literally it's (0.2) nothing more s more  
 860 special than (0.2) counting her breaths. And you  
 861 [will be] m [might be noticing that sitting with her]  
 862 DAU: [Mmm ]  
 863 SON: [So is that is that what ]  
 864 usually happens to:: (1.0) uh the:: patients with  
 865 er (0.4)[that ]  
 866 DOC: [Brain] tumours,  
 867 (0.5)  
 868 SON: That brain tumour, is it where: (1.1) when  
 869 there's:: when they're dyin::g is that (.) what  
 870 causes it the brain to: stop communicating with the  
 871 heart,

At this point, the son provides some signs of recognition that his mother may be dying (lines 863-71). His question is depersonalised as he refers to ‘patients’ and when ‘they’re’ dying, therefore distancing the process of dying from his mother. However he links the previous description of his mother’s current state (‘that’ in line 863 refers to the doctors last turn describing his mother’s breathing), to what happens when people die. He also uses the term ‘dying’ for the first time, reflecting the doctor’s language in Extract 7.9b.

The son’s question about the process of dying resembles the sorts of questions seen when exiting prognostic talk discussed in the previous chapter. However, following 57 omitted lines of talk about what happens to the body at the end of life, prognosis is re-topicalised with further disagreement, this time from the son:

**Extract 7.10** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient), SON: R20 (Son of patient), 22:06-23:00

929 SON: But that's:: the er the way like er that you're  
 930 saying days (.) I don't know if the when: .hhh the  
 931 thing with the brain is: (0.7) just I: eh from  
 932 r:researching just reading other patients er:: (0.6)  
 933 that've gone through similar experiences they say  
 934 (0.5) like the last stages, we notice: (0.3) a lot  
 935 of memory loss and a lot of (0.4) confusion,



936 DOC: [Mmm]  
 937 (0.2)  
 938 DOC: m↓mm  
 939 (0.4)  
 940 SON: But that's not what we're seeing right now. So:: (.)  
 941 I'm just wondering (0.8) is that (0.5) is tha:t  
 942 (0.5) what's it called a:: (0.6) high factor,  
 943 (0.5)  
 944 SON: something that (0.4) [will ] determine (0.3) the last  
 945 DOC: [°So°°]  
 946 SON: days. The memory loss and the confusion, .h  
 947 (0.3)  
 948 SON: or:: °#n-eh-er#° (0.3) [is that not separate  
 949 DOC: [It doesn't need to be.]  
 950 (0.4)  
 951 SON: [It doesn't,]  
 952 DOC: [It can ] it happens often, (0.2) that people  
 953 with brain tumours will get confused an:d and (0.4)  
 954 SON: But it [doesn't ]  
 955 DOC: [don't rec]ognise people it doesn't have to.  
 956 [.hhh] So if the: (0.3) .hh (0.9) if the  
 957 SON: [Mmm ]  
 958 DOC: [other: if the other control levels starts earlier,]  
 959 SON: [Just depends on wha:t section of the brain yeh. ]  
 960 DOC: exactly.  
 961 SON: [Yea::h I get it.  
 962 (0.3)  
 963 DOC: °°Then that'll do that.°°

It could be suggested that this is a stronger challenge to the doctor than the daughter's previous challenges because over lines 929-940 in Extract 7.10 the son questions the prognosis itself, not just how it was reached. However the design of the son's disagreement downgrades the strength of the challenge and is more fitted to the doctor's talk than the daughter's previous challenges were. He follows the conversational norm of providing an account for his disagreement in lines 929-940 (Pomerantz, 1984; Sacks, 1987), throughout which there are numerous self-initiated self-repairs where he switches between upgrading and downgrading his own epistemic access. He begins with 'the way like er you're saying days', which displays scepticism as it suggests the prognosis is just something that has been said, not a clinical opinion based on evidence. His 'I don't know' (line 930) reduces his own authority, but he then repairs to 'the thing with the brain is', which resembles an expert view. Whilst the doctor's account for the prognosis was based on descriptions of signs of dying generally, he introduces specific knowledge about brain tumours. He backs this up with 'from researching' but this is then downgraded to 'just reading'. He draws on the epistemics of experience (other people's experiences of memory loss and confusion at the end of life) to challenge the doctor's epistemics of expertise (Heritage, 2013). In line 940, he makes his statement of disagreement ('that's

not what we're seeing right now'). This contrasts his and his sister's experience of what they can see now, with his reference in line 930 to what the doctor was simply 'saying'.

However the son then downgrades his statement of disagreement to a question about whether they should be seeing memory loss and confusion if their mother is in fact dying (lines 941-6). This shifts the epistemic gradient (Heritage & Raymond, 2012) back in favour of the doctor. He downgrades his challenge further at line 948 by suggesting another possibility ('or:: °#n-eh-er#° (0.3) is that not separate').

There are numerous opportunities throughout the son's turns where the doctor could take over the talk but does not (lines 936-939, 943, 947 and the abandoned whispered 'so' at line 945). By allowing the son time to talk further, he talks himself out of his challenge somewhat. It also means that the son elaborates further, giving the doctor more options for her response and meaning she can address everything the son has said within this response.

A similar occurrence is seen in the conversation about pain medications. In lines 1, 4, and 6-7 of Extract 7.vi (which occurred 52 seconds prior to Extract 7.v), the family refer to their experience of the patient's past behaviour to disagree with the doctor's suggestion of increasing pain medications:

**Extract 7.vi** DOC: HCP02 (Consultant), PAR: R06 (Partner of patient),  
MOT: R07 (Mother of patient), 07:02-07:15

01 PAR: She was always resis re[sisted them] for [years]  
02 DOC: [Yeh ]  
03 MOT: [Mmm ]  
04 PAR: even the morphine she [resist]ed it [until well] she  
05 DOC: [Yeah ] [I know ]  
06 PAR: couldn't resist [it anymore ]  
07 MOT: [Until the bit]ter [end sort] of  
08 DOC: [Okay. ]  
09 MOT: thing [and ] [yea::h ]  
10 PAR: [But ]  
11 DOC: [Well] [in that] case (0.3) em: (0.7)  
12 PAR: But when you say increasing the [morph]ine  
13 DOC: [Mmm ]  
14 PAR: maybe that is a good idea cause that's that's the  
15 pain relieving [side of it.]  
16 DOC: [It is ] it is.

At line 11 the doctor appears to be beginning to concede to the family's point of view, but at lines 12 and 14 the partner begins to talk himself around to the idea. The doctor quickly abandons his turn to support the partner's suggestion that morphine could be a good idea. In the omitted lines that follow, the partner elaborates on his concerns, which the doctor is then able to address, leading to his concessionary treatment recommendation seen previously in Extract 7.v. Had the doctor continued

his turn, it could have blocked the partner talking further and coming round towards the doctor's point of view, as was seen here and in Extract 7.10.

Returning to Extract 7.10, in line 952 the doctor validates the son's understanding ('it happens often'), again resembling the beginning of supportive disagreement (Weiste, 2015). The son begins to display that he has understood (lines 954 and 959) as the doctor describes in overlap with him that patients are not always confused when they are imminently dying. At line 961, there is an explicit statement of understanding from the son ('yeah I get it'). This marks the end of the talk on prognostication as the doctor concludes her explanation (line 963). Whilst the daughter's stance remains somewhat unclear, the son's display of understanding appears to be sufficient for the doctor not to pursue prognostic talk any further.

What follows is 45 omitted lines of talk about where the tumour is in the brain, from which the doctor initiates the topic of pain and pain relief. She does this by linking pain to the part of the brain where the tumour is located and then in further omitted talk explains that she is not concerned about thalamic pain and that any emerging pain could be treated:

**Extract 7.11** DOC: HCP05 (Consultant), DAU: R19 (Daughter of patient),  
SON: R20 (Son of patient), 23:40-23:51

1009 DOC: thalamus ↑yeh .hh so that's what I've (0.2) ↑I've  
1010 sp- (.) what I spoke about (.) where you can get  
1011 (0.4) p↓ain as well [caused by] (0.2) by ↑tumours  
1012 DAU: [mmm ]  
1013 DOC: [there] .hhh so that's why we- why I'm particularly  
1014 DAU: [mm ]  
1015 DOC: (.) I'd be particularly careful to watch her for  
1016 ↑pain

The omitted talk about the location of the tumour in the brain means that this talk about pain relief does not flow immediately from the prognostic talk as was seen in examples in the previous chapter. Instead, the doctor topicalises pain and pain relief in a stepwise fashion (Jefferson, 1984) by linking pain to the part of the brain where the tumour is located and then in further omitted talk explains that she is not concerned about thalamic pain and that any emerging pain could be treated. The use of 'so' in line 1009 presents the topic as relevant and an action already on the agenda (Bolden, 2009), further supported by describing it as 'what I spoke about' (lines 1009-10). Whilst the action of informing the family of the prognosis is much more complex and drawn out than the examples in Chapter 5, the doctor uses the same strategy of discussing what can be done to treat pain in order to exit prognostic talk.

## 7.7 Discussion

This chapter has described the multiple ways in which relatives resisted prognostic talk and disagreed with prognostic statements, and how the doctor responded to this in pursuit of a display of prognostic understanding.

The first section showed that when relatives did not acknowledge the doctor's prognostic statements, this was treated as passive resistance. Previous research has shown that whilst doctors' diagnoses do not require displays of acknowledgement or agreement for the conversation to progress, treatment recommendations do (Stivers, 2005). Further evidence for this norm during treatment recommendations was presented in the example of relatives' passive resistance to a doctor's recommendations for sedative medication (see Extract 7.i). The main analysis presented in this chapter revealed that in conversations with relatives at the terminal phase, prognosis was treated similarly to treatment recommendations in that unmarked acknowledgements were treated as passive resistance and so resulted in the doctor pursuing a display of understanding. When we consider what actions providing a diagnosis vs a terminal-phase prognostic estimate perform, this difference makes sense. A diagnosis alone would not be considered adequate provision of information from a doctor without a related treatment recommendation. It is therefore understandable that patients and families may reserve displays of acknowledgement or acceptance until they hear the treatment recommendation. However at the terminal-phase, whilst HCPs often went on to discuss comfort care (as described in Chapter 6), the prognosis was the key part of the information provision that the relative needed to understand and therefore acknowledge.

The result of the relatives' resistance to prognostic talk was that doctor made increasingly explicit prognostic statements, eventually leading to an absolute categorical prognostic statement and direct reference to 'dying'. In studies of consultations with oncology and palliative care patients, doctors have also been observed to become increasingly explicit in their references to prognosis and end-of-life issues following a lack of patient uptake (Lutfey & Maynard, 1998; Pino et al., 2016). However the least explicit statement in the conversation analysed in this chapter ('I'm concerned about how long her body can carry on living like this') was already much more explicit than the most overt statements in these previous studies (e.g. 'after a lot of thought we haven't come up with any treatment for the melanoma', Lutfey & Maynard, 1998; 'do you ever wonder what will happen if they don't have treatment that works?', Pino et al., 2016). This could reflect the necessity for relatives to understand the prognosis at this point so close to the end of the patient's life. Whilst the directness of prognostic talk in Chapter 5 reflected an orientation to the relative's rights to prognostic information, the

directness and the doctor's pursuit of prognostic talk in this chapter appear to reflect the responsibility to provide this information, even in the face of resistance. The complexity of this process and the time it took for the doctor to give an absolute categorical time estimate is further evidence for the preference for the relative to request this information, as identified in Chapter 5.

As the doctor pursued prognostic talk, the relatives used different practices to resist this talk and disagree with the doctor's stance. One example of this was to question the doctor's certainty about the prognosis. In their study of the delivery of uncertain diagnostic genome test results to parents, Stivers and Timmermans (2016) found that parents sometimes questioned the clinician's certainty. The authors argued that the parents in this study were trying to elicit greater certainty from the clinician, but this actually led to clinicians downgrading their certainty. In contrast, in the conversation presented in this chapter, the daughter was arguing that the doctor should display less certainty and this led to the doctor upgrading her certainty. Whilst the doctor did highlight the uncertainty of prognostic predictions, the relatives' disaffiliating stance meant that she had to balance being honest about her level of certainty with ensuring the relatives understood their mother was likely to die soon. She achieved this by using certain, unequivocal language when discussing prognostic issues about which she could be sure (i.e. that there was no curative treatment and their mother was dying), while being honest about her uncertainty relating to exactly when this was likely to happen.

The most striking form of resistance was the daughter's use of disaligning responses to the doctor's statements about the lack of treatment options and the patient's short prognosis. When a speaker makes an assessment, the relevant next turn from the recipient is to provide an acknowledgement, agreement or disagreement, and if this doesn't happen it is noticeably absent (Schegloff, 1968). The daughter's response to the doctor's prognostic statement did what Goodwin (2006) described as 'refusing to provide a sequentially relevant next action'. Whilst initially this was simply the passive resistance described earlier, she then went on to provide disaligning responses to prognostic statements, usually questions. Goodwin (2006) described how these types of responses reject the constraints placed on them by the previous turn. Therefore by refusing to provide a sequentially relevant next action in response to the doctor's statement, the daughter rejected the requirement for her to engage directly in prognostic talk or display acceptance of the lack of treatment options. This makes it difficult to assess the potential effectiveness of the doctor's various communicative strategies. No matter how effective certain strategies are generally in prognostic conversations, during a disagreement relatives can ignore the previous action and provide a disaligning response.

In contrast, later in section 7.6, the son's disagreement with the doctor was more straightforward to deal with as it was fitted to the doctor's talk. In particular, he accounted for his disagreement with the doctor, a practice usually associated with dispreferred responses (Pomerantz, 1984; Sacks, 1987). He used his knowledge of his mother's specific situation to challenge the doctor's general statements about the dying process. This utilisation of the 'epistemics of experience' (Heritage, 2013) to challenge a doctor was also seen in the sedation medication conversation (see Extract 7.vi) and has been identified in a range of other healthcare contexts, often leading to concessions from HCPs (Ekberg & LeCouteur, 2015; Lindström & Weatherall, 2015; Stivers & Timmermans, 2016). Throughout and following this challenge, the doctor did not take opportunities to take over the talk, enabling the son to elaborate, eventually resulting in the son downgrading his challenge. Pino et al. (2016) identified doctors' use of 'elaboration solicitations' to create opportunities for patients to raise and articulate end-of-life concerns. Elaboration solicitations allowed doctors to gauge the patient's level of understanding and readiness, and were participatory as they did not push end-of-life talk on the patient. In this chapter, we saw that once a concern had been raised, simply allowing space in the conversation provided the opportunity for elaboration from the relative. Allowing elaboration meant that the doctor had a better understanding of the son's perspective before responding and reduced the level of disagreement between them.

In addition to the challenges to the doctor's attempts at prognostic talk, the main conversation in this chapter differed to those in Chapter 5 in the treatment of the valence of the news. Providing a short prognosis to relatives at the end of life cannot be simply described as 'breaking bad news'. As seen in Extract 7.iii, when relatives are already aware that the patient is dying, a short prognosis can provide them with an element of relief that the patient will not be suffering for much longer. However in the conversation presented in this chapter, the relatives' lack of awareness and understanding of their mother's prognosis meant that there were more features of typical 'bad news' provision than in the prognostication sequences seen in Chapter 5. A clear example of this was in Extract 7.9a where the doctor checked the family's willingness to be provided with a prognostic estimate. Checking readiness and willingness to receive a prognosis following life expectancy estimate requests is often seen in prognostic talk with patients (Pino & Parry, 2018), but as discussed in section 7.6, was not seen in any other conversations within the corpus. Preparing the conversational environment in this way could be seen as an attempt to avoid bluntness in the giving of bad news (Maynard, 1996; Pino & Parry, 2018). This was also seen in signs of cautiousness in the doctor's delivery of the prognosis that have previously been associated with breaking bad news and addressing unrealistic expectations. These

included employing litotes (Maynard, 2003; Maynard et al., 2016), minimising language (Land et al., 2019) and forecasting the negative valence of the news (Beach, 2002; Lutfey & Maynard, 1998).

Further evidence that this was more typical of a bad news conversation is the doctor's orientation to the potential for 'blaming the messenger'. The doctor in this conversation was after all simply a messenger; she was not responsible for their mother's deterioration and was not even involved in the decision not to use any further curative treatment. Maynard (2003) described how when giving bad news, the bearer of this news takes steps to avoid attribution of blame to themselves, for example by placing the blame elsewhere or presenting the bad news as a "logical sequence of progressive events" (p.213). The doctor did this at several points during the conversation. For example in Extract 7.4b she placed the responsibility for the lack of treatment options to the patient's condition, rather than any HCPs. In Extract 7.4c, she then presented a set of circumstances in which patients cannot be treated, the logical upshot of which was that their mother could not have treatment. This type of general case formulation where a doctor guides the recipient to make inferences about their own situation has been observed in other studies, including surgeons recommending no surgery and palliative care clinicians addressing patient's unrealistic expectations (Clark & Hudak, 2011; Land et al., 2019). These practices move the agency for the bad news away from the doctor and point to it being due to circumstances out of their control.

Linked to this practice of avoiding being blamed as the messenger, were the elements of moral positioning in the ways the doctor gave the bad news and explained it to the family. In his description of the ways professionals avoid blame, Maynard (2003) points to Clark and LaBeff's (1982) interview study which found that when informing family members of a patient's death, physicians will stress that they and the family had done everything they could for the patient. The systematic review in Chapter 1 (Anderson et al., 2019) found similar practices, as physicians and families justified their decisions as 'right' with references to the treatments that had been tried and the patient's wishes. This was seen in section 7.5 where the doctor explicitly stated that their mother would have been offered every possible treatment by the national centre for brain tumours. Whilst the main result of this was to shut down further questions from the daughter about treatment, there was a clear moral element as the doctor 'promised' that no appropriate treatments have been held back. A further example was the doctor positioning herself as wishing the patient could be treated employing hypothetical situations where the patient would have been treated. Clark and Hudak (2011) also found the use of hypothetical scenarios to rule out treatment, but in the current chapter, this was combined with the doctor displaying her negative stance towards the situation and keenness to treat in other circumstances. She did this by using language such as 'unfortunately' and 'we would do

everything of course'. These practices allowed the doctor to present as empathetic and appreciating the relatives' point of view, whilst not changing her position of disagreement (Ford et al., 2019; Land et al., 2019; Weiste, 2015).

This chapter has demonstrated that, despite evidence in Chapter 5 that most relatives had a pre-existing awareness of their family member's short prognosis and the related uncertainty, this was not always the case. Instead, in this conversation, prognostic talk was much more reminiscent of 'breaking bad news'. This left the doctor more open to resistance and disagreement from family members as practices that were successful in eliciting displays of understanding in previous conversations did not have the same result here. The analysis described the different ways in which relatives challenged the doctor's perspective and the strategies used by the doctor to pursue displays of prognostic understanding.



## **Chapter 8   Relatives' and healthcare professionals' perceptions of communication: Interview and focus group findings**

This chapter outlines the findings from the interviews with relatives and the interview and focus group with healthcare professionals (HCPs). A description of the sample is provided followed by a thematic analysis of the interviews and focus group. The analysis explores relatives' and HCPs' perceptions about their experiences of communication at the end of life in a hospice, and what they consider important for this communication. In section 8.3, the findings are discussed in reference to existing literature and the conversation analytic findings from Chapters 5-7.

### **8.1   Sample**

All senior HCP and relative participants who gave consent for the use of their recordings were asked if they would be willing to be contacted for an interview. Thirty-one out of 51 relatives agreed, 12 of whom were interviewed. Of the remaining 19 who agreed to be contacted, 12 could not be contacted and seven decided not to take part, citing not feeling comfortable talking about their experiences (n=4), not having enough time (n=2) and being out of the country (n=1). Four relative interviews were conducted at participants' homes, three at UCL, two at the hospice, two over the phone, and one at a café. Interviews with relatives lasted an average of 50 minutes (range=29-75 minutes) and took place between 140 and 197 days after their conversation was recorded. The majority of relatives interviewed were White British or Irish, and two thirds were female. Half were the partner or spouse of a patient and a third were adult children of a patient (see Table 8.1 for full demographic details).

All five senior HCPs whose recordings were included in the study took part in an interview or focus group. Four doctors (two consultants and two registrars) took part in a focus group together at the hospice, but the clinical nurse specialist (CNS) could not be contacted prior to the focus group and so was interviewed separately in her home. By the time of the interviews, due to training rotations and job changes, only the two consultants were still working at the hospice.

**Table 8.1** Demographics of participants in interviews/ focus group

	HCPs (N=5)	Relatives (N=12)
Female, N (%)	3 (60)	8 (66.7)
Mean age, years (range)	40.8 (31-53)	56.0 (27-80)
Ethnicity		
White British or Irish, N (%)	2 (40)	11 (91.7)
White Other, N (%)	1 (20)	1 (8.3)
Mixed white/Asian, N (%)	2 (40)	0
Mean years in palliative care (range)	9.4 (1.7-19)	-
Job title		
Consultant, N (%)	2 (40)	-
Specialist registrar, N (%)	2 (40)	-
Clinical nurse specialist, N (%)	1 (20)	-
Relation to patient		
Partner/Spouse, N (%)	-	6 (50)
Adult child, N (%)	-	4 (33.3)
Friend, N (%)	-	1 (8.3)
Adult grandchild, N (%)	-	1 (8.3)

## 8.2 Analysis

The themes presented in Table 8.2 were identified from both the interviews with relatives and the HCP interview and focus group. These themes describe four key elements of communication that were identified as important: the context in which conversations take place; the time and availability of HCPs; building relationships between HCPs and relatives; and the ways in which information was provided to relatives.

**Table 8.2** Themes from analysis of interviews and focus group

Theme	Sub-themes
8.2.1 Context of the communication	<i>a) 'It was just a very comfortable place to be': Welcoming atmosphere</i> <i>b) 'It caused quite some trouble': The calmness or chaos of individual patient situations</i> <i>c) 'We assume the patient can still hear us': Discussions at or away from the bedside</i> <i>d) 'People really respected the space': Presence and privacy</i>

Theme	Sub-themes
8.2.2 Time and availability of healthcare staff	<i>a) 'If you rang the bell, somebody would come': Availability</i> <i>b) 'You could ask them anything': Allowing time</i> <i>c) 'She kind of disappeared': Consistency of care</i>
8.2.3 Relationships with staff	<i>a) 'Those bits of individuals' respect in humanity': Informal conversations and personalised care</i> <i>b) 'It was really nice that people asked': HCPs' roles in providing emotional support</i> <i>c) 'You don't have to worry about that': Explaining and reassuring</i>
8.2.4 Delivery of information	<i>a) 'Very calming and very measured': Bedside manner</i> <i>b) 'Seeds can fall on stony ground': Clarity of communication</i> <i>c) 'You're no longer at doctor knows best': Consultation and compromise</i> <i>d) 'The prognosis is not in my tick list': Prognosis for practical planning</i> <i>e) 'I tell them we're really bad at it': Honesty and uncertainty</i>

### **8.2.1 Context of the communication**

The context in which the communication took place impacted relatives' opinions of the communication they experienced. This included the wider environment of the hospice in general, patients' individual circumstances, and when and where conversations with HCPs took place. HCPs also described the importance of creating a comfortable environment where families could feel relaxed, as well as discussing the challenges of complex situations for their communication with relatives. The following four sub-themes discuss each of these features of the context of communication and how they impacted relatives' and HCPs' experiences and perceptions.

#### *a) 'It was just a very comfortable place to be': Welcoming atmosphere*

Relatives described a general welcoming atmosphere within the hospice and this arose through the actions of hospice staff, the facilities available and the general ethos of the hospice. This went beyond the medical staff to include receptionists, cleaners, housekeepers and kitchen staff. Sometimes they provided examples such as reception staff knowing their names or doctors making an effort to speak to them in the canteen. Often however, they simply described a general feeling of compassionate care. The son of one patient echoed what many relatives explained about feeling that the staff genuinely cared about the patient and family:

It was quite reassuring that some of the people seemed to really enjoy what they do. So some of the staff had been there for a long time and had sort of chosen the hospice as a career if you like, and that came across

**Was there anything in particular that made you feel that way?**

I think it was just, the general discussions with all the staff. Those who were kind of engaging, you felt that they were doing this because they, I don't think enjoyed the work is the right word, but fulfilled (R32, Son of patient)

Relatives felt confident in the patient's care, and secure and welcomed at the hospice. Organisational factors such as open visiting hours, the option to stay overnight, and providing a family room and canteen further added to the feeling of being welcome in the hospice and therefore of compassionate communication. They felt assured that their relative was being looked after, as well as feeling comfortable that they could be in the hospice and near the dying patient:

They did say to me, if you like you can stay here. And I thought that that was amazing and they put up a bed in the room for me which was just wonderful because I could be with him all the time and that was fantastic... They had a family room which was fantastic too and that was lovely because a lot of my family were coming and going and it was very good and we could make coffee for ourselves and it was just a very comfortable place to be, and very warm, it had a warm atmosphere (R47, Wife of patient)

HCPs also highlighted the importance of a welcoming atmosphere. They discussed encouraging families to keep talking with the patient and to feel comfortable to make noise, bring in drinks and make the room feel like home. Both HCPs and relatives talked about "de-clinicalising" the space, particularly in comparison to hospitals. In the focus group, the doctors explained the impact of a lighter atmosphere in which families can relax, as opposed to a morose environment in which people feel they should remain silent and mournful:

HCP09: Morbid scene of someone dying in the bed and there's laughter in the room. That's a wonderful thing because death is part of life. That's our belief and one of our core philosophies. So being able to laugh is incredibly empowering, and a doctor validating that saying, even coming up with a joke or whatever is very powerful. It lifts the mood.

HCP05: Because it's a bit like putting some normal

HCP09: Yes, exactly.

HCP05: Normal breaths back into the room because those rooms can be really heavy. So if you manage to do that, that's great.

(HCP09, registrar; HCP05, consultant)

*b) 'It caused quite some trouble': The calmness or chaos of individual patient situations*

The simplicity or complexity, and calm or chaotic nature of individual situations impacted on the quality of the communication. In more positive accounts, when patients had a gradual decline or followed a predictable course, this allowed clearer communication and often meant information was drip-fed over time so that families had a clear idea of what was happening and what to expect. Conversely, in more complex situations such as when the patient's decline was rapid or their condition was unstable, the quality of communication suffered. This showed that no matter how much the hospice promoted the 'welcoming atmosphere' described in the previous sub-theme, the stable or fluctuating decline of a patient could still have an impact on relatives' perceptions of communication. Some families described how the HCPs did the best job they could within difficult circumstances. Whilst they were sympathetic to the circumstances, some of the negative comments about communication arose in these more complex contexts. For instance one relative, whose mother's disease course had been unpredictable, had numerous conversations about discharging her mother to a nursing home. She was sympathetic to the reasons behind this but spoke of one conversation she found particularly distressing:

She was like well I think it's time I think she needs to go to a nursing home and I thought she was a bit harsh... and actually at that time I didn't think that mum was that stable as they thought, but equally I couldn't predict, and I said look I don't think, but she was quite she was quite pushy  
(R01, Daughter of patient)

For HCPs, the main patient-related situation which could impact communication was an unstable, unpredictable prognosis. They described patients, similar to the one referenced in the relative's quote above, who seemed like they were imminently dying but lived for weeks or longer, making it difficult to give relatives a consistent message. In other situations, the patient had rapidly deteriorated between their referral to the hospice and their arrival, and so relatives had different expectations for the patient's time at the hospice and their prognosis. In these situations HCPs described "falling foul of expectations" and needing to remember to check what relatives' expectations were at the beginning of conversations:

We had a patient referred for a rehab, and there was a wait for them to be transferred from the hospital to the hospice, and in that time they deteriorated. Then the message we got from the referring team and the palliative care team in the hospital was this patient is dying now. This is a terminal care admission. That was entirely not what the family understood, and it caused quite some trouble. Even though I've been doing it a long time, and I'm aware of the pitfalls, I still miss that (HCP02, Consultant)

c) *'We assume the patient can still hear us': Discussions at or away from the bedside*

Relatives described the importance of the settings in which conversations took place. Many appreciated conversations being had with the patient present, even once the patient had lost consciousness. There were also certain conversations which they did not want to have with the patient present and they felt that HCPs were good at sensing when it would be best to meet away from the bedside. Some would have conversations in the patient's room but then have a further conversation with the HCP elsewhere afterwards. HCPs stated a preference to have sensitive conversations, particularly relating to prognosis, away from the bedside, but that ultimately it was down to the relatives' preference. They described preparing in advance by looking for a private room before going in to see the relatives so that they could move straight into the conversation. When having conversation in the patient's room, HCPs assumed that the patient could still hear and so were cautious about how they spoke:

I don't think it's particularly in the best interests of the patient to have that conversation in front of them, because when capacity is lost it is technically academic. There's no blood test to say they can't understand everything we're saying, so I think it's professional and in the best interests of the patient to have it outside of the room. However, if that relative does not want to let go of that person's hand we can talk quietly and we need to be quite diplomatic about how we're talking because I think we might have to assume that patient can hear us (HCP01, Clinical Nurse Specialist)

HCPs would also offer to speak to relatives separately if they felt someone had seemed quiet or awkward within the larger group conversation. Some relatives also raised this, finding it helpful to be able to have one-to-one conversations with the HCP or a social worker, without other relatives being present.

*d) 'People really respected the space': Presence and privacy*

Relatives spoke of situations in which simply having someone sit with them was comforting. HCPs also talked about the value of being comfortable with silence and letting relatives cry without saying anything to move the conversation on. Relatives also spoke of the balance between this presence of HCPs and allowing privacy. Although they described having people come in to check on them as comforting, knowing when not to do this was also important. There was a feeling that being given privacy was a key part of the care they received, allowing them time alone with the patient:

I suppose in these situations in life, what you really want more than anything is lots and lots of privacy really, and we got that really, people really respected the space and they didn't just barge in and so it was quite important, more than anything just to have that space as if you're at home (R06, Partner of patient)

**8.2.2 Time and availability of healthcare staff**

A key part of communication identified by relatives was the time and availability of healthcare staff. It was important to know that there was always someone they could speak to and that they would have time to have their questions answered. They often made comparisons to experiences in hospital where they had struggled to find staff to talk and felt rushed through conversations. HCPs discussed the ways they were able to provide this time and availability as part of a multi-disciplinary team. The following sub-themes describe the three key elements of this: the availability of HCPs; the time HCPs gave relatives for conversations; and the consistency of care across HCPs.

*a) 'If you rang the bell, somebody would come': Availability*

Relatives described feeling that there was always someone available to speak to if they had any questions or concerns. The majority of the time this was nurses, with whom they could speak by ringing the bell or finding them on the wards. This was sometimes contrasted with different experiences they had in other healthcare settings, particularly in hospital:

I am not criticising [the hospital] at all because I think it's really good, but they were so busy there... it was really difficult to find a member of staff at the hospital if you needed something. Whereas at the hospice there were lots of staff around, and if you rang the bell or asked somebody, somebody would come and sort out whatever it was you wanted. And they were always really nice and really friendly and really helpful (R42, Friend of patient)

Being able to speak to the consultant or registrar was particularly important as relatives felt that the consultant could answer questions which other staff either did not know the answer to or did not want to commit to answering. Many described timing their visits to coincide with when the consultant would be doing their ward rounds. The grandson of a patient described how he and his mother would get information from different members of staff:

My mum would try and get there whilst the doctor was doing his rounds in the morning, so she got the full update in terms of everything from him and then there'd be an update just after lunch. We'd normally get an update then and then we'd get the, whichever nurse we were working with him that day, or was going to work with him that night, we'd just get a final update before we was about to leave (R15, Grandson of patient)

Most felt that they were given ample opportunities to speak with the consultant, but others would have liked to have seen the consultant more often. These relatives, did not feel that care would necessarily have been improved by seeing the consultant over, for instance, a registrar, but they would have appreciated more opportunities to see the consultant:

I mean although Alexa's mother spoke to the doctor at the beginning, I didn't really meet him until the much later stages of everything and I think it would have been nice for me to have met him a bit earlier (R06, Partner of patient)

Whilst some relatives stated a preference for speaking to the consultant or registrar over nurses, HCPs highlighted the strength of a multidisciplinary approach and that there are some issues where conversations with a nurse would be more appropriate. They highlighted that nurses and foundation year doctors in palliative care are highly skilled and often have important conversations with families. This view was supported by some of the relatives who described their relationships with nurses or individual foundation year doctors as their most significant relationships with hospice staff. Both HCPs and relatives described these ongoing relationships as important, and HCPs described how different members of the team working with patients helped to inform their communication with relatives:

That's where the MDT is the most helpful, and you share that and someone might have a different stance. Someone from spiritual care might say, actually that's completely against their beliefs...Or someone else might share with you, a social worker might say, actually that relative shared a story where their dad died and they dictated it as a really bad death so they think the same might happen again, and you're like, oh! (HCP01, Clinical Nurse Specialist)



*b) 'You could ask them anything': Allowing time to talk and ask questions*

When families did speak to HCPs they described having plenty of time to talk and not feeling rushed. Some people described how they felt confident to raise concerns, for instance about the patient needing pain relief, and that HCPs would be responsive to this and not make it seem like they were bothering them. They felt comfortable asking questions and that people took the time to answer questions and talk them through any issues:

If I had questions, I felt very happy to ask, and people were very good at, again, not dismissing it. Because to them it might seem a bit, why is this person bugging me, sort of thing. I was never made to feel that. I was never made to feel that what I was asking was superfluous (R09, Wife of patient)

HCPs also recognised the importance of families feeling comfortable to ask questions and that it is rewarding when they feel comfortable enough to ask questions that might otherwise be deemed “silly”. Their descriptions of how they closed conversations demonstrated an intention for relatives not to feel rushed. They spoke of leaving a pause for the relatives to fill and if the family members chose not to, asking if there was anything else or highlighting that they can come back to them with any questions. The CNS explained how she closed conversations whilst still making families feel they had time to talk:

You could create another pause. And if they didn't feel comfortable filling that you could say something like, is there anything else you'd like to ask me? Or is there anything you feel we could be doing better? Anything else we should be doing for you and mum. Yes, it's just putting it back to them. And if they want to keep going and you've got the bells going and the phones going and your bleeps going, I think that's just down to experience as well and being like, how about we have this conversation again when I come back round tomorrow? And if there's anything you need sooner please let one of us know. (HCP01, Clinical Nurse Specialist)

*c) 'She kind of disappeared': Consistency of care*

A key factor in relatives' perceptions of the availability and communication from HCPs was the consistency of the staff looking after the patient. Some relatives recalled that when new staff took over they were up to date with who the patient was and their situation, making communication easier. In these cases, communication between different healthcare staff had been thorough and families did not need to continually update new staff. All patients had the same consultant and junior doctors throughout their time at the hospice, which helped to create a sense of stability. When they were

able to have the same group of nurses this improved day-to-day communication about the patient's care:

There were a couple of really very kind nurses who were there from the beginning and knew what I was talking about if I went back sort of two days later, you didn't have to keep having the same conversation all the way through (R18, Daughter of patient)

In contrast, there were some complaints of a lack of consistency, particularly overnight and on weekends. Relatives described having to explain things repeatedly to different staff members and worried that agency staff may not pass on messages. Some had negative experiences with individual members of staff who did not understand the patient's needs as well. One relative described having an intense and helpful conversation with a nurse about her feelings but then never seeing her again, leaving her with a feeling of a lack of continuity:

There was a woman who came quite near the end who was a nurse, so I think senior nurse of some kind, who started talking to me quite intensely. In a way it was odd because I felt I opened up to her a lot, but then she kind of disappeared... it seemed odd having had this quite intimate conversation and then she sort of went away (R09, Wife of patient)

### **8.2.3 Relationships with staff**

Much of the communication described by relatives as being helpful was not formal or even medical, but general day-to-day talks with staff. For many relatives there were no major decisions to be made and they did not feel they needed much information, and so these smaller updates and friendly conversations were what stuck in their minds when reflecting on their experiences of communication. Whilst HCPs could provide a level of emotional support, relatives focussed more on the practical support they provided as well as how they reassured them about patients' symptoms and medications. HCPs reflected on how building relationships with families made communication easier as they had built trust and rapport, and could tailor their communication to the individual family.

#### *a) 'Those bits of individuals' respect in humanity': Informal conversations and personalised care*

Relatives valued how some members of staff got to know them personally and so understood their and the patient's individual situation better. Sometimes this was through talking about non-medical issues and their life away from the hospice, with relatives describing connecting on a "human level" and developing relationships with specific members of staff which were more like friendships. In the

quote below, the partner of a patient described the value of the HCPs' friendliness towards the family and having conversations with them about their lives, not just medical and patient issues:

We, struck up, you know, fair acquaintanceships with a number of them. I mean the girls were very good because they knew most of them by name, they knew when they were on, and they'd pop their head around the door and say hello and, I think it was those bits of individuals' respect in humanity and shone through I think, the way the girls they came in and talked about how they'd been in the pub the night before or you know, whatever it was happening in their lives as well (R02, Partner of patient)

At other times conversations related to care, as staff got to know how involved relatives had been in the patient's care and what their and the patient's preferences were. Staff would also give informal updates on the patient as they provided daily care for them. This all allowed relatives to be more informed and staff would let them be responsible for certain elements of the patient's care if they wanted this. Where reports of negative experiences were made, relatives often described certain members of staff lacking this individual care. Complaints included not listening to relatives who felt they knew best about what the patient needed and staff who seemed more focused on getting a job done than being empathetic. When these complaints were made, relatives often made comparisons between this and the personalised care they had received from other staff:

I think it's a very good place and if I have to end up anywhere I would prefer to be there, knowing that the care is very good, that there is concern for the patient and the relatives. So I really have no complaint about it, only this one nurse I didn't gel with... I just felt there was a certain hardness about him (R41, Wife of patient)

HCPs also acknowledged the value of getting to know a patient's family. They talked about how things like hugs and jokes can help relax a situation but that this is only appropriate with certain people. The CNS explained the value of asking questions about the relatives or what the patient was like as a person:

Be like, who was she? Where did you guys meet? Did she used to work? And if you open up with those conversations, it's human and it's friendly and you will stand in a strong position for the rest of your conversations to go well. So rapport, be personal, you can start it off with idle chat. How was your journey? Did you sleep all right? Have you eaten today? Oh they care for me as well, what's this about? I thought they were just caring for my mum. (HCP01, Clinical Nurse Specialist)

*b) 'It was really nice that people asked': HCPs' roles in providing emotional support*

Reports of the roles of HCPs in providing emotional support were varied. The CNS spoke more than the doctors about providing emotional support and exploring potential psychological issues with families. She felt that understanding the relatives' emotional state by giving them space to talk was a key part of her role, and explained how she did this:

They've got their own story, they've known their relative a lot longer than I have so let them speak, let them vent, speak, get it off their chest... Letting them talk first of all is really important and then you might choose what to support them with. So that's when using skills in advanced communication, as simple as listening and making sure they're heard... They might start crying while telling their story and you could just stop and pause. The palliative pause, it's very powerful. Create a silence and actually you will see them react to something (HCP01, Clinical Nurse Specialist)

Some relatives described feeling comforted by HCPs and having helpful conversations about the emotional impact of the situation, but others preferred to get this support elsewhere. This support came from their own friends and family or sometimes from other people at the hospice, particularly social workers. Despite doctors asking about how they were coping, they felt that the doctor's role was to focus on the patient and so it was helpful to have someone to speak to specifically about themselves. One relative described his experience of how talking to a social worker at the hospice differed from conversations with nurses and doctors:

Someone, it wasn't about medical care, or dad's needs or anything it was about me quite honestly and that was helpful (R32, Son of patient)

The main source of support tended to come from HCPs' concern for relatives' general welfare. HCPs and relatives reported that HCPs would make sure relatives were taking breaks would highlight the importance of the relatives' wellbeing as well as that of the patient. One relative whose mother was at the hospice for a particularly long time described how the consultant supported her and her family:

There were times that he and Anna [junior doctor] and the rest of the team played as much a caring role to us as it was an advisory role because we were getting into a time when the amount of time we were there visiting and upending our lives to try and be there as much as we could was actually having impacts on our health. He was really, really good at saying, go on holiday. Don't worry about it here. Go and have a weekend away. We're looking after your mother (R05, Daughter of patient)

HCPs talked of the importance of acknowledging the difficulty of relatives' situations and that they would often signpost to other services such as social workers or counsellors to provide further emotional support:

I think the important thing is just to not shy away from it. You might not have the skills equipped to manage the situation, but you might just need to acknowledge it, and then if it's clearly building into something that is beyond our capabilities to manage, then, yes, we can refer outside (HCP09, Registrar)

Relatives explained that whilst they did not necessarily go into detail about emotional concerns with doctors and nurses, just being asked or offered counselling services was appreciated:

They did quite often ask if I wanted to be referred to see a counsellor. It's a bit difficult because somebody asks you how you are, and it's, I suppose, and at that time you don't think about you. You're thinking about the person that's in the hospice. So I think it's, yes. But it was really nice that people asked (R42, Friend of patient)

*c) 'You don't have to worry about that': Explaining and reassuring*

As would be expected, a key part of HCP communication was to explain signs, symptoms and medications to families. For relatives, the purpose of this was to keep them updated and help them to understand, but also to provide reassurance. HCPs reassured families that the changes happening to the patient were part of the normal process of dying, and that they could treat any pain or unexpected symptoms. In particular, explaining that it is normal to stop eating and drinking towards the end of life helped to comfort families:

I said, how can I get him to eat it? Then the doctor said it doesn't really matter. He doesn't have to eat it... So to be told again that it's not, you don't have to worry about that. You don't have to, and if he doesn't want to, don't try and of course that got more so towards the end. Just as long as he's comfortable. You need to be reassured about that (R09, Wife of patient)

Relatives described the importance of being updated on patients' care, but their preferences about the level of detail and regularity of these updates varied. For some this meant wanting daily updates and there were occasions where they felt they needed more regular updates than they received. Others felt they only needed to be updated if something changed and were happy as long as they could see that good care was being given, without needing to discuss it:

There wasn't much to tell about his caring because I saw that they were caring for him, so I didn't have to ask a lot of questions about why are you doing this, or what are you doing that for, and all of this. I saw what they were doing and it was just, it was amazing (R47, Wife of patient)

All of the relatives appeared satisfied with the general level of information they received. One relative described how they were not given enough information to begin with, but that following a conversation with a senior nurse they were updated more often and in more detail. A further complaint was that whilst the overall treatment plan was explained well, sometimes those coming into the room to provide care did not explain who they were and exactly what they were doing. From a HCP perspective, there was also a problem with the move from agreeing a treatment plan to carrying this out. A consultant recalled situations in which families agreed to certain medications but then refused when the nurse came to administer them:

We do have families who will block administration of symptom-control medication... I find having conversations about it relatively straightforward enough, and often the patient's family's going yeh yeh yeh yeh. Then when the nurse is there at three o'clock in the morning they won't let them give some morphine or midazolam (HCP02, Consultant)

HCPs described trying to reduce the uncertainty as much as possible and explaining what to expect. They highlighted the importance of letting families know in advance what impacts drugs are likely to have and what changes are likely to happen due to the dying process. One talked about how sometimes this is not done in advance and this can cause difficulties later on. Doctors also stressed the need to discuss on admission the change of focus towards comfort care in the hospice compared to hospital, and to reassure families that this is not a withdrawal of care, but a change in the focus of care:

HCP09: I generally have that on a psychological tick list or whatever to say, what's the emphasis in care here? ...

HCP07: You don't want them to think of this as a sort of well, this is a sort of inferior hospital actually saying no it's not a case of better or worse. It's about, because Tom [HCP09] used the phrase emphasis of care, that now, less on the number and more on comfort and explaining why we're not doing them. It's not because we don't care or we're not doing things properly. It's because of a different focus of what we do

(HCP09, Registrar; HCP07, Registrar)

#### **8.2.4 Delivery of information**

The ways in which information was provided to relatives impacted their experiences of communication. The first sub-theme describes relatives' general perceptions of HCP communication as compassionate. However communication of information was not always straightforward and the following two sub-themes describe the challenges of communicating clearly and joint decision making. The final two sub-themes highlight which elements of how prognosis was communicated were seen as important and why.

##### *a) 'Very calming and very measured': Bedside manner*

Relatives were positive about HCPs' style of communication with them, describing a good "bedside manner". They described communication as compassionate and respectful, and that they felt listened to and not patronised. This applied during day-to-day interactions with staff throughout the hospice and also when having potentially difficult conversations such as discussing prognosis, dealing with complex and challenging symptoms, or following "near misses" where staff had thought the patient may die. One relative described a consultant's communication during one such near miss:

He has a very good, calm manner and he obviously because he. Because he deals in difficult situations like this all the time he has a very good reading of his audience and the issues and handles that very well. So I think he was a very calming and very measured, measured response to us... he relayed that very well, and settled what could have been a quite an emotional response (R02, Partner of patient)

Relatives talked in general terms about "nice", "understanding" or "excellent" communication, but often could not explain exactly what it was about the communication that made it feel that way:

I think they were really really brilliant I mean they were um, um, and that's everybody from doctors to nursing assistants to the kitchen staff you know they all seemed really uh. I can't I'm just trying to think was there um, no but they were very, they had much more. I wasn't sure cause afterwards or even during I was thinking what is it? You know it can be done, you know why does this not happen more? (R01, Daughter of patient)

##### *b) 'Seeds can fall on stony ground': Clarity of communication*

Generally, relatives felt the communication from HCPs was clear and without any language that they did not understand. They described clear messages being delivered and further explanation where they did not understand. However for some relatives, there were some things that they were still

unsure about at the point of the interview. In particular, some felt that the medication the patient was given may have hastened their death (a concern the doctors described as being difficult to dissuade relatives of). This was not a complaint and some described HCPs explaining to them that this was not the case, but this did not change their belief:

I wouldn't be surprised if somebody had actually just thought let's make this easier and make this faster. I know they said they're not allowed to do that, but or maybe he turned it up, you know I don't know and if that happened that's okay (R18, Daughter of patient)

A further issue with the clarity of the communication was that some people found it more difficult to communicate on day-to-day issues where there was a language barrier:

One of the slightly tricky bits was that the for numbers of the support staff English is not necessarily their first language and so sometimes there was a bit of a gap there, but it was never, it was never a material issue it was just you can generally get the message over (R02, Partner of patient)

HCPs described the challenge of having conversations with relatives in which they appeared to understand what had been discussed, but it later becoming clear that they either did not understand or were not fully in agreement with the plan:

You can have that conversation and literally the same day they will be asking those questions. Why aren't you giving fluid? Can you give them artificial food or put a tube down the nose? With the best will in the world, but seeds can fall on stony ground (HCP02, Consultant)

This was most often in relation to conversations in which decisions not to use certain treatments were made, but was also raised as an issue with families continuously asking about the patient's prognosis.

*c) 'You're no longer at doctor knows best': Consultation and compromise*

For the most part, when discussing decision making, relatives described a situation in which doctors consulted them, but where disagreements about the patient's care were rare and so there was little to discuss. For general medical decisions, some relatives preferred to leave the healthcare staff to decide what to do, and if they did have concerns about other issues, they felt listened to and that their views were taken into account:



They really wanted her wedding ring to come off because her hands were swelling. And we really did not want her wedding ring to come off, and we just said, what ways can we work together to make this happen? They managed to show us positions to put her arm in, how we could massage her when we were just there and just a few little bits and bobs like that. That was really helpful (R05, Daughter of patient)

There were however some reports of individual situations where relatives felt frustrated that they were not listened to:

I called one of the nurses and said look she can't swallow. I could see she was just holding it in her mouth, and this nurse was just and I think she just didn't want to see it, she was like no no no she can... and then she put a few like mouthfuls in my mum's mouth and she could see and I was like she's just holding it in her mouth you know please don't do that (R01, Daughter of patient)

These types of disagreements and complaints generally related to the day-to-day care of the patient, rather than in more significant decision making conversations. They were rare, but often stuck in the relatives' minds as negative experiences compared to the rest of their time at the hospice.

HCPs found it most challenging when families disagreed with what they believed to be in the best interests of the patient. They explained that the relationship with the family is of therapeutic importance and so balancing the maintenance of that relationship with doing what they thought was best for the patient could be an ethical dilemma:

If you think of what a good death is, how much is that about the person dying and how much is it about the memory that stays behind for the ones who live on? And if the memory for them is it was terrible and the doctors just drugged my mother, and I couldn't speak to her, and it was all terrible. If that's their memory, or the memory is, she was writhing around the bed, but I think that was okay because she was trying to wake up, and the doctors agreed not to give her medicines, which one's the better one? (HCP05, Consultant)

Compromise was the key theme that came out of HCPs' descriptions of disagreement during decision making. All HCPs spoke of getting relatives to explain their perspective and demonstrating how their aims are aligned, and said they were willing to use treatments with no benefit as long as they did not harm the patient. Implementing a decision on a "trial" basis was one way of reaching a compromise with families:

The benefit of palliative care is that you're no longer at doctor knows best. So of course the principle is to do no harm, so I wouldn't want to do anything that clearly will harm the patient...the first step is to understand why they objected, so what their aim is, and then explain what your aim is and try and work out a way forward. Usually, so if it's, for example, the fluids, if you say let's try it for 24 hours, you have to watch that it doesn't do any harm. You explain what the harm could look like and then review. Then they feel more as if they're listened to rather than we're in a fight, and we're taking things away and not allowing them to have things (HCP05, Consultant)

d) *'The prognosis is not in my tick list': Prognosis for practical planning*

Whilst not all relatives could recall a specific conversation about prognosis, they had been aware when the patient was imminently dying. Those who could recall conversations were mostly told by a doctor, but several were told by nurses with whom they described having a good relationship and who they reported knowing better than doctors. One reason relatives thought it was important to have prognostic conversations was for practical reasons. In particular to make decisions about whether to come into the hospice, stay overnight or tell relatives who lived further afield to come to the hospice. For some this was in order to see the patient for a final time before they died, and for others it was important for them to be there at the time when the patient actually died:

[The conversation about prognosis] gave us an idea that he hadn't got long left. I suppose the nice thing about that, my uncle who lives in Birmingham he managed to get the chance to come down and actually see him before he passed, so it gave us that time frame to kind of say, if it's not today, it's tomorrow. It would be a wise idea to come down sort of thing. So that was helpful (R15, Grandson of patient)

There was however an example of miscommunication from a prognostic conversation. One relative knew that his father was dying (he described being told "it's really going to be a few days now"), but he felt HCPs could have made it clearer just how imminent it was as the patient died in the night without he or his mother being present:

If they had said I think it's highly likely to happen tonight, then I think she would have definitely stayed the night. Even if it had been in a you know chair or whatever, she would have definitely, she was very disappointed to not have been there (R32, Son of patient)

In this situation, whilst HCPs may have felt they had made the family aware that the patient was imminently dying, they may not have been clear enough that they could not predict exactly when and that it was possible it could happen that night.

Prognostic discussions were raised a lot in HCP interviews, but they did not consider this an essential thing to raise with all families. They thought it was important that families are aware that the patient is imminently dying, but that as long as they know this they do not necessarily need to know timelines:

We try to talk about hydration and nutrition. We try to talk about the fact that they'll get more sleepy, and it's not necessarily, they would do that even without drugs. That's something I try to get in early even if I don't always succeed. But the prognosis is not on my tick list. I don't feel that I have to tell the family how long it is. If they ask me, yes, and if there are any practical reasons why it might be helpful (HCP05, Consultant)

Like families, they highlighted the practical reasons for providing a timeline and suggested that this was also a way to initiate prognostic conversations. They also talked about preparing families for the possibility of the patient dying when they are not in the room (although as illustrated by the previous quote from R32, this was not necessarily always done or understood). If families repeatedly asked about prognosis, HCPs would be concerned as this could be exhausting for families. In these circumstances they would try to move the focus away from prognosis:

People getting massively fixated on prognosis and that being a source of incredible stress. So you want to be able to highlight the fact that someone is dying, and you think time is short, but at the same time you have people that are so fixated on it that they don't leave the room... In those scenarios it's clear that they know the person is dying, and so that job has been done, and the family are all present. Then I try and take the focus away from prognosis and counting each moment as it comes and looking after yourself (HCP09, Registrar)

Beyond time to death, an important element of prognostic conversations for relatives was knowing what to expect from the dying process. This allowed relatives to recognise the signs that death was becoming more imminent and not to panic when signs such as changes in breathing occurred:

She said, have confidence that you know, you'll get a gut feel, and you will know, and you just stay calm. You don't necessarily need to call a nurse... I saw Mum's breathing slowing, and I was like, this is what Daisy [CNS] was talking about. I know she's about to go. I'll quickly make the calls, and she was dead within four minutes. But it allowed us time to literally send the text out to my sisters in the family room saying get in here now (R05, Daughter of patient)

This quote demonstrates the importance to some relatives of knowing what to expect from the dying process. Although some participants did not want that level of detail, others who did not have this sort of conversation commented that they would have liked more information about what to expect from the dying process:

One thing that I was a little bit upset about is once Alexa passed away I'd read through the leaflet which was all about what to expect when somebody is dying and I was never given that leaflet earlier on so I never saw it... I think that should be given maybe when they first get there. It's quite important really. It's a good preparation I suppose (R06, Partner of patient)

*e) 'I tell them we're really bad at it': Providing an honest prognosis*

HCPs outlined strategies they use when delivering prognoses. A common approach was asking relatives to describe what had been happening up to this point. This strategy had three purposes. Firstly, if the patient was newly admitted it helped HCPs to develop their own prognosis. It also gave an idea of what the relatives' understanding and expectations were. Finally this could help the family to see that the patient was deteriorating before a prognosis was actually provided. The participants in the focus group described this process:

**How would you assess whether they've understood prognosis?**

HCP05: Just ask them, what do you see is happening? How do you see your, dot, dot, dot, father is doing? Start with a very open question

HCP02: I sometimes go back through the preceding days and weeks and get them to describe what has happened, and then hopefully that will be a good way to illustrate what is happening without me telling them. Doesn't always work

HCP09: No

HCP07: No, and it's good if they do the work for you when they say they're not doing very well or kind of ill, we're getting there, or something like that

HCP09: I think that's a very important step... Just opening the conversation by saying, what's been happening in the last week, few days? Describe how your dad, mother, whatever, son, brother, sister. What's been happening to them? And then it's really helpful for me actually because then it helps me start to form a prognosis in my head as well

(HCP05, Consultant; HCP02, Consultant; HCP09, Registrar; HCP07, Registrar)

When asked about the language they used in prognostic discussions, HCPs said they avoid euphemisms, using words like dying and referring to time getting short. Some also talked about phrases they use repeatedly like comparing birth and death or saying "I would not be surprised if they

died in the next few days”. They highlighted the importance of being completely honest and upfront about the uncertainty whilst giving the information that they could:

I tell them we’re really bad at it. People always ask things, and say, often quite in general terms it might be days, weeks or months but even, I remember one of Andrew’s patients who was admitted and seemed to be dying... but went on for a couple of weeks post-stroke. And you know I’d then say, I wouldn’t be surprised if it was today, but equally I’ve seen people who’ve changed rapidly and go on for a few more weeks as she did (HCP07, Registrar)

Uncertainty was prevalent throughout relatives’ descriptions of their time at the hospice, making their experiences of communication more difficult. They valued HCPs being honest about the uncertainty:

We did say, how long do you think it will be? They were very very honest and we really don’t know, and it could be a week it could be, and that was good because they really didn’t know. But again, in the end it was shorter, but that’s okay as well and I’m actually quite glad that nobody said, you know it’ll be tomorrow, it’ll be the next day because it just you don’t know (R18, Daughter of patient)

Other relatives referred to “being treated as adults” and not being “condescended to” or “mollycoddled”. They felt that HCPs being direct was important:

It’s very good to talk to people who are not embarrassed. Embarrassed is the wrong word, but you know how death obviously, people find it difficult to talk about death, and so they talk around the subject, and I really don’t like that. That’s what I really don’t like. I always say he died. He did not pass away. He died. I don’t like all these euphemisms (R09, Wife of patient)

### **8.3 Discussion**

This chapter has presented the ways in which relatives and HCPs described the important elements of communication at the end of life. Themes outlined the content, purpose and delivery of specific information, as well as providing insights into how experiences beyond individual conversations with HCPs can impact relatives’ perceptions of communication. This section considers the findings from the thematic analysis of the interviews and focus group in the context of existing research and the findings from the conversation analysis (CA) of recorded conversations presented in the prior three chapters.

The first theme, ‘Context of the communication’ (section 8.2.1) demonstrated how the environment in which conversations took place influenced the perceived quality of communication. When

articulating their experiences of communication, relatives could not separate their perceptions of HCPs' communicative practices from their perceptions of the hospice as a whole, the people delivering the information, and their actions beyond communication. That is, their previous experiences at the hospice and the quality of care their relative received influenced their perceptions of communication. This focus on the importance of the day-to-day experiences at the hospice, as well as the content and style of communication, reflects findings from other studies of communication at the end of life in palliative care, hospital and paediatric intensive care settings (Gott et al., 2019; Hebert et al., 2009; Meert, Briller, Myers Schim, Thurston, & Kabel, 2009). The main driver behind the welcoming environment that relatives described was the hospice staff, but they also highlighted the importance of the facilities at the hospice, such as catering, having a family room and the option to personalise patients' rooms. Whilst it was not explored in detail in these interviews, elements of the 'built environment' including views from the bedroom, comfortable rooms, personalisation and privacy have been identified previously as having the potential to improve quality of life for patients and families at the end of life (Zadeh & Eshelman, 2019).

The theme 'Time and availability of healthcare staff' (section 8.2.2) showed the importance of HCPs appearing available to talk to relatives and that conversations did not feel rushed. In support of this finding, previous studies have described the negative impacts of HCPs appearing inaccessible to families (Caswell et al., 2015; Russ & Kaufman, 2005). These studies took place in a hospital setting, which relatives in the interviews often compared unfavourably to the hospice, demonstrating the benefits of this less time-pressured setting. Highlighting availability and consistent communication also suggest continuity of care and an ongoing relationship between HCPs and families. This reflects the findings from the systematic review in Chapter 1, which showed that following decisions to withdraw life-sustaining treatments, HCPs and relatives emphasised the continued care of the patient (Anderson et al., 2019). This suggests that the need to highlight non-abandonment does not just apply to the continued care of the patient, but also of the family.

This theme also included HCPs' descriptions of how they closed conversations whilst highlighting that there was always time to talk. Their descriptions of the ways in which they closed conversations were reasonably accurate descriptions of the closing moves identified in Chapter 6. HCPs described leaving a pause to allow relatives to speak and that if relatives did not take a turn, they would ask if there was anything else they needed and offer to speak to them again. In Chapter 6, we saw that closing moves followed opportunities for relatives to take a turn, which were not taken. As suggested by HCPs, final-concern solicitations were also common as were offers of availability. Offers of availability identified

in this chapter and Chapter 6 show how HCPs can maintain the emphasis on continued care and having time for the family, whilst still managing to end the conversation.

Section 8.2.3 described relatives' relationships with HCPs and which elements of communication from them were important to relatives. Informal conversations, often not even about the care of the patient, were valued by relatives and improved their experiences at the hospice. HCPs described the importance of these sorts of more personal relationships in order to show families that they care about them, not just the patient. Emotional support was not always seen as a key part of HCPs' roles, but providing reassurance and displaying concern for the relatives' wellbeing were. In Chapter 6, the analysis showed examples of the balance between caring for the relatives, but not being responsible for providing emotional support. During transitions out of prognostic talk or into closings, HCPs' advice statements and offers displayed concern for relatives' wellbeing and highlighted their ongoing relationships, but did not project an extended telling of the relatives' experiences. Offers and advice were focused on practical or 'doctorable' (Heritage & Robinson, 2006) issues and where more psychological issues were raised, HCPs would signpost to other services. Relatives' suggestions that they did not expect HCPs to 'console' them also fits with the CA literature on institutional vs non-institutional responses to troubles-tellings (Jefferson & Lee, 1981; 1992; see Chapter 2).

The final theme, 'Delivery of information' (section 8.2.4), discussed the ways in which information was communicated to relatives from HCPs. Relatives generally described positive experiences with HCPs and how their communication displayed compassionate care. In terms of prognostic talk, this theme demonstrated that HCPs did not think it was always necessary to provide families with a prognostic estimate, as long as they were aware that the person was dying. In support of this finding, there were six conversations in the corpus in which prognostic talk did not occur at all, and four in which descriptive, rather than absolute categorical estimates were given. The analysis in Chapter 7 where the relatives' resistance to prognostic talk and questions about curative treatment led to the doctor pursuing prognostic talk, also demonstrated the responsibility for doctors to ensure families were aware the patient was dying.

Analysis of how HCPs described delivering prognoses was also presented in section 8.2.4. Firstly, HCPs said that discussing the patient's deterioration was a helpful way to initiate prognostic talk. The analysis in Chapter 5 fits with this description as it showed how both HCPs and relatives often topicalised prognosis through a stepwise topic transition from talk about deterioration, as well as how HCPs used descriptions of deterioration to account for their prognostic estimates. HCPs' honesty about prognostic uncertainty was also seen as important by HCPs and relatives, reflecting findings

from previous interview studies (e.g. Apatira et al., 2008; Evans et al., 2009). In the analysis in Chapter 5 we saw that HCPs gave either descriptive or absolute categorical time estimates, rather than precise ones. Relatives in interviews appreciated not being given an exact date because they knew this was not possible and could have given them unrealistic expectations. HCPs described making explicit statements about the uncertainty, which were also identified in Chapter 5. However neither HCPs nor relatives raised the role of the relatives in highlighting their own awareness of the uncertainty and short prognosis that emerged from the CA findings. Further, some HCPs stressed that they would explicitly use words like 'death' and 'dying' when discussing prognosis, and this was not reflected in the CA findings. Chapters 5 and 7 found that these terms were rarely used during prognostic talk, but were used when referencing death in a more depersonalised way or when discussing practicalities for after death. Instead, during prognostic talk, references to time being short were used by both HCPs and relatives and understood as referring to death.

Relatives varied in how involved they wanted to be in decision making, but all stressed the importance of being consulted. HCPs highlighted the need to involve relatives and to reach compromises when disagreements occurred. Whilst disagreements were rare in the corpus of recorded conversations, there was evidence of compromise when this did take place. Chapter 7 showed examples from two conversations where disagreement occurred and doctors attempted to reach a compromise (agreeing to check on the patient more regularly in one case, and using a patch rather than an injections for pain relief in the other). The CA showed how doctors used different language in each of these conversations to upgrade the level of compromise being made.

This chapter has demonstrated the perspectives of HCPs and relatives about communication at the end of life and considered how these findings fit with the existing literature and the conversation analytic findings from Chapters 5-7. The different contributions to the analysis from the HCP and relative interviews reflected the findings from the systematic review in Chapter 1 (Anderson et al., 2019). The relatives' accounts described their experiences in terms of what was important to them and how the environment and their relationships with staff contributed to their positive or negative experiences of communication. The topic guide for relatives focussed more on general experiences and less on individual conversations; when they were asked in more detail about these, they often struggled to articulate exactly what made the communication effective. HCPs often echoed relatives' descriptions of important factors for good communication, and also gave more insight into how this communication is accomplished in practice. The findings reflected some elements of the communicative practices identified in Chapters 5-7, but are not as in-depth as the conversation analytic findings. In particular, they provide little insight into the role of the relatives in these



conversations. However the interviews and focus group identified key contextual information that could not be obtained through CA, such as the role of the environment, ongoing relationships with staff and the impact of individual situations on perceptions of communication.

## Chapter 9 Discussion

This thesis has addressed the gap in the existing literature, identified in the systematic review in Chapter 1 (Anderson et al., 2019), regarding research into conversations between healthcare professionals (HCPs) and relatives of patients at the terminal phase in a hospice. This was done by carrying out a conversation analytic study of 29 conversations between HCPs and relatives of terminal phase patients, interviewing 12 bereaved relatives, and carrying out an interview and focus group with five HCPs.

This final chapter begins with a summary of the key findings from each of the analytic chapters of the thesis (Chapters 5-8). These findings are then discussed in terms of their contributions and implications for research into end-of-life interactions. Section 9.3 provides recommendations, based on these findings, for training to improve communication with relatives of patients at the terminal phase, including the possible format and content of this training and how it could start to be developed. The challenges and limitations of the conversation analysis (CA) and interview/focus group studies are discussed in section 9.4, and suggestions are made for possible future research. The strengths of the thesis are then considered and the final section presents a concluding summary.

### 9.1 Summary of key findings

Chapter 4 provided a descriptive overview of the recorded conversations, presenting the topics that regularly arose, including: an update on the patients' current situation; an explanation of symptoms and medications; a discussion of what to expect in the coming days; talk about the relatives' wellbeing; and talk on other topics such as practicalities following the patient's death or decisions about medications. The following four sub-sections present a summary of the key findings from each of the conversation analytic chapters (Chapters 5-7) and the interviews and focus group chapter (Chapter 8).

#### 9.1.1 *Terminal-phase prognostication sequences*

Prognostic talk took place in 23 of the 29 conversations in the corpus. Chapter 5 began with a description of how this talk was initiated. Prognostic talk was found to regularly occur following talk on deterioration, which allowed a stepwise topic transition (Jefferson, 1984; Sacks, 1992) into prognostication. In the majority of cases, prognostic information was elicited through relatives making 'time estimate requests'. These requests were mostly formatted as interrogatives, but when

declarative statements were used (e.g. “I wish I could know”), these too were treated as prognostic requests by HCPs. During these requests relatives displayed their awareness of the prognostic uncertainty by using words like ‘think’ which reduced the HCP’s epistemic status (Heritage, 2013). HCPs reflected this uncertainty in their responses, using qualifying language, accounting for their estimates and making explicit statements about the uncertainty of the situation, referencing their significant experience with dying patients. Both HCPs and relatives oriented to the relatives’ high entitlement to prognostic information, as relatives did not account for their requests and HCPs provided estimates without checking their readiness to hear the prognosis.

HCPs mostly provided prognoses using absolute categorical time references (i.e. hours, days or weeks). This allowed them to provide an absolute, unitised prognostic estimate without committing to a most likely inaccurate and overly specific estimate. Where relatives’ time estimate requests did not strongly project an absolute estimate (e.g. “how do you see the progression with him now?”), HCPs gave more descriptive answers describing the likely future deterioration of the patient. Additionally, when HCPs provided prognostic estimates without being prompted by a time estimate request, they were more cautious, forecasting their absolute categorical estimates with more descriptive statements about ‘time’ being ‘short’. Such references to time were used throughout prognostic talk by both relatives and HCPs and were always understood as referring to death without needing to use words like ‘die’ or ‘dying’ explicitly. Explicit references to death were rarely used in prognostic talk, but were used when referring to death in a depersonalised way or in the context of discussions about practicalities following death.

### ***9.1.2 Closing the business-at-hand: exiting prognostic talk and transitions into closing sequences***

Chapter 6 addressed how the ‘business-at-hand’ was closed in the conversations, focussing first on how prognostic talk was exited and then how the conversation as a whole was brought towards closing. Following on from the description of terminal-phase prognostication sequences in Chapter 5, the analysis showed that prognostic talk was exited by moving from the uncertain and uncontrollable topic of prognosis, to more certain and controllable topics. Relatives did this by asking questions to which the HCPs were more likely to have answers, mostly about the process of dying. HCPs generally moved onto talk about comfort care, demonstrating to relatives what they could do to help the patient and relatives in the coming hours and days. As prognostic talk was exited into this more action-oriented talk, HCPs’ language moved from being uncertain and depersonalised (e.g. suggesting they

*think* this could be *the* last days), to being more certain and personalised (e.g. *promising* they would keep *him* comfortable).

The analysis then moved to focus on how the main business of the conversation was closed to transition into a closing-relevant environment (Robinson, 2001; Schegloff & Sacks, 1973). Final-concern solicitations from HCPs and gratitude statements from relatives were both identified as common practices that move out of the business of the conversation but not directly into closing. HCPs making offers or providing advice to relatives could move out of the business of the conversation and into closings. Much like the practices for exiting prognostic talk, offers and advice are action oriented and promote the ongoing relationship between the HCP, patient and relative. There were often limits to what offers were made and what advice was given, focusing on practical actions that could be taken. They included advice such as relatives taking breaks from the patient's room or offers to meet with the HCP again, whereas when more emotional issues were raised, signposting to counselling services was used. This allowed HCPs to demonstrate their concern for the relatives without initiating an extended conversation about emotional issues which they may not have felt they had the time or professional capabilities to address.

### **9.1.3 Disagreement during talk about prognosis and comfort care**

The final conversation analytic chapter (Chapter 7) was an analysis of a single conversation in which there was disagreement between the doctor and relatives when discussing prognosis and comfort care. The chapter first demonstrated the relatives' resistance to prognostic talk. When the doctor first raised the issue of prognosis there was minimal uptake from the relatives, which was contrasted with those extracts presented in Chapter 5 in which prognostic statements received signs of acknowledgement or acceptance. This was, therefore, treated as passive resistance by the doctor who pursued prognostic talk. Throughout the conversation as the relatives resisted or disagreed with her prognostic statements, the doctor became progressively more explicit in her language regarding the patient's prognosis, suggesting a responsibility to ensure that the relatives were aware that their mother was imminently dying.

The contrast between this and the other conversations in the corpus became clearer when the doctor raised the lack of curative treatments available to this patient, a topic that did not feature in any other conversations. The relatives disagreed with this and with the doctor's eventual explicit absolute categorical prognostic estimate by using a variety of practices including questioning the doctor's level of certainty and her account for the prognosis. This demonstrated that whilst accounting for

uncertainty produced agreement in other conversations, uncertainty can leave HCPs open to challenges from relatives. The doctor responded by continuing to be honest about her prognostic uncertainty, but using certain, unequivocal language when discussing prognostic issues about which she could be sure (i.e. that the patient was dying and there were no curative treatment options). A final form of disagreement from the daughter that was identified in the analysis, was to not only disaffiliate with the doctor's statements, but to provide disaligning responses which were not fitted to the doctor's previous turn. This was difficult for the doctor to respond to as she first had to respond to the daughter's disaligning turn, and then try to re-engage her in prognostic talk.

#### ***9.1.4 Relatives' and healthcare professionals' perceptions of communication: Interview and focus group findings***

Overall, relatives described positive experiences of communication with HCPs from their time in the hospice. Creating an environment in which relatives felt at ease in their surroundings and in which they were comfortable talking with HCPs were identified as key parts of good communication by both relatives and HCPs. Factors contributing to this environment included providing personalised care and building rapport through informal conversations, meaning that relatives felt listened to and that they could ask questions. The availability of HCPs to talk to and the time available during these conversations further added to this environment of open communication. Relatives felt that generally, communication from HCPs was clear and displayed compassion and care. Negative experiences of communication for relatives mostly related to a lack of individual communication and listening, and involved staff who did not provide the same level of personalised care they had experienced from other HCPs. There was also evidence of miscommunication as relatives remained unsure about certain issues. In particular, despite being told otherwise, several relatives felt that the patient's death may have been hastened by the administration of opioids in a syringe driver.

The need to reduce uncertainty and provide reassurance was apparent throughout the HCP and relative accounts of communication. Clear communication about symptoms and medication was a key part of communication so that relatives could feel informed and understand what was being done to ensure the patient's comfort. HCPs' honesty when there was uncertainty was also seen as important by HCPs and relatives. There was no one preferred level of involvement in decision making about patient care, but a common thread throughout was the importance of consulting with relatives, listening to their perspectives, and where disagreements occurred, finding compromises.

These findings from the interviews and focus group explored relatives' and HCPs' experiences of communication and what they felt was important. They also provided insights into how HCPs believe they communicate, and much of what they described was reflected within the CA findings from real conversations (e.g. using final concern solicitations at the end of conversations and explicitly stating prognostic uncertainty). However they could not provide the same level of depth and detail as the CA findings, and did not discuss what practices the relatives used during these conversations (e.g. reducing the burden of uncertainty by highlighting their awareness of it when making prognostic requests). The strengths of combining the interviews and focus group with the CA approach are discussed in section 9.5.

## **9.2 Contributions and implications of findings for end-of-life interaction research**

In the discussion sections of each of the analytic chapters (Chapters 5-8), individual findings were discussed in relation to existing literature. There were however several themes which arose throughout the chapters and have implications for current issues in end-of-life interaction research. The contributions and implications of these findings are discussed in this section.

### ***9.2.1 Prognosis as an evolving concept***

Prognosis is not a static concept, and patients' and relatives' prognostic awareness and preferences are changeable over the course of an illness. Whilst in research studies patients and relatives generally express a desire for prognostic information (Evans et al., 2009; Innes & Payne, 2009; Steinhauser et al., 2000), the level of this information and their readiness to hear it often depends on the stage of the disease (Parker et al., 2007). A stepwise approach to prognostic discussions is often recommended, suggesting clinicians cultivate prognostic awareness gradually over the course of the illness, with the steps suggested depending on their level of understanding, readiness to talk, and whether the disease is worsening (Jackson et al., 2013). This is the optimal situation and involves early palliative care input. However, for the HCPs in the recordings for this thesis, the first time they met the patient and their relatives was often at the point when the patient had been admitted to the hospice. In the focus group, the HCPs explained that whilst they have medical notes from the referral, these notes do not always match up with relatives' levels of prognostic awareness. They therefore have to judge which step along the process these relatives are at before considering whether prognostic talk is necessary and how to approach it.

As well as changes to how much patients and relatives want to know about prognosis over the course of the illness, the meaning of prognosis also changes. When a patient is first diagnosed, particularly

with cancer, prognosis is often spoken about in terms of survival rates and patients need to know what functional declines are likely so that they can make informed decisions about treatment and personal goals (Paladino, Lakin, & Sanders, 2019). Once a disease is terminal, life expectancy is key, but depending on the stage of illness, the question may be whether the patient will live for months or years, or whether or not the person is imminently dying. The stage of disease, as well as the patient's and relatives' prognostic awareness, will therefore have implications for how prognosis is communicated.

These differences, even in very similar contexts, were demonstrated in Chapter 5 where terminal-phase prognostication sequences were compared to Pino and Parry's (2018) findings of patients making life expectancy requests in hospice consultations. The patients, companions and HCPs in that study did much more to 'prepare the conversational environment' before a prognosis was given, whereas in the corpus in this thesis, requests and responses were more direct. The language used in the authors' descriptions of the requests reflects these differences, as Pino and Parry (2018) refer to 'life expectancy' and their participants often referred to time using possessive language (i.e. 'have' or 'got' a certain amount of time left) and therefore with a focus on what life they had left to live. In the conversations presented in Chapter 5 however, the focus was on how long it would take until the person died. Prognosis here was not in months or years, but instead hours, days, or occasionally weeks. These conversations took place in a context where the relatives were likely to have an existing awareness that the prognosis was short and indeed, they often displayed this within their time estimate requests. All of this meant that delays in requesting or providing a prognostic estimate until the relative was ready to hear it were not an option as there was not time for this. This conversation may have been their last chance to discuss this before the person died.

However even in the same setting, the required approach to prognostic talk can differ. Whilst the majority of relatives had relatively high prognostic awareness, Chapter 7 presented an example in which this was not the case. Throughout the analysis in Chapter 7 the doctor was shown to adjust her approach to prognostic talk based on the relatives' resistant responses. It became clear that the relatives were at an earlier step in the prognostic awareness trajectory, but the fact that the doctor believed their mother was imminently dying meant that she had a responsibility to inform them of the short prognosis. The eventual terminal-phase prognostication sequence in which the doctor provided an absolute categorical estimate was both more cautious and more explicit than the other examples in the corpus. This demonstrated the doctor's responsibility to provide a prognosis as well as her judgement that this may be more distressing than in other conversations in the corpus.

Much that has been written about prognostic communication references ‘breaking bad news’ (e.g. Beach, 2002; Griffiths, Ewing, Wilson, Connolly, & Grande, 2015; Kawashima, 2017; Lutfey & Maynard, 1998). Whilst this is unquestionably an accurate description in most situations, in the conversations recorded for this thesis the valence of the news was more complex. In fact, the conversation presented in Chapter 7 was highlighted as unique in the corpus because it resembled typical bad news giving to a much greater extent than the other conversations. In contrast, in extracts from other conversations (e.g. Extract 7.iii, Chapter 7) some relatives spoke of hoping for a shorter prognosis to relieve the patient’s suffering. This supports findings from previous interview studies with bereaved relatives who expressed a level of relief when the person they were caring for died (Almberg, Grafstrom, & Winblad, 2000; Vlachogianni, Efthymiou, Potamianou, Sakka, & Orgeta, 2016). That is not to say that giving a short prognosis in this context is good news, but that it cannot be understood as unequivocally bad news.

These findings all demonstrate that there is no one clear way to discuss prognosis across a patient’s disease trajectory. Whilst it is useful to consider the timing and context of conversations, families’ prognostic awareness and information preferences can differ. What is clear, is that when a patient is imminently dying, there is a responsibility for HCPs to ensure that relatives are aware of this. This was demonstrated through the interactions in Chapter 7, the interviews and focus group in Chapter 8, and is reflected in policy documents that have highlighted this as an area of end-of-life care which requires improvement (LACDP, 2014).

### ***9.2.2 The holistic nature of palliative care***

In Chapter 1, the GMC definition of palliative care was provided which included references to “holistic” care for both “patients and their family” (General Medical Council, 2010, p.84). Throughout the thesis there has been evidence of how this definition is applied in a hospice during the terminal phase. Firstly, the findings demonstrated that care for the family was a core part of HCPs’ practice. Chapter 4 demonstrated that addressing relatives’ wellbeing was a part of the institutional agenda, as this came up in every conversation. Far from simply being a ‘companion’ to the patient, care for their wellbeing was seen as part of the HCP’s role. This was articulated by HCPs in the interviews and focus group, as they described their relationships with families as being of therapeutic importance and discussed the ways they addressed relatives’ wellbeing. The analysis in Chapter 6 showed that HCPs did not avoid discussing relatives’ emotions. Instead they allowed them time to describe their concerns, acknowledged the difficulty of the situation, and tried to address the concerns with practical advice and offers. This fits with the aims of palliative care to address psychosocial as well as biomedical



issues (Saunders, 2000), but also maintains the institutional norm of responding to troubles-tellings with advice (Jefferson & Lee, 1981, 1992). This norm was also reflected in relatives' accounts in Chapter 8, where many did not think that it was the HCPs' role to provide emotional support, but felt cared for nonetheless.

A further way in which the holistic nature of palliative care was reflected in HCPs' practice was through shared decision making. Shared decision making is defined as clinicians, patients and families sharing information and preferences to come to a mutual agreement on the best course of action (Coulter & Collins, 2011). In Chapter 8, relatives and HCPs described decision making as a process of consultation and compromise. The preferences for the consultation element of decision making varied across participants, with some wanting to know every detail of the patient's care and others preferring HCPs to make decisions and inform them of major changes. This finding supports research that shows decision making can be burdensome and cause feelings of guilt for family advocates (Braun, Beyth, Ford, & McCullough, 2008; Wendler & Rid, 2011; Yamamoto et al., 2017). It highlights that shared decision making is not as simple as providing all of the information, but instead working to find out what level of information and involvement in decision making people want. Shared decision making should therefore be seen as a continuum ranging from full patient/relative autonomy to physician decision making, and the position on this continuum should be negotiated based on patients' and relatives' values and preferences (Kon, 2010). In the interviews and focus group, HCPs and relatives reported that when families did want more involvement in decisions and disagreements occurred, compromises were reached. Whilst decision making was not a focus of the conversation analytic chapters, there was evidence of compromise observed in the recorded conversations (e.g. the compromise on which medications to use seen in Extract 7.v in Chapter 7). Further analysis of the corpus could provide more in-depth insights into decision making and how compromises are made.

### ***9.2.3 Discussing difficult and uncertain topics***

It is often suggested that an important part of discussing difficult topics, particularly in palliative care, is using explicit language. As discussed in Chapter 1, end-of-life communication guidelines often recommend using the words 'death' and 'dying' (e.g. Clayton et al., 2007). Whilst from the interviews relatives expressed that they wanted HCPs to avoid euphemisms such as 'pass away', the analysis of recorded conversations suggested that the use of terms like 'death' and 'dying' is complex. In recorded conversations, HCPs did not avoid these terms, mostly using them when referring to the dying process in a depersonalised way. However, as previous CA studies have found, during prognostic talk the use of these terms was rare (Ekberg et al., 2019; Lutfey & Maynard, 1998). Instead, both HCPs

and relatives mostly used references to 'time' and this was understood as referring to prognosis and death. It is not clear however, whether this finding would apply in other settings. As discussed in Chapter 5, the hospice setting and interactional context are likely to have enhanced the mutual understanding of the intended meaning of references to time. In other settings in which families may have less prognostic awareness (e.g. acute hospital settings), there may be a need for more explicit language. Witkamp et al. (2015) found a disparity between how much hospital clinicians thought they had communicated to families about dying patients' prognoses, and families' prognostic awareness. Using more explicit language may be one way to reduce this disparity. Indeed one of the only cases in the corpus of a HCP referring explicitly to death in prognostic talk was in the conversation in Chapter 7 in which the family had lower prognostic awareness. The doctor in this conversation may have resorted to using the word 'dying' due to the relatives' lack of acknowledgement of her previous, more implicit prognostic statements.

When asked about the barriers to discussing prognosis, HCPs cite the sensitivity of the subject of dying, but often a more significant barrier is the uncertainty involved in prognostication (Hancock et al., 2007; McLennon et al., 2013; Travers & Taylor, 2016). Previous studies have shown that HCPs often attempt to shift prognostic talk towards controllable factors (Gramling et al., 2013; Norton & Bowers, 2001). Throughout the conversation analytic chapters, a common theme was HCPs and relatives attempting to move from a state of uncertainty and a lack of control, towards discussing what can be known and what can be done. In Chapter 6, the analysis showed that this was often accomplished by HCPs moving the conversation towards how they would treat any discomfort. This may at first seem similar to previous CA findings that when breaking bad news clinicians moved straight to treatment talk, but in those cases this move was made at the expense of discussing prognosis (Cortez et al., 2019; Singh et al., 2017). In the conversations presented in the thesis, this move only came once a prognostic estimate (either absolute categorical or descriptive) was given. In Chapter 7, there was further evidence that HCPs did not avoid prognostic talk as the doctor repeatedly re-topicalised prognostic talk until there was a display of acknowledgement from the family (much like treatment recommendations in primary care, unmarked responses were treated as passive resistance by the doctor; Stivers, 2005). The analysis therefore highlighted the need for families to display their prognostic awareness in order for the conversation to move on. Once this happened, HCPs and relatives moved towards action and certainty.

Chapter 6 also showed a similar action orientation during closings of conversations as HCPs made offers and gave advice to relatives. These practices also highlight the ongoing relationships between HCPs and relatives. West (2006) argued that in her primary care data, even though doctors always

initiated closings, they used arrangements and recommendations during closing sections to show that they were still attentive to the patient's needs. She used Button's (1991) description of how arrangement-making during closings presents relationships as 'standing', to argue that this practice in primary care invokes continuity of care. In the hospice setting in which no active treatment is being provided and families may have been told previously 'there's nothing we can do', the need to highlight continued care and attentiveness to patients and relatives is clear. Offers and advice fulfilled this requirement in a setting where clear arrangements could not easily be made.

### **9.3 Recommendations for training**

This thesis is the first step towards developing a package to train less experienced clinicians to improve their communication with relatives of patients receiving terminal care. The full development of this training is beyond the scope of the thesis, but this section provides initial suggestions for ways in which this could be done. The recommendations are evidence-based from the findings of this thesis, as well as existing evidence from palliative care and communication research and training. These recommendations are made with less experienced clinicians working in palliative care settings in mind, but could be adapted for other groups working with families of patients at the terminal phase. Following specific recommendations for a training programme, some of the organisational and contextual factors identified as important in the interviews and focus group are discussed.

#### **9.3.1 *Format of training***

The consent obtained from participants in the study included agreement to use the recordings in communication training. Following the format of other CA-based communication training (e.g. O'Brien et al., 2018; Parry et al., 2018; Stokoe, 2014), these clips could be played to trainees so that they can reflect on how practices work in a variety of situations. As well as the clips from recorded conversations, quotes from interviews with relatives and HCPs could be used to further demonstrate the value of different communication practices. Key messages from each clip would then form recommendations for practice (see Table 9.1 in section 9.3.2 for examples).

In terms of the delivery of the training, a face-to-face training programme would allow more in-depth training and opportunities to engage with the clips and make suggestions about what works well and less well. It would also allow the opportunity to practice skills learnt from discussions of the clips. Role plays are often inaccurate representations of real interactions (Stokoe, 2013), but Pilnick et al. (2018) argue that using CA to inform role plays can enhance the training of actors for role plays. The VOICE study took this approach, training simulation actors to play people with dementia based on real

interactions analysed with CA. They reported improvements in dementia communication knowledge, confidence and some communication behaviours (O'Brien et al., 2018). However, this level of training for actors is expensive and face-to-face training would require a significant time commitment for staff. An online module may therefore be more practical. There are other benefits of online learning, such as the flexibility to pause the module and return to it at a later time, as well as having time for personal reflection during learning (Carroll, Booth, Papaioannou, Sutton, & Wong, 2009).

Examining the HCP interview and focus group alongside the recorded conversations showed that clinicians do in fact have some clear insights into their own practice. Evidence from previous interview studies also shows that HCPs often cite informal learning from colleagues as their main source of communication training (Bloomer et al., 2017; Price & Schofield, 2015). A training programme could therefore formalise this through a mentor system. Senior experienced mentors reflecting on conversations that trainees have observed could help these less experienced HCPs understand what practices work well. Trainees could also meet with a more senior mentor following their own conversations with relatives to reflect on what went well or less well, and their emotional responses to the situation. The second conversation project took a similar approach. This project involved a senior doctor having an end-of-life conversation with a patient or relative, observed by a foundation doctor who followed up with a second conversation soon after. The foundation doctor would then have a reflective session with the senior doctor to discuss this second conversation. Foundation doctors in the project found this process beneficial for the development of their communication skills and senior doctors commented that the reflective element was helpful for both parties (Mathew et al., 2019).

### **9.3.2 Content of training**

Table 9.1 provides some initial recommendations for trainees that could be provided alongside clips. Each point indicates the section of the thesis from which the evidence for the recommendation has been drawn. In order for the recommendations for training to be robust, they should be based on evidence beyond this thesis alone. Therefore, for each recommendation, additional evidence from other studies is provided. Further research is needed to provide evidence to support these recommendations and provide additional suggestions. Ways to provide this evidence include recording more conversations with different staff members in different settings, and doing further analysis on the existing dataset focusing on other issues such as discussing pain relief and sedation (see section 9.4.1 for suggested further CA research). Carrying out interviews with a more diverse range of family members and staff would also contribute to the further development of the training.

**Table 9.1**      **Recommendations for communication training**

Recommendation	Evidence for recommendation within thesis	Other evidence for recommendation
<b>Initiating prognostic talk</b>		
Discussions about the patient's deterioration or the likely impact of medications on the patient's alertness/consciousness can provide a suitable conversational context in which to initiate prognostic talk. Discussing deterioration with families can also provide clues about their current prognostic awareness.	<p>Chapter 5, section 5.1: Prognostic talk was frequently topicalised by both HCPs and relatives using stepwise topic transition from deterioration talk. The analysis showed that this was an unproblematic way to initiate prognostic talk.</p> <p>Chapter 8, section 8.2.4: HCPs described using this approach to demonstrate deterioration to relatives and therefore to cultivate prognostic awareness, as well as to judge relatives' understanding of the prognosis.</p> <p>Chapter 1, section 1.4.3: The systematic review identified 'highlighting deterioration' as a strategy for communicating prognosis in various settings (Anderson et al., 2019).</p>	In stepwise topic transitions, pivotal utterances are designed to fit the previous turn allowing a smooth topic transition which could otherwise appear disjunctive (Holt & Drew, 2005; Jefferson, 1984; Sacks, 1992).
Prognosis does not always have to be discussed. Knowing that the patient is imminently dying is enough for some people without needing to know when this is likely to happen. Think about why you might discuss it: Is it for practical reasons? Because the family have asked? Because of a recent deterioration? Because the family appear to have unrealistic expectations?	<p>Chapter 8, section 8.2.4: HCPs had concerns that relatives could become fixated on prognosis if discussed too often.</p> <p>Chapter 7 was an example of a case where the doctor needed to raise and pursue prognostic talk. Relatives raised issues such as curative treatment, which demonstrated their lack of prognostic awareness, and their passive resistance to prognostic talk suggested a lack of acceptance.</p>	Whilst most relatives want prognostic information, the level of information wanted varies between relatives (Parker et al., 2007; Russ & Kaufman, 2005).

Recommendation	Evidence for recommendation within thesis	Other evidence for recommendation
<b>Providing a prognostic estimate and managing uncertainty</b>		
It is important to be honest and explicit about prognostic uncertainty. It is possible to state prognostic uncertainty without losing relatives' trust or your authority. One way to do this is to draw on your own experience and the experience of the profession as a whole e.g. 'we have learned that it is impossible to predict'.	Chapter 5, section 5.2: Relatives displayed their existing awareness of prognostic uncertainty in their time estimate requests. The analysis also showed how HCPs used references to their experience when stating uncertainty.  Chapter 8, section 8.2.4: Relatives appreciated honesty about uncertainty from HCPs	Interviews with relatives consistently report the importance of honesty about uncertainty to build trust in HCPs (e.g. Apatira et al., 2008; Evans et al., 2009; Krawczyk & Gallagher, 2016).
Despite the uncertainty, it is still often appropriate to provide a prognostic estimate. If relatives ask for a time estimate, use absolute categorical estimates with qualifying language e.g. 'I think it could be [hours/days/hours to days]'. This provides prognostic information without giving an overly specific prognosis that is likely to be inaccurate.	Chapter 5, section 5.2: This was a common practice used by HCPs in combination with accounts for the prognosis and statements of uncertainty, and received acknowledgement from relatives.  Chapter 8, section 8.2.4: Relatives stated that they were glad they were not given an exact time to count down to, but appreciated knowing that death was imminent.	Clinician prognostic predictions are typically inaccurate with a tendency to overestimate (White et al., 2016) and so specific estimates would be inappropriate.  The other alternative to a categorical estimate is a probabilistic estimate (i.e. the percentage chance of dying within a certain time period). Interviews with cancer patients earlier in the disease trajectory suggested they found probabilistic estimates difficult to interpret (Thorne, Hislop, Kuo, & Armstrong, 2006).  In an observational study of oncologists' consultations with advanced cancer patients, HCPs used categories to describe prognosis (Henselmans, Smets, Han, de Haes, & Laarhoven, 2017), suggesting that clinicians may already be comfortable using these types of estimates.

Recommendation	Evidence for recommendation within thesis	Other evidence for recommendation
<p>Explain how you reached your prognostic estimate and do this at the same time as providing it so that relatives can understand the patient's deterioration. Explanations should relate to recent changes which the family can observe themselves e.g. that the patient is no longer communicating or is spending more time asleep.</p>	<p>Chapter 5, section 5.2: This practice resulted in displays of acknowledgement/acceptance from relatives.</p> <p>Chapter 7, section 7.6: When there was a long inferential distance between the account and the prognosis, this was easier to challenge.</p> <p>Chapter 8, section 8.2.4: HCPs described discussing the changes that relatives had observed as a useful approach to demonstrate deterioration to them.</p>	<p>When a professional is uncertain they cannot rely on their expertise and so must provide evidence for their assertions. A longer inferential distance between the assertion and the evidence means the link between them is less apparent (Peräkylä, 1998, 2006).</p>
<p>Give families the option to discuss what to expect from the dying process. This can help them to understand the patient's signs and symptoms and moves the conversation away from the less predictable time to death and towards more predictable elements of the dying process.</p>	<p>Chapter 8, section 8.2.4: Relatives who received this information found it helpful in the final days and hours of the patient's life. Some who did not discuss this with HCPs expressed that they would have liked more information about what to expect from the dying process.</p> <p>Chapter 6, section 6.1: Relatives sometimes asked questions about what happens during the dying process and this moved the conversation away from a focus on time estimates.</p>	<p>Families of palliative care patients have expressed a desire for information about the terminal phase, particularly when the patient becomes unconscious (Clayton, Butow, Arnold, &amp; Tattersall, 2005; Harrop, Byrne, &amp; Nelson, 2014; Steinhäuser et al., 2014).</p>
<b>Moving on from prognostic talk</b>		
<p>Once relatives have acknowledged the short prognosis, you can then move towards talk on comfort care. This is an opportunity to describe what can be done to ensure the patient will be well looked after and highlight your ongoing relationship with the patient and family.</p>	<p>Chapter 1, section 1.4.3: The systematic review showed that some relatives were disappointed that HCPs did not emphasise their continued availability and care for the patient and family (Anderson et al., 2019), suggesting a need to highlight the treatment the patient will continue to receive.</p>	<p>Emphasising symptom control can provide hope to terminally ill patients and their families (Clayton et al., 2008). Nurses have described redirecting hope towards symptom control when shifting from curative to palliative care (Norton &amp; Bowers, 2001).</p>

Recommendation	Evidence for recommendation within thesis	Other evidence for recommendation
	<p>Chapter 6, section 6.1: Discussing comfort care was a common practice and resulted in an unproblematic transition from prognostic talk. In the deviant case in which this was not done, the more experienced HCP treated this as problematic and returned talk to comfort care.</p> <p>Chapter 7, section 7.1: This conversation showed the need for a display of acknowledgement of the prognosis from relatives. When this did not happen it was treated as passive resistance by the doctor and prognostic talk was pursued. Later in the conversation it became clearer that the daughter was not accepting of the short prognosis, suggesting the doctor was correct to pursue further prognostic talk.</p>	<p>Quantitative analysis of recordings of ‘expert’ palliative care clinicians showed that their prognostic talk often focused on quality of life (i.e. symptom control; Gramling et al., 2013).</p> <p>Unmarked acknowledgments (e.g. ‘mm’s) or a lack of response have been shown in other settings to suggest passive resistance to treatment recommendations (Heritage &amp; Sefi, 1992; Stivers, 2005). The evidence from Chapter 7 suggests this is also the case in response to prognostic talk and therefore acceptance/acknowledgement should be pursued.</p>
<p>There are some things that are certain. Take the opportunity to use certain language when you can e.g. if describing a lack of curative options or explaining the comfort care that will be provided to the patient.</p>	<p>Chapter 6, section 6.1: As HCPs moved from prognostic talk to comfort care, they were able to use more certain, personalised language.</p> <p>Chapter 7, section 7.5: When the doctor switched to unequivocal language about the lack of treatment options, this prevented the family making further challenges to her perspective.</p>	<p>Uncertainty is often described as one of the most difficult aspects of terminal illness for patients and families, and they express a need for control at this time (Kimbell, Boyd, Kendall, Iredale, &amp; Murray, 2015; Lowrie, Ray, Plummer, &amp; Yau, 2019).</p>
Moving towards the closure of the conversation		
<p>When closing a conversation, asking for final concerns closes the main business of the conversation and gives relatives the opportunity to raise additional issues (this is clearly not the</p>	<p>Chapter 6, section 6.3.1: Final-concern solicitations led either to a further issue being raised or to relatives confirming that all of their concerns had been addressed.</p>	<p>In primary care, patients were more likely to raise additional issues when HCP used final-concern sequences (Robinson, 2001).</p>



Recommendation	Evidence for recommendation within thesis	Other evidence for recommendation
only time relatives' concerns should be elicited, but provides an opportunity for final concerns to be addressed).	Chapter 8, section 8.2.2: HCPs described using final-concern solicitations to give relatives an opportunity to control the agenda of the conversation.	
Once you feel you have covered everything the family wish to talk about, use phrases that highlight action and your ongoing relationship with the patient and family. Offers (e.g. to use the facilities or highlighting your availability to talk again in the future) and advice (e.g. suggesting taking breaks from the room) are ways to do this whilst closing the conversation.	Chapter 6, section 6.3.2: Offers and advice from HCPs proposed future action and therefore highlighted the continuing relationship with families. They were shown to be common practices to move out of the business of the conversation and into closings.	<p>These practices resemble arrangement making, which has been identified as a common practice for shutting down topics and moving towards conversational closure in various settings (Button, 1991; Robinson, 2001; Schegloff &amp; Sacks, 1973).</p> <p>In primary care, using arrangement making and recommendations demonstrated attentiveness to patient needs and highlighted continuity of care (West, 2006).</p>
Discussing emotional issues		
Some HCPs will feel confident talking about emotional issues and have the time to do so, but if not, it is possible to show that you are attentive to relative's wellbeing without putting yourself in the position of counselling them. One way to do this is to acknowledge the difficulty of the situation and offer practical ways to help. If you have concerns or feel they would benefit from it, signpost to psychological or other appropriate services. Relatives don't generally expect you to 'solve' their problems unless they are 'doctorable'.	<p>Chapter 8, section 8.2.3: Relatives rarely saw it as HCPs' role to provide emotional support, but felt cared for by their concern for their wellbeing.</p> <p>Chapter 6, section 6.1: Extract 6.3 showed how acknowledging the difficult situation and signposting psychological services received a positive response from relatives and allowed the HCP to maintain an orientation to action.</p> <p>Chapter 6, section 6.3.2: Offers and advice from HCPs during closings tended to be limited to doctorable issues such as offering hospice facilities or availability for questions.</p>	<p>CA research has shown that the norm for responding to troubles-tellings in institutional settings is advice giving, not consoling (Jefferson &amp; Lee, 1981, 1992), but that statements of affiliation can be used to close troubles-tellings and move to problem solving (Ruusuvuori, 2007).</p> <p>In palliative care consultations, displays of empathy were integrated into institutional tasks (Ford et al., 2019).</p>

### **9.3.3 Co-producing a training intervention**

In order for a communication training programme to be implemented, it must be feasible in practice and empirically tested in a research trial. One approach to designing applied clinical research is co-production, which calls for the involvement of different stakeholders throughout the whole research process. When describing their NIHR INVOLVE approach to co-production, Hickey et al. (2018) argue that co-production differs from standard Patient and Public Involvement in that the stakeholders involved are considered partners in the research, rather than simply people to consult in researcher-led projects. They highlight the importance of sharing power between all involved in the research and ensuring that everyone benefits from the project. Whilst not all members are involved in all parts of the project, they decide together who will be responsible for which parts and agree on defined roles for all members (Hickey et al., 2018). This section only covers the development of a potential intervention, but co-production partners should be involved throughout the process from conception to dissemination.

Any training that is likely to arise from this project would be aimed at less experienced HCPS working in end-of-life settings. Therefore potential members of the co-production team would be foundation year doctors and GP trainees who have worked in palliative care, clinical nurse specialists with some palliative care experience, and/or foundation year doctors who do not yet have palliative care experience. Involving managers or other staff members responsible for training in palliative care settings may also be beneficial. Additionally, bereaved relatives with experience of communication at the end of life in different settings could add valuable insights. Involving these stakeholders throughout the process would make training more relevant for HCPS and relatives, and more feasible, as potential implementation issues are more likely to be raised early on.

In the previous section, it was highlighted that further analysis of the current corpus and possibly recordings from other settings would be needed (see section 9.4.1 for suggestions of what topics and actions may be useful to consider). Involving co-production partners (both HCPS and relatives) in this analysis through data sessions would be a valuable first step. The data session is an analytic process particularly suited to involvement of non-researchers. Data sessions allow participants to learn through experience and if organised appropriately, should allow equal contributions from participants with a range of expertise, backgrounds and experience (ten Have, 2007).

A further area in which to involve co-production partners is when deciding which recommendations should be included in the training programme and how they should be presented. This would help to identify any inappropriate recommendations or recommendations that are unlikely to be implemented in practice. For instance, Heritage et al. (2007) found that

asking patients “is there *something* else you want to address in the visit today?” reduced unmet patient concerns whereas asking “is there *anything* else you want to address in the visit today?” did not. However, in the focus group for this thesis, one doctor raised this advice unprompted, saying he could not remember what the wording was and that he did not use it because it felt awkward. The recommendations suggested in Table 9.1 therefore generally avoid suggesting specific words to use (beyond hours, days and weeks for prognosis, which are already commonly used), but further feedback from HCPs would help to consider the best ways to present recommendations. Equally, relatives could provide input into how appropriate they think the recommendations are and whether there are important elements of communication that have not been considered.

In terms of designing the delivery of training, HCPs and managers would be the key stakeholders to involve. HCPs could present what they feel their training needs are, how they currently use their training time and what format would work best for them. Consulting NHS and hospice managers about their current training provision, requirements and expectations would also be beneficial. The potential psychological impact that having multiple difficult conversations with families of patients in the terminal phase of their illness may have on HCPs must also be considered. A recent interview study with generalist staff providing palliative care suggested that support needs may include time to reflect on difficult situations, and that confidence and experience with end-of-life communication improves emotional wellbeing (Brighton et al., 2019). It would therefore be valuable to ask HCPs to what extent coping with the psychological impact of these conversations should be addressed in the training and involve them in the design of any such aspect of the training programme.

#### **9.3.4 Organisational factors**

In addition to recommendations specific to developing training, several organisational factors affecting the perceived quality of communication were identified in the interviews and focus group. Relatives felt that the hospice had provided a welcoming environment, which contributed to their overall positive perceptions of communication. In particular, having open visiting hours and the option to stay overnight, were valued by relatives. Whilst this is common practice in hospices, it is often not the case in hospitals where nearly half of people in England die (Public Health England, 2018). Previous studies have also identified open visiting hours as an important factor for relatives of patients at the end of life in the ICU (Nelson et al., 2010; Noome, Dijkstra, van Leeuwen, & Vloet, 2016). This further supports Baroness Neuberger’s recommendations to improve the recognition and communication of when a person is dying, and to allow visiting hours to be relaxed in these circumstances (Neuberger et al., 2013). HCPs in the focus group also

highlighted that talking about practicalities such as staying overnight was a useful way to bring up prognosis, and so this change in visiting hours could be a prompt for HCPs to have prognostic discussions with relatives. Other important environmental factors highlighted in interviews included maximising privacy and having conversations in the appropriate setting (i.e. having certain conversations away from the patient room). HCPs stressed the need to prepare for sensitive conversations by planning what to say in advance and ensuring there was a private room available in which to have the conversation.

A source of complaints from relatives was a lack of consistency in terms of the staff looking after the patient. Whilst the ideal situation would be always to have the same staff member looking after the same patients, the realities of busy wards and stretched health services mean that this is not always possible. This means that good communication between HCPs is vital to ensure consistency and to give families confidence that all HCPs understand the patient's individual needs. Nursing handovers could be key points at which consistency of care can be affected, and implementing standardised content to discuss in handovers has been suggested as a way to improve patient care and communication (Fenton, 2006; Johnson, Sanchez, & Zheng, 2016). This could include information about relatives such as their information preferences, alongside patient information. A systematic review also found that having one key clinician who knew the patient well was important for enhancing feelings of continuity of care (Haggerty, Roberge, Freeman, & Beaulieu, 2013), and this was supported by reports from relatives in the interview study. In particular, the consultant often played this role for relatives, although some said they would have wanted more opportunities to speak with the consultant. Ensuring the consultant speaks to patients' main companions soon after admission and letting them know when the consultant is likely to be on the ward would therefore be beneficial.

## **9.4 Challenges, limitations and future research**

The previous section highlighted the need to collect further evidence to support the development of training programmes. In order to inform future research projects it is important to reflect on the challenges of data collection and if/how these challenges were overcome, as well as the limitations of the current study and how future research could address some of these limitations.

### **9.4.1 *The conversation analytic study***

Overall the experience of collecting data within the hospice was a positive one. Staff were interested in the project and open to participating. The hospice staff already regularly took part in research projects and so were used to having researchers on site. Whilst participating HCPs did not express any reluctance to record conversations, recruitment rates were not consistently high.

One helpful element to improve recruitment was talking to non-participating foundation year doctors and GP trainees about the study, as they identified potential eligible families and reminded senior doctors on the ward rounds about the need to record conversations. This experience showed that for any similar research in the future, the researcher being present on site and building relationships with HCPs are vital to improve recruitment levels.

It was also clear there were some conversations that HCPs chose not to record despite fitting the eligibility criteria. It could be speculated this may have been due to the particularly sensitive nature of some of these conversations. However, on reviewing the recordings in the corpus, some extremely difficult topics, such as euthanasia and the unexpected rapid deterioration of patients, were discussed. Reiterating to the participating HCPs that it did not matter what content they were expecting to cover in the conversations improved recruitment rates somewhat, but there was still some gatekeeping. Whilst some conversations were missed, enough of a range of conversations were recorded to provide a varied and interesting corpus. The collection of recordings is not intended to be a definitive illustration of these types of conversations, but instead they illustrate some commonly used practices within this setting.

There were also some difficulties with the recordings themselves. HCPs were asked to approach relatives immediately before the conversation to give them a brief explanation of the study and obtain verbal consent. This was done to minimise the disturbance in the conversations and capture more informal conversations that had not been arranged in advance. One consequence of this was that openings of conversations could not be examined as there had to be a discussion of the research at the start of the conversation. Similarly, the use of an audio-recorder as more discreet and requiring less preparation than video, meant that it was difficult to tell whether the conversation was actually closed (i.e. co-presence was broken) at the end of the recording. Additionally some recordings were low quality due to background noise and the lack of video-recording also meant that non-verbal communication was not captured.

These issues demonstrate the difficulty of working with naturally occurring data, but on balance, this was the right approach for this study, as attempts to reduce them would have meant delaying the conversation and thereby affecting the experience of the participants. However, future research using video-recording in similar settings is needed. Setting up a camera for the full recruitment period in one room where many of these conversations took place, and then only turning it on when a recording needs to be made is one possibility. This would mean that bedside conversations and those in other rooms would not be recorded, but this approach would add valuable non-verbal details to the analysis. For audio-recordings, HCPs could be asked to keep the recorder on until they are no longer with the relative to ensure closings are captured.

Following the recordings, written consent had to be obtained after at least one day. Patients were in the final days of life and so this was clearly a difficult time for participating families. Consulting with nursing staff about the patient and family and whether it was appropriate to approach them was vital to ensure this was done sensitively. In general, families were approachable and happy to talk. However, there were numerous occasions when the patient died before written consent was obtained, which meant calling participants to arrange consent visits. It was sometimes difficult to contact participants and it would not have been appropriate to call them repeatedly in this short period. For this reason, as described in Chapter 3, an amendment was made to increase the time permitted to obtain consent from six to twelve weeks. A further amendment was made to allow for postal consent (following a phone call) so that participants, particularly those who did not live in the area, did not need to arrange a consent appointment.

A further limitation was that no data were collected from patients' medical records. Information about patient characteristics such as age and diagnosis may have been helpful, for instance to compare conditions that have more or less certainty associated with the illness trajectory. However this would have meant asking all patients for their consent whilst they had capacity, some of whom would never have been a part of the study. The few extra benefits of having access to patient notes were not considered worth this extra burden on patients. Additional demographic information about families such as religion would have been easier to collect and may have added further insights. For instance different religions and denominations within religions can have different viewpoints on end-of-life care decisions (Bradley, 2009; Kinzbrunner, 2004). However in terms of the analysis, this would only be relevant if oriented to by the participants and could otherwise cause biased assumptions (Schegloff, 1991).

One way to compensate for some of the missing information would be to collect more contextual information, such as where the conversation took place and any existing relationships between HCPs and families. Being present at the hospice and carrying out post-bereavement interviews with families went some way towards addressing this, but another approach would have been to carry out ethnographic interviews following each recorded conversation. Lutfey and Maynard (1998) used this approach to explore how an oncologist gave patients bad news about a lack of treatment options. This provided additional insights such as the impact of knowing the patient well on the doctor's comfort with discussing death, and what difficulties the doctor felt during certain conversations. In the conversations presented in this thesis, such interviews would have provided valuable extra information. For instance, there were only six conversations in which HCPs initiated prognostic talk and so ethnographic interviews could have asked HCPs what made them feel that they needed to discuss prognosis unprompted in these conversations. However, this

approach would be more practical in a clinic with specified appointments, rather than during busy ward rounds.

Another possible approach for future research would be to carry out a longitudinal CA study, recording every conversation the HCP has with families at the hospice. This would allow insights into whether interactional features change as relationships between families and staff develop and as the patient's condition changes. This approach was taken by Shaw et al. (2019) who recorded seven consecutive psychotherapy sessions for individual advanced cancer patients and found that mentalization to introduce alternative perspectives was used successfully in earlier sessions than had previously been recommended.

A further limitation of the study is the range of conversations captured. For instance, there was only one conversation in which relatives strongly challenged the prognosis provided by the HCP (see Chapter 7). This meant that the only way to compare different ways of dealing with such disagreements was to look at different strategies within that one conversation. Recording a higher number of conversations in the hospice, or looking at other settings such as acute care may have provided more examples of this to strengthen the analysis and allow clearer recommendations to be made. Relatives and HCPs in interviews and the focus group highlighted the important roles of nurses, social workers and less experienced doctors, and so recordings of different professions having conversations with relatives of terminal-care patients should also be made. Making further recordings to increase the size and range of the corpus could allow quantitative coding to be conducted on the data leading to the possibility of comparing different settings, professions and practices statistically.

There were also a disproportionate number of recordings from one doctor, as HCP05 recorded 14 of the 29 conversations. In an ideal situation, there would have been a more even spread of recordings across the HCPs involved. However from a pragmatic perspective, there was a limited amount of time to collect the data and so stopping HCP05 from collecting further data would have reduced the corpus and therefore hindered rather than improved the analysis. With the exception of the single case presented in Chapter 7, all analysis was based on data from all HCPs within the sample, meaning a range of individuals were included in the analysis. Finally, the thesis does not aim to identify how communication is always accomplished in this setting, but instead to understand ways that this can be done. One of the aims of the thesis was to provide recommendations for communication training. The recommendations in section 9.3 provide suggestions of practices based on one group of senior, experienced clinicians, but do not suggest that these are the only possible approaches.

A final limitation is that due to the labour-intensiveness and level of analytic detail required for CA research, only a small number of social actions could be addressed in the thesis. As described in Chapter 3, these were chosen for pragmatic reasons to complement the wider I-CAN-CARE programme and to focus on aspects that may be useful to address in training. A range of other issues that could have been included were identified during the ‘unmotivated looking’ phase of data analysis or elicited during interviews. For instance a recurring topic, both in the recorded conversations and interviews, was the discussion of trying to achieve a balance between pain relief and sedation, and distinguishing between drowsiness caused by medication and that caused by the natural dying process. Exploring how these topics are discussed could provide useful findings for clinicians, particularly given recent controversies in the media related to the use of syringe drivers and opioids, leading to some reluctance from patients and families to agree to this highly effective way of managing pain at the end of life (Knights, Knights, & Barclay, 2018). The consent obtained from participants means that the current corpus could be used in the future to explore these issues.

A further area for future analysis on this corpus is looking at talk between relatives in these conversations. There were some examples of this in Chapter 7 in which the patient’s son appeared at points to move the conversation on despite the daughter not accepting the lack of treatment options. Previous research in other settings has looked at how patients and their companions interact with each other within appointments and found that companions could provide both informational and emotional support (Doehring, 2018; Laidsaar-Powell, Butow, Bu, Fisher, & Juraskova, 2016; Laidsaar-Powell et al., 2013). In the corpus in this thesis the patient is not involved in the conversation and so examining the interactions between relatives when a patient is not present could provide interesting new insights. Similarly, conversations with different relatives (i.e. spouse vs child vs friend) could show whether communication practices differ between these groups. Other potential avenues for future analysis which arose during ‘unmotivated looking’ and/or in interviews include expressions of a wish for hastened death, the use of medical and lay language, talk about emotions (this was briefly covered in Chapter 6 but could be looked at in more detail), and decision making.

#### **9.4.2 *The interview and focus group study***

A limitation of the interviews with relatives was that they took place up to 6 months following bereavement and therefore participants were unlikely to be able to recall their experiences with accuracy. In fact this was spoken about in the interviews themselves as relatives stated that they couldn’t remember or that it was ‘all a bit of a blur’. With this in mind, the topic guide was designed to gauge general perceptions and identify elements of communication that had stuck out to



relatives as particularly important, rather than to obtain detailed descriptions of specific conversations. The likely inaccuracy and incompleteness of relative and HCP accounts were key reasons for recording the initial conversations to obtain an accurate impression of communication. Future research could use a prospective ethnographic approach, interviewing and observing families throughout the disease process to elicit their immediate reactions to experiences of communication, and to gauge how these change over time and across experiences with different HCPs.

A further limitation of the interviews was the limited sample of participants. Whilst all 51 relatives whose conversations were recorded were offered an interview, only 12 were interviewed. The sample may have therefore been biased towards those who were happy with their experiences (van Der Steen, Deliens, Ribbe, & Onwuteaka-Philipsen, 2012). For instance, the family who disagreed with the doctor's prognosis (the focus of Chapter 7) and therefore may have had a more negative view of the communication, did not agree to be contacted for an interview. Additionally, the link between the interview and the hospice may have made participants more reluctant to share negative views. However some negative experiences were identified through the interviews, and participants expressed a desire for both the positive and negative to be fed back to the hospice. A larger sample (perhaps including those who did not have a conversation recorded to widen the recruitment pool) may lead to a more diverse range of participants and viewpoints. In particular, 92% of relatives interviewed were white British or Irish and so the sample was not representative of the local population. Due to the impact of involving an interpreter on the analysis of recorded conversations, as well as not having a budget for an interpreter for interviews or transcription, all participants were also English speaking, further reducing the diversity of the sample. A common criticism of CA is that it does not take into account the wider cultural context (e.g. Hammersley, 2003). Had the interview sample been more diverse, interviews may have provided insights into the potential impacts of culture on communication that were not obtained through CA. Additionally, participants described an important role for less senior staff such as ward nurses, but they were not interviewed as part of the study. As with the CA study, future research should include a broader range of HCPs and allied health professionals.

The sensitivity of discussing a significant other's end of life was a challenge during the interview process. Relatives were asked to go back over a difficult time in their lives several months later. Indeed several participants decided against taking part in the interview because they did not feel ready or able to talk about it. Those who did take part were told they did not have to answer any questions they were not comfortable with. The interview began with more general questions about relationships with staff, before moving onto potentially more emotional questions. Whilst some participants did become upset whilst talking, none asked to stop the interview. Afterwards

some commented that it had been helpful to talk about their experiences and their time at the hospice had been positive. It was also more comfortable talking about such sensitive issues in face-to-face interviews and participants appeared more relaxed. Whenever feasible, interviews were therefore conducted in person and with flexibility to allow the participants to choose where and when the interview would take place.

A final challenge related to the HCP focus group. By the time of the focus group, only two of the HCPs were still working at the hospice and so arranging a time when they were all free was difficult. Building relationships with the HCPs over the fourteen-month data collection period made it easier compared to being an outsider coming in and asking them to find time in their schedule. However due to their busy work load, the time available for the focus group was limited and so not all topics were explored in as much detail as they may otherwise have been. Further, the focus group was arranged at short notice and so there was not time to arrange for a co-facilitator to attend. Whilst this was not problematic at the time, it is often recommended to have a co-facilitator present to organise the recording and take notes on non-verbal behaviours (Carey, 2015).

## **9.5 Strengths of the thesis**

This is the first study to record conversations between HCPs and the relatives of patients at the terminal phase in a hospice. The systematic review in Chapter 1 (Anderson et al., 2019) highlighted that whilst previous studies have used CA, discourse analysis and observations to explore naturally occurring conversations with families in acute settings, these focused mostly on formal family meetings involving decision making related to withdrawal of active treatment. In contrast, the conversations in this study covered a range of issues, and were mostly informal conversations without necessarily having one specific concern to address. Other CA studies in adult palliative care have included the role of companions in their analyses (e.g. Pino & Parry, 2018), but in the conversations in this thesis the relatives were the focus of the analysis. By the time of these conversations, relatives were no longer ‘companions’ and instead were the primary people with whom the HCPs needed to communicate. Their role was as an advocate for the patient but also as a person going through a difficult experience who needed to be informed and supported. The insights into these interactions gained by this thesis therefore provide original contributions to the fields of both CA and medical interaction more generally.

From a methodological perspective, the main strengths of the conversation analytic approach and the use of interviews and focus groups for this project were discussed in Chapters 2 and 3, and so this section mostly focuses on the strengths of combining these approaches. This approach allowed a broader picture of communication with families of terminal-care patients to be

developed. The insights obtained from interviews were inevitably influenced by the assumptions underpinning the questions in the topic guide and the ways in which questions were asked and answers were probed. In contrast, the recordings of conversations passed what Potter refers to as the 'dead social scientist test'; the conversations would have taken place whether or not a researcher was recording them (Potter, 2002). The recordings of conversations provided an accurate picture of communication in the terminal phase which was analysed in detail using CA. However, these conversations occurred in a wider context which should not be ignored. By using interviews and a focus group alongside these recordings, it was possible to understand this context and identify important factors which could not be found through analysis of recordings. For instance, relatives spoke about the importance of the availability of HCPs and identified topics that were not always discussed in their conversations with HCPs.

The focus group and interview with HCPs showed their insights into their own communication practices. The focus group was particularly valuable as the doctors built on each other's points and discussed issues with each other, generating findings that would not have been elicited through individual interviews. The fact that the doctors had all worked together over several months enhanced this, as their shared experiences allowed a more detailed discussion about specific experiences, and meant that they were a group who may naturally talk about these sorts of issues outside of a research context (Kitzinger, 1994). Whilst this may have been enhanced by having the clinical nurse specialist (CNS) also present, the separate interview allowed more time to explore the role of the CNS.

Comparing the findings from the focus group and interview with the conversation analytic findings showed that HCPs do in fact have a reasonable insight into their own behaviours. Their descriptions in the focus group added detail about when and why they use certain practices during these conversations. For example they described closing conversations by leaving a pause in order to give relatives time to process information and the opportunity to bring up other issues or concerns. If the relative did not introduce a new topic they would offer their future availability. This description was reflected in the CA analysis of transitioning into closings. However, the level of detail obtained from the CA findings could not be elicited through interviews with HCPs and relatives. For example HCPs referred to using words like 'death' and 'dying' when talking about prognosis, whereas in fact the CA analysis revealed that these terms were mostly used when referring to practicalities or in a depersonalised way about the dying process, and were rarely used in prognostic talk. Similarly, relatives spoke in quite general terms about the positives of the communication they experienced and struggled to articulate exactly what it was that gave them such a positive view. Combining the CA findings from recorded conversations with the thematic

analysis of interviews and the focus group therefore provided a richer understanding of this communication as a whole.

## **9.6 Conclusion**

This research has explored how expert HCPs and the relatives of terminal-phase patients in a hospice navigate difficult and uncertain issues during talk about end-of-life care and prognosis. Using CA allowed the analysis to go beyond the content of these discussions to identify how activities such as prognostication and topic transitions were accomplished during interactions. Both HCPs and relatives oriented to the rights of relatives to be given prognostic information. The inherent uncertainty of prognostication was highlighted through qualifying language both in time estimate requests and responses, and through explicit statements about the uncertainty from HCPs. Most prognostic talk was unproblematic, but where disagreement and resistance occurred, the responsibility of the HCP to cultivate prognostic awareness was displayed through pursuing acknowledgement of the short prognosis. During prognostic talk, disagreements, and closings, both HCPs and relatives shifted from talk on uncertain and uncontrollable matters towards certainty and action orientation. The thematic analysis of the interviews and focus group also provided an understanding of the perspectives of HCPs and relatives about this communication. It identified the contextual factors that can affect relatives' perceptions of communication, as well as factors more specific to individual conversations such as honesty about uncertainty and providing reassurance about symptoms.

Combining the accurate, in-depth description of interactions obtained through CA of recorded conversations, with the personal reflections from those involved in the interactions, provided a holistic view of communication in this setting. This thesis is the first step towards improving communication with families of patients in the terminal phase and has provided an outline for how training for less experienced clinicians could be developed.

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## **Appendices**

- Appendix 1. Outputs related to thesis**
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## Appendix 1. Outputs related to thesis

### **Published articles:**

**Anderson, R. J.,** Stone, P., Low, J., & Bloch, S. (in press). Managing uncertainty and references to time in prognostic conversations with family members at the end of life: a conversation analytic study.

**Anderson, R. J.,** Bloch, S., Armstrong, M., Stone, P. C., & Low, J. T. S. (2019). Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative Medicine*, 33(8), 926-941. doi:10.1177/0269216319852007 [Citations: 4; Altmetric: 61]

### **Conference presentations:**

**Anderson, R.,** Stone, P., & Low, J., Bloch, S. (2019, July). *Disagreement in prognostic talk between doctors and families at the end of life*. Oral presentation at Conversation Analysis in Clinical Encounters, University of Bristol.

**Anderson, R.,** Stone, P., & Low, J., Bloch, S. (2019). *Discussing Prognosis and Managing Uncertainty in End-of-Life Conversations with Family Members: A Conversation Analytic Study*. Poster presented at the 16th World Congress of the European Association for Palliative Care, Berlin. doi: 10.1177/0269216319844405

**Anderson, R.,** Stone, P., & Low, J., Bloch, S. (2018, July). *End of life prognostication talk between doctors and family members*. Oral presentation at the International Conference on Conversation Analysis, Loughborough University.

**Anderson, R.,** Armstrong, M., Bloch, S., Stone, P., & Low, J. (2018). *Communication between healthcare professionals and relatives of patients approaching the end of life: A qualitative systematic review*. Poster presented at the 10th World Research Congress of the European Association for Palliative Care, Bern. doi: 10.1177/0269216318769196

**Anderson, R.,** Stone, P., Low, J., Parry, R., Tookman, A., Lodge, P., . . . Bloch, S. (2017). 3 Conversation analytic study of communication with the relatives and friends of patients in a hospice: study protocol. *BMJ Supportive and Palliative Care*, 7(3), A348. doi:10.1136/bmjspcare-2017-001407.3. Poster presented at Marie Curie Palliative Care Research Conference, London.

### **Other:**

*Podcast to accompany systematic review paper:*

Available at <https://journals.sagepub.com/doi/suppl/10.1177/0269216319852007>

**Anderson, R.,** Armstrong, M., Bloch, S., Stone, P., & Low, J. (2017). Communication between healthcare professionals and relatives of patients approaching the end of life: a qualitative systematic review. [http://www.crd.york.ac.uk/PROSPERO/display\\_record.php?ID=CRD42017065560](http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017065560)

### **Other related outputs during PhD:**

Chu, C., **Anderson, R.,** White, N., & Stone, P. (2020). Prognosticating for Adult Patients With Advanced Incurable Cancer: a Needed Oncologist Skill. *Current Treatment Options in Oncology*, 21(1), 5. doi:10.1007/s11864-019-0698-2

Kaasa, S., Loge, J. H., Aapro, M., Albrecht, T., **Anderson, R.,** Bruera, E., . . . Lundebj, T. (2018). Integration of oncology and palliative care: a Lancet Oncology Commission. *The Lancet Oncology*, 19(11), e588-e653. doi: 10.1016/S1470-2045(18)30415-7 [Citations: 53; Altmetric: 181]

White, N., Chu, C., Oostendorp, L., **Anderson, R.,** & Stone, P. (under review). Predicting Prognosis. (Chapter for ESMO Handbook of Supportive and Palliative Care)

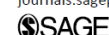


## Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence

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Patrick C Stone<sup>1</sup> and Joseph TS Low<sup>1</sup>

### Abstract

**Background:** Effective communication between healthcare professionals and relatives of patients approaching the end-of-life is vital to ensure patients have a ‘good death’. To improve communication, it is important to first identify how this is currently being accomplished.

**Aim:** To review qualitative evidence concerning characteristics of communication about prognosis and end-of-life care between healthcare professionals and relatives of patients approaching the end-of-life.

**Design:** Qualitative systematic review (PROSPERO registration CRD42017065560) using thematic synthesis. Peer-reviewed, English language articles exploring the content of conversations and how participants communicated were included. No date restrictions were applied. Quality of included studies was appraised using the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research.

**Data sources:** An electronic database search of CINAHL, MEDLINE, PsycINFO and EMBASE was performed.

**Results:** Thirty-one papers were included. Seven themes were identified: highlighting deterioration; involvement in decision-making, post-decision interactional work, tailoring, honesty and clarity, specific techniques for information delivery and roles of different healthcare professionals. Varied levels of family involvement in decision-making were reported. Healthcare professionals used strategies to aid understanding and collaborative decision-making, such as highlighting the patient’s deterioration, referring to patient wishes and tailoring information delivery. Doctors were regarded as responsible for discussing prognosis and decision-making, and nurses for providing individualized care.

**Conclusion:** Findings suggest training could provide healthcare professionals with these strategies to improve communication. Interventions such as question prompt lists could help relatives overcome barriers to involvement in decision-making. Further research is needed to understand communication with relatives in different settings and with different healthcare professionals.

### Keywords

Communication, terminal care, palliative care, family, caregivers, qualitative research

#### What is already known about the topic?

- Poor communication from healthcare professionals is a common complaint from relatives of patients at the end-of-life.
- Communication with relatives at this time is important for high quality end-of-life care and for relatives’ long-term well-being.

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**What this paper adds**

- Common communication strategies are identified including highlighting the patient's deterioration to aid decision-making, references to patient wishes, providing relatives with options, tailoring information to individuals and using pacing and staging of information.
- Healthcare professionals state a belief in using honest, direct language and involving families in decision-making, but there is variation in the extent to which this is implemented in practice.
- Nurses and allied healthcare professionals play an important role in providing individualized communication with relatives.

**Implications for practice, theory or policy**

- There is a need for more research on communication with relatives in palliative care settings and with different members of the multidisciplinary team.
- Training is needed to help healthcare professionals to translate communication guidelines into practice while considering their own emotional needs.
- Interventions such as question prompt list could also be used to help relatives get the information they need.

**Introduction**

Family members of patients at the end-of-life value high quality communication about their relatives' prognosis and care.<sup>1-4</sup> Patients in the terminal phase of their illness often have difficulty communicating and so their relatives need clear information to make decisions on their behalf. Honest and timely communication can give relatives time to say goodbye and improve psychological outcomes and satisfaction with end-of-life care.<sup>5-10</sup>

Healthcare professionals report finding end-of-life communication challenging and often wait for patients or families to initiate these conversations.<sup>11</sup> In an international survey of palliative care experts, 83% agreed more evidence-based guidance on strategies for communication with relatives would improve end-of-life decision-making.<sup>12</sup> A report by the English Parliamentary and Health Service Ombudsman found a key area of complaints about end-of-life care was failing to recognize when a person was dying and communicate this to the patient and their relatives.<sup>13</sup>

In response to criticisms of end-of-life care in the United Kingdom, the National Institute for Health and Care Excellence (NICE) have produced guidelines for healthcare professionals, including advice on communication.<sup>14</sup> NICE make recommendations including discussing what patients understand and want to know, explaining uncertainty, avoiding false optimism, providing opportunities to ask questions and highlighting opportunities for further discussions. Bernacki and Block<sup>15</sup> made similar recommendations for a conversation guide to support clinicians in the United States. However, the primary focus of these recommendations is communication with patients rather than relatives. While these recommendations can be useful for relatives, their communication needs are different. For example, a previous review found caregivers wanted more information about the dying process than patients.<sup>16</sup>

Recommendations about what to discuss with relatives are needed, alongside specific strategies on how to do this. Previous reviews have explored relatives' communication preferences and how they are prepared for the patient's death more generally. They found a desire for honest information about disease progression, the dying process and pain management; jargon-free information with time to understand; and opportunities to discuss spiritual needs.<sup>16-20</sup> However, these reviews did not focus on how healthcare professionals discuss these issues with relatives. To provide recommendations for change, we must first understand how this communication is currently being accomplished. Healthcare professionals and relatives sometimes have different perceptions of how much prognostic information relatives have been given.<sup>21,22</sup> It is therefore important to consider a range of perspectives when addressing this issue.

**Objectives**

The primary objective of this article is to review existing qualitative evidence about the characteristics of communication about prognosis and end-of-life care between healthcare professionals and relatives of patients approaching the end-of-life:

- From the perspective of healthcare professionals;
- From the perspective of relatives;
- As identified from observational studies.

**Method**

An initial scoping of the literature suggested only qualitative literature could explore what happens during these conversations in sufficient depth. A qualitative systematic review was therefore conducted.

### Search strategy

A comprehensive electronic database search was last updated on 16 July 2018. The databases searched were CINAHL plus (1937–2018), MEDLINE (1950–2018), PsycINFO (1967–2018) and EMBASE (1980–2018). Text and MeSH terms for the following word groups were searched: communication, relatives, healthcare professionals, settings with patients at the end-of-life and qualitative methodology. Searches included peer-reviewed, English language articles, and there were no search restrictions based on the date of publication (see full electronic search strategy in Supplementary Table 1). Reference lists of all included studies were hand-searched and citation searching was performed. Reference lists of five relevant reviews were hand-searched.<sup>16,17,19,20,23</sup>

### Study selection

The lead author (R.A.) ran the searches, removed duplicates and screened titles and abstracts to exclude ineligible papers. Full texts of all remaining papers were reviewed for inclusion/exclusion by R.A. and M.A. Studies identified from the search had a broad range of research questions and so study selection was complex, requiring numerous decisions within the research team. For example, articles involving both relatives and patients were included only if the findings relating to relatives could be separated from those relating to patients. Disagreements and uncertainty were resolved through discussion and referral to a third reviewer, J.L. when required.

Inclusion criteria included qualitative studies focusing on communication between adult relatives and healthcare professionals, in settings with patients at the end-of-life, about prognosis and end-of-life care and exploring what and how communication occurs (as opposed to preferences or challenges). Authors were contacted when the eligibility of papers was unclear. A full list of inclusion and exclusion criteria is included in Supplementary Table 2.

### Quality appraisal

The 10-item Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research<sup>24</sup> was used to assess the quality of included articles. While there is no 'gold standard' tool for quality appraisal of qualitative studies, a comparative analysis concluded the JBI checklist was the most coherent.<sup>25</sup>

R.A. and M.A. assessed all studies against the JBI checklist. Disagreements were resolved through discussion and referral to other authors (J.L. or S.B.). The JBI checklist does not allocate scores to studies and papers were not excluded based on the checklist; instead, results were used to identify weaknesses in the literature and considered when synthesizing the data. Authors' descriptions/interpretations

were only included in the synthesis if they were supported with illustrative quotes.

### Data extraction and synthesis

The following data were extracted by R.A. and checked by M.A.: title, authors, year, journal, country, setting, research question/aims, theoretical/philosophical perspective, research methodology, data collection/analysis, study population and relevant findings. Only findings relevant to the aim of this review were extracted. For example, one study<sup>26</sup> included findings related to physicians' beliefs on children's best interests. These were not extracted but all findings relating to communication with parents were.

Findings, including participant quotes and authors' descriptions/interpretations, were entered into NVivo 11. Thematic synthesis, which allows conclusions to be drawn across heterogeneous methodologies, was used to synthesize findings. Thomas and Harden's<sup>27</sup> steps of thematic synthesis were followed, beginning with line-by-line coding of findings. Initial codes were grouped into descriptive themes and put into a coding framework, which was applied to the whole dataset. These themes were discussed within the team to develop analytic themes. For example, descriptive themes 'problem listing' and 'perspective display invitations' both highlighted a patient's deterioration, and so this became an analytic theme.

R.A. coded findings with regular discussions with the analytic team, which included five researchers (three with Psychology backgrounds, one with a speech and language background and one palliative care consultant). An interpretivist approach was taken towards the synthesis, which involves providing narrative descriptions to represent the subjective experiences of a range of stakeholders.<sup>28</sup> A broad range of populations and clinical settings were therefore included in the review and are presented together within the synthesis.

## Results

### Search results

The search strategy identified 2195 unique citations published between 1975 and 2018, 31 of which were included in the review (Figure 1). The 31 articles originated from 10 countries and reported results from 25 individual studies (see Table 1). Fourteen papers were observational (non-participant observations or video/audio-recordings), 10 used interviews or focus groups with healthcare professionals, five used interviews with relatives and two used a combination of these approaches in ethnographic studies. The majority of studies were based in adult acute care (18 papers); eight were in paediatric or neonatal intensive care units (ICUs), three in palliative



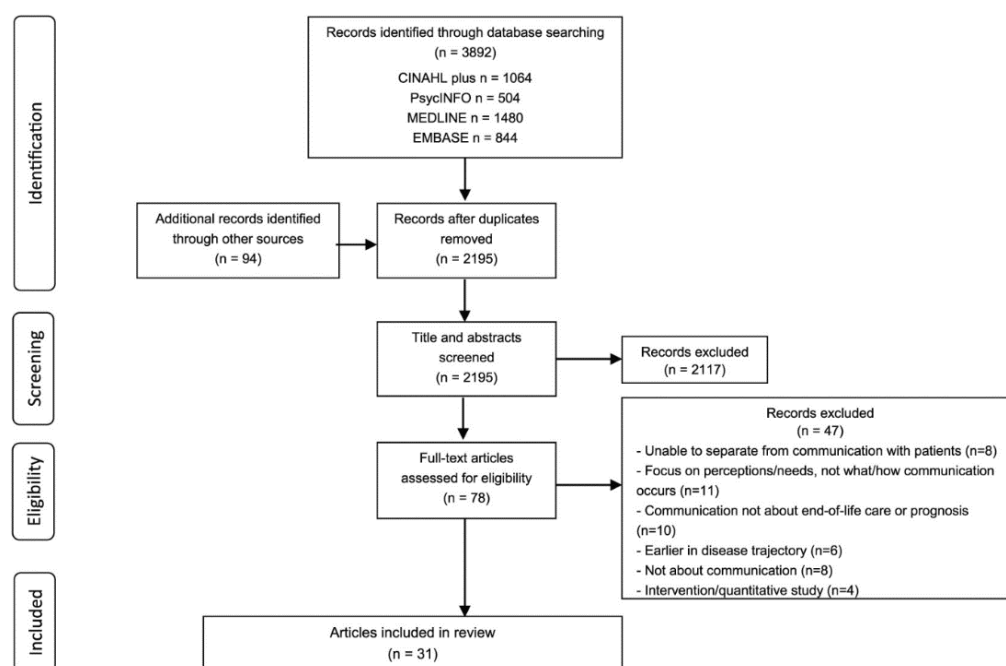


Figure 1. PRISMA diagram of included articles, adapted from Moher et al.<sup>29</sup>

care settings and two in other settings (older adult wards and family physicians).

### Study participants

Overall, sample sizes are reported below. In samples used for multiple papers, only the original sample size is included in this total. Further demographic information for study participants is included in Supplementary Table 3.

Observational, ethnographic and interview/focus group studies with healthcare professionals had a total sample size of 343 healthcare professionals (170 physicians, 127 nurses, 9 other healthcare professionals, 37 unspecified), with a median sample size of 19 healthcare professionals (range = 1–37). Numbers of healthcare professionals were not reported for two primary observational studies. Physicians were mostly attending, resident and fellow physicians, intensivists and palliative care consultants, although this information could not be obtained for five studies. Nurses worked in ICU, paediatric ICU, other acute care or hospice. Other healthcare professionals such as social workers were also present at observations but were not the focus of these observations. Two studies interviewed other healthcare professionals. Where reported, healthcare professionals' years of clinical or specialty experience ranged from <2 to 40 years.

Observational, ethnographic and interview studies with family members had a total sample size of 495 individual

family members with a median sample size of 27 (range = 12–227). The number of individual family members could not be obtained for five primary studies. These five studies reported a total sample size 92 families with a median sample size of 19 families (range = 8–36). Where reported, family members included parents, spouses, adult children, siblings, friends and other family members. Six primary studies reported including multiple different family members and five reported including parents only.

### Quality appraisal results

The main findings from the quality appraisal were the high number of articles which did not report a philosophical perspective (22 articles), the researchers' background (21 articles) or address the influence of the researcher on the research (21 articles). All studies used quotes to support their analysis, but there were seven papers where it was unclear if an adequate range of participants' views were represented, mostly due to a lack of patient identifiers. Ten papers did not report their analysis in a way that was wholly consistent with their stated methodology. The full results of the quality appraisal are reported in Supplementary Table 4.

### Overview of findings

Included papers described how healthcare professionals and relatives discussed the patient's deterioration, made

Table 1. Summary of included papers.

Author	Country	Research question/aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<i>Observational studies</i>						
Aldridge and Barton <sup>30a</sup>	USA	Compare the 'description of current status' in end-of-life discussions with family members that did and did not result in a change from therapeutic to comfort care	Surgical ICU	Critical care intensivists, surgeons and families of current SICU patients	Secondary analysis of audio-recordings of family conferences Discourse analysis	Highlighting negative outcomes and direct summaries implying terminal status led to more decisions to move to comfort care Decisions were less likely to be made when more positive outcomes were described and possible treatment was discussed
Barton et al. <sup>31a</sup>	USA	1. Describe the structure and variations within each phase of the end-of-life discussion 2. Look specifically at interaction between physicians and families within each phase	Surgical ICU	Critical care intensivists, surgeons and families of current SICU patients	Secondary analysis of audio-recordings of family conferences Discourse analysis	Description of current status used to develop consensus on terminal status. Some used perspective display questions. Framed decision as expressing patient's wishes. If no consensus of terminal status was established, decisions were not made Explained logistics of dying (often initiated by family) with more direct language
Barton <sup>32a</sup>	USA	Describe how physicians and families construct an ethical frame to present the decision to withdraw life support as the 'right' decision	Surgical ICU	Critical care intensivists, surgeons and families of current SICU patients	Secondary analysis of audio-recordings of family conferences Discourse analysis	Process of dying and comfort care repeated by doctors and families Doctors repeated problem listing and emphasized the decision as being a consensus between the medical team Families discussed personhood and consciousness – doctors repeated 'best interests' and described the decision as ethical because of loss of consciousness Both families and doctors described the decision as 'right'
Curtis et al. <sup>33b</sup>	USA	Establish a framework that will allow future analyses and studies to describe and understand the communication in family conferences in which the issue of withholding or withdrawing life support is discussed	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences Limited application of grounded theory	Discussed substituted judgement: encouraged the family to describe personhood to elicit patient wishes Described the dying process (often raised by family) Stressed continuing care, patient comfort and supported decision to withdraw treatment Varied in directness and use of strategies (e.g. repeating what family says, allowing silence, confirming understanding) 15/51 family conferences had examples of missed opportunities: Some avoided answering difficult questions and didn't ask for clarification about families' vague concerns Failed to explore/acknowledge expressions of emotion Missed chances to explore comments about patient treatment preferences
Curtis et al. <sup>34b</sup>	USA	Identify missed opportunities for physicians to provide support or information to families during family conferences	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences Limited application of grounded theory	Discussed deterioration: 1/3 asked for parents' perspective on child's condition. Parents demonstrated good understanding when asked Physicians expressed a team preference. Parents often gave their preference unprompted Most presented as medical decision and didn't ask parents. Parents expressed concern about suffering and physicians reassured them of comfort and peace Nurses often spoke with parents at the bedside after the meeting (not recorded)
De Vos et al. <sup>35</sup>	Netherlands	1. How do physicians and parents communicate about decisions to withhold or withdraw life sustaining treatment 2. To what extent do parents share in the decision-making process?	Paediatric ICU	Physicians and parents of children currently in PICU	Audio-recording of conversations Qualitative coding	

(Continued)

Table 1. (Continued)

Author	Country	Research question/aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
Ekberg et al. <sup>36</sup>	Australia	Explore how discussions about deterioration are managed within actual paediatric palliative care consultations	Paediatric palliative care service (inpatient, outpatient, telehealth and home)	Specialist palliative care consultant and parents of children in a paediatric palliative care service	Video-recordings of consultations Conversation analysis	Solicited the family's agenda to allow opportunity for them to raise prognosis/deterioration Used topic shading (brought up another issue where deterioration may be relevant). This allowed the family to raise deterioration if they wished to 6/51 family conferences had unresolved questions about patient movement: Majority responded with clinical information (physiological reasons) Acknowledged emotions (e.g. with active listening) Only one physician explored emotions and gave the family more time to consider Contradictions identified included: killing versus allowing to die, death as benefit versus burden, patient wishes versus family wishes Physicians' decision-centred strategies: argued against one side (e.g. killing), argued for one side (e.g. patient over family wishes) or avoided Physicians' information-seeking strategies: acknowledged the contradiction, clarified family's statements, emphasized patient wishes and segmented decision Storytelling: Physicians described what has happened or asked relatives what has happened to forecast bad news Online commentary: Physicians used sight and touch to explain symptoms Paradoxical proposals: Physicians sometimes put forward continuing treatment despite suggestion that treatment is futile, giving time for families to make the decision or express deontic authority Physicians left sentences unfinished to allow for co-completion of final decision Following online commentaries/paradoxical proposals, families themselves sometimes raised the possibility of stopping treatment
Engelberg et al. <sup>37b</sup>	USA	Describe physicians' responses to families' questions about the meaning of critically ill patients' movements	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences Limited application of grounded theory	
Hsieh et al. <sup>38b</sup>	USA	Identify inherent tensions that arose during family conferences in the ICU, and the communication strategies clinicians used in response	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences Qualitative content analysis from a dialectic perspective	
Kawashima <sup>39</sup>	Japan	Explicate the structure of interactions between medical professionals and patients' family members in a Japanese emergency room, when the patient is seriously ill and may be at the point of death	Emergency room	Physicians and family members of patients at risk of imminent death in an emergency room	Video recordings of consultations Conversation analysis	
Miller et al. <sup>40</sup>	USA	Examine the decision-making process to withhold or stop life support	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recordings of family conferences Conversation analysis	Framing of options 'shaded' (e.g. not all options presented) in 6/15 cases Framed decision as consensus between healthcare professionals, the family and the patient's wishes When couldn't agree, gave family time to decide (but imposed time limit) Clinicians used 'perspective-display invitations' to elicit the surrogate's view of patient preference – used this as basis for shared decision-making Direct questions were more successful than tact invitations Perspective display invitations were reformulated when unsuccessful
Pecanac <sup>41</sup>	USA	Explore how clinicians introduce the need to make a decision about the use of life-sustaining treatment and how surrogates respond	ICU	Physicians and families of current ICU patients	Audio-recordings of family conferences/ Conversation analysis	



Table 1. (Continued)

Author	Country	Research question/aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
Shaw et al. <sup>42</sup>	UK	Explore decision-making related to the move from active to palliative care in the neonatal ICU	Neonatal ICU	Consultants and families of babies currently in NICU	Audio-recordings of discussions/ Conversation analysis	Identified two different ways doctors initiated the decision-making process: 1. Making recommendations: Presented strong recommendation as coming from the medical team in the best interests of the baby. Parents often asked challenging questions, about options and responded negatively to explanations 2. Providing options: Presented as a joint plan for parents and doctors to make. Told parents the decision can be deferred and options for the decision were provided. Parents could ask questions without appearing challenging 44/51 family conferences contained expressions of non-abandonment from either the family or clinician: Clinicians: Highlighted continuing care; emphasized physician availability; gave the family the choice of when treatment is removed Family: expressed decision as reducing suffering and following patient wishes; expressed a desire to be at the bedside
West et al. <sup>43b</sup>	USA	Identify the categories of expressions of non-abandonment and develop a conceptual model describing the ways this is expressed by families and clinicians, in ICU family conferences concerning withdrawing life-sustaining treatments or the delivery of bad news	ICU	Attending, resident and fellow physicians and families of current ICU patients	Audio-recording of family conferences Limited application of grounded theory	
<i>Family perspective</i>						
Abib El Halal et al. <sup>44</sup>	Brazil	Explore parents' perspectives of the quality of care offered to them and their terminally ill child in the child's last days of life	Paediatric ICU	Parents of children who died in PICU	Interviews Thematic content analysis	Parents reported healthcare professionals using medical jargon Decisions were communicated but families not involved Lack of communication around the time of death
Gordon et al. <sup>45c</sup>	USA	Examine bereaved parents' perspectives of their and clinicians' communicative roles and responsibilities in the PICU	Paediatric ICU	Parents of children who died in PICU	Secondary analysis of interviews Discourse analysis	Varied in how much parents were included in decisions Some struggled to understand uncertainty. Clarity varied (e.g. medical jargon) Some felt clinicians created false hope by saying child was going to be ok Parents were sometimes 'rude' or shouted at clinicians Three variants of involvement in decisions: 1. Informed not involved: families told of decision with a medical explanation 2. Informed and asked for approval (directly or waiting for a nod/yes) 3. Involved — shared decision-making: Discussed what the patient would want
Lind <sup>46</sup>	Norway	Examine and describe relatives' experiences of responsibility in the ICU decision-making process	ICU	Relatives of patients who died in ICU	Secondary analysis of interviews Narrative analytical approach	Honest communication built trust and prepared parents. Others held back prognostic information leading to false hope Honesty was either communicated with empathy which was appreciated or as 'matter of fact' which felt cold and insensitive Some felt healthcare professionals used medical jargon or too much information was given at once
Meert et al. <sup>47c</sup>	USA	Describe parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the PICU	Paediatric ICU	Parents of children who died in PICU	Secondary analysis of interviews Qualitative coding	Some felt doctors were not clear and honest with them (e.g. used euphemisms and were indirect about prognosis) Others had open conversations including discussing patient wishes
Odgiers et al. <sup>48</sup>	Australia	Explore the family's experience of end-of-life care for their relative during the dying process	Acute hospital	Next of kin to patients who died in acute hospital	Interviews Thematic analysis	

(Continued)

Table 1. (Continued)

Author	Country	Research question/aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
<i>Healthcare professional perspective</i>						
Bach et al. <sup>49</sup>	Canada	Bring to light the role of critical care nurses in decision-making at the end-of-life	ICU and cardio-respiratory care unit	Critical care nurses	Interviews Grounded theory	Nurses clarify information and help families see the whole picture Act as a go-between for the physicians and families Felt that honesty is important (but balanced with hope) Provide families with options and they make the final decision Denial common in families – physicians repeat information and give time Highlighted the role of nurses/social workers taking time with families Identify a family spokesperson Try to give clear summaries, non-medical language, staged information and not give false hope Look for non-verbal cues that a relative does/doesn't want to talk and verbal signs of understanding Identify a spokesperson Use staging of information to give families time to digest it Following family meetings check understanding and discuss the process of death
Bartel et al. <sup>50</sup>	USA	Describe physicians' experiences in attempting to provide optimal care for families of children who suffer sudden, acute life threatening conditions	Paediatric ICU	Resident, attending and fellow PICU physicians	Interviews and focus groups Qualitative coding	
Bloomer et al. <sup>51</sup>	Australia and New Zealand	Explore how nurses navigate communication with families during treatment withdrawal processes	ICU	Critical care nurses	Focus groups Inductive content analysis	
Epstein <sup>52</sup>	USA	Explore nurses' and physicians' end-of-life experiences in the new-born ICU	New-born ICU	NICU registered nurses, nurse practitioners and resident and fellow physicians	Interviews Hermeneutic circle approach	Physicians delayed conversations to give families time to understand patients' terminal status Nurses felt false hope could be promoted Nurses informally/gently discussed options with parents in more detail Physicians begin more indirectly but use direct language if families don't understand Explain what changes to expect in dying process Involve parents in decision but take responsibility themselves Discuss signs/symptoms of death and time to death (including uncertainty) Repetition to ensure the message gets through, staged preparation over time Use active listening/questions to tailor content and delivery Building trust improves acceptance of messages Nurses bring together information from different physicians to provide the 'big picture'. Draw attention to quality of life consequences of treatment Highlight deterioration and prepare families for death Changes in the patient's status can a trigger conversations Nurses check understanding and explain consequences of treatment after discussions with physicians Ask about the patient, emphasize quality of life and what they would want Help families see deterioration. Tailor to what the person is ready to hear
Kehl <sup>53</sup>	USA	Describe how hospice clinicians prepare family for the final days of life	Home hospice	Nurses, nursing assistant, social workers, bereavement counsellors and chaplain	Interviews Conventional content analysis	
Liaschenko et al. <sup>54</sup>	USA	Understand factors that influence ICU nurses' inclusion of families in end-of-life care	Critical care unit	Experienced critical care nurses	Focus groups Content analysis	
Peden-McAlpine <sup>55</sup>	USA	Describe the communication practices experienced intensive care nurses use with families to negotiate consensus on withdrawal of aggressive treatment and/or shift to palliative care	ICU	ICU nurses comfortable with dying patients/families	Unstructured interviews Narrative approach	

Table 1. (Continued)

Author	Country	Research question/aim	Setting	Population	Data collection Data analysis	Summary of relevant findings
Rejno et al. <sup>56</sup>	Sweden	Deepen the understanding of stroke team members' reasoning about truth-telling in end-of-life care due to acute stroke	Acute stroke ward	Physicians, registered nurses and enrolled nurses	Interviews Qualitative content analysis	Truth above all: approach discussions with complete honesty and direct language to prepare them and establish trust Hide truth to protect: Withhold certain distressing information if don't feel it's necessary to tell; wait until have clearer info/ better environment to discuss; some nurses waited for doctor to give the bad news Limiting options: don't mention treatment options that they believe to be futile Being directive: when feel parents can't make decisions, physicians take control to relieve burden and give families 'permission' to remove life support Staying neutral: by providing options and avoiding giving own opinion Allowing parents to come to own conclusions (e.g. delay decisions/discussions and give time so that parents can see that their child is dying) Staged information as trust increases; gauge surrogate's understanding; use patient's previous statements to help decisions Bringing other professionals in can help resolve conflict
Richards et al. <sup>26</sup>	USA	Understand how neonatal and paediatric critical care physicians balance and integrate the interests of the child and family in decisions about life-sustaining treatments	Paediatric and Neonatal ICU	Attending paediatric critical care physicians	Interviews Content and thematic analysis	
Tan and Manca <sup>57</sup>	Canada	Describe conflict experiences that family physicians have with substitute decision-makers of dying patients and identify factors that facilitate or hinder the end-of-life decision-making process	Family physicians	Family physicians	Interviews Grounded theory	
<i>Mixed perspectives</i> Caswell et al. <sup>58</sup>	UK	Understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers	Hospital wards caring for older adults	Healthcare professionals and bereaved relatives of older patients who died	Ethnographic: interviews, focus groups, non-participant observations and review of case notes Constant comparative method	Doctors discussed prognosis, nurses translated into lay language Staff thought often one conversation wasn't enough but didn't always repeat this Observations showed it was rare to explain process of dying Euphemistic/vague language meant carers didn't always understand that their relative was dying Healthcare professionals elicited understanding to ensure their views were aligned on prognosis (e.g. discuss prior symptoms that signal dying). Families described patient's personhood Explained process of dying, paced info in line with family responses Separated the person from the illness (e.g. explaining agitation), gave time to ask questions
Meeker et al. <sup>59</sup>	USA	Examine the nature of family meetings as conducted in an inpatient hospice care unit in order to generate an inductive theoretical model	Hospice inpatient unit	Nurses, social workers, physicians and family members of current hospice inpatients	Ethnographic: observations of family meetings, informed by healthcare professional interviews Constant comparative method of grounded theory	

SICU: surgical intensive care unit, ICU: intensive care unit, PICU: paediatric intensive care unit, NICU: neonatal intensive care unit. Detailed demographic information is provided in Supplementary Table 3 and quality appraisal information in Supplementary Table 4.

<sup>56</sup>papers using data from Cassell.<sup>60</sup>

<sup>57</sup>papers using data from Curtis et al.<sup>33</sup>

<sup>61</sup>papers using data from Meert et al.

decisions and the interactional work accomplished by both parties following decisions. Papers identified communicative practices from healthcare professionals and family members and the roles different healthcare professionals played in communication. The synthesis identified seven key themes to describe this communication: highlighting deterioration, involvement in decision-making, post-decision interactional work, tailoring, honesty and clarity, specific techniques for information delivery and roles of different healthcare professionals. Supplementary Table 5 provides extracts from original papers demonstrating these themes.

### *Highlighting deterioration*

The first theme identified was highlighting deterioration, which was found in 11 papers.<sup>26,30–32,35,36,39,54,55,58,59</sup> This describes how healthcare professionals enabled relatives to recognize the patient's deterioration (referred to as 'establishing terminal status' by one study<sup>30</sup>). Highlighting deterioration involved listing the patient's previous and ongoing problems to provide evidence that further active treatment was futile and the patient was reaching the end-of-life. Often this was accomplished by healthcare professionals, but studies also found evidence of perspective display invitations,<sup>62</sup> where healthcare professionals asked relatives to describe what had happened so far and how the patient was doing.<sup>31,32,35,36,39,55,58,59</sup> Perspective display invitations highlighted deterioration in collaboration with families and provided healthcare professionals with information about their level of acceptance and understanding.

Usually, this phase ended with a summary statement to demonstrate they had reached a consensus that the patient was dying. However, one study described more ambiguous problem listing, including references to treatment. In these conversations, a consensus on terminal status was less likely to be reached and decisions relating to withdrawal of treatment were made less often.<sup>30</sup>

The practice of highlighting deterioration was identified in healthcare professional interview and focus group studies<sup>54,55,58,59</sup> and observational studies,<sup>30–32,35,36,39,59</sup> but not interviews with families. It was seen in adult and paediatric settings, but was not always consistent. For example, in an ethnographic study on older adult wards, only one healthcare professional described this practice and there was no evidence of it from non-participant observations.<sup>58</sup>

### *Involvement in decision-making*

Varied levels of family involvement in patient care decisions were identified, particularly relating to withdrawal of treatment. The reported styles of involvement can be divided into presenting the medical team's decision (either as what has already been decided<sup>35,44–46</sup> or

a recommendation for families to agree with previous studies<sup>26,42,45,46,52</sup>) or a collaborative process where the family made the final decision. Reports of less collaborative decision-making were more common in paediatric settings and were found mostly by observational studies<sup>35,42</sup> and those interviewing family members.<sup>44–46</sup> Healthcare professionals rarely described non-collaborative decision-making, but in two healthcare professional interview studies, some described taking responsibility for decisions to relieve burden for families.<sup>26,52</sup> While this could be helpful when families felt unable to make decisions, it could cause interactional difficulties. Where healthcare professionals presented recommendations, family members often passively agreed, without always receiving clear information about the reason for the decision. At other times, family members objected to the decision. One conversation analytic study<sup>42</sup> described how giving recommendations made it difficult for families to ask questions as they came across as challenging the medical team's opinion. However, there was evidence of families actively involving themselves in these conversations by asking questions and expressing preferences.<sup>32,35,39,42,45</sup>

Collaborative decision-making was reported across observational studies and interviews/focus groups with healthcare professionals and relatives, and in both child and adult settings.<sup>26,30–33,35–43,45–50,52,55,57</sup> When papers reported collaborative decision-making, several strategies were used. In adult settings only, the most common identified was invoking the patient's wishes.<sup>31–33,38,40–42,46–49,55</sup> Healthcare professionals asked families what the patient was like prior to hospitalization and whether they had discussed their care preferences. They emphasized the family member was a voice for the patient, rather than making decisions based on their own feelings. There were, however, examples in observational studies and one nurse interview study, where doctors missed opportunities to discuss patients' wishes or did not clarify the meaning of surrogate decision-making.<sup>33,34,46</sup>

Another strategy was presenting options to the family (e.g. to remove some life-sustaining treatments and leave others in place) and framing the discussion as forming an evolving plan, rather than one overall decision.<sup>26,35,38–40,42,50,52</sup> Options could be presented with a subtle preference for a certain course of action,<sup>40</sup> but it was stressed the family's decision would be supported. Families were given time to make decisions and if withdrawing treatment, control over how and when this would happen.<sup>33,37,39,42,43,46</sup> These practices were mostly identified by observational studies,<sup>33,37–40,42,43</sup> but some relatives described the same practices<sup>35,46</sup> and healthcare professionals reported providing options.<sup>26,50,52</sup>

### *Post-decision interactional work*

Observational studies and healthcare professional interviews reported that healthcare professionals emphasized



the continued care of the patient<sup>33,35,43,47,57,59</sup> (described in one study as 'expressing non-abandonment'<sup>43</sup>), particularly following decisions to withdraw active treatment. Healthcare professionals stressed they would ensure the patient was comfortable, explained what would happen next and reassured families they would be available for further discussions. There were however reports from families<sup>44,58</sup> and some observations<sup>43</sup> of healthcare professionals failing to do this and where it appeared to families that healthcare professional involvement would reduce following the move to comfort care.

Families also displayed their commitment to their relatives' continued care by discussing the patient's comfort and emphasizing their continued presence, often wanting to be with the patient when they die.<sup>32,35,43</sup> Observational studies found families asked questions about patients' consciousness and awareness, the dying process and what to expect.<sup>31–33,37</sup> Healthcare professionals were generally forthcoming with this information,<sup>31–33,47,52,53,59</sup> but there were some reports from observational studies where details about the dying process from healthcare professionals were lacking.<sup>33,58</sup> Only two articles (from the same observational study) described how healthcare professionals responded to families' displays of emotions, finding such displays were rarely explored in depth.<sup>34,37</sup>

Observational studies and one study interviewing nurses reported both healthcare professionals and families justified decisions to withdraw life-sustaining treatments as 'right'.<sup>31–33,38,43,55</sup> They repeated medical justifications for the decision and referred to patients' wishes. Healthcare professionals often referenced their medical knowledge and experience<sup>32,33</sup> and stressed they were allowing the patient to die, not having an active role in the death.<sup>38,43</sup>

### *Tailoring*

Healthcare professionals reported and were observed to tailor their communication to individual families.<sup>33,36,38,50–53,55,57,59</sup> Healthcare professionals gauged levels of understanding and willingness to discuss dying through questions and observing verbal and non-verbal cues from families.<sup>38,50,55,57,59</sup> The content, delivery and timing of communication was tailored to families' previous experiences of death, levels of understanding, desire for information and the patient's current symptoms.<sup>36,38,51–53,55,59</sup> Healthcare professionals were also observed to take into account different cultural and religious backgrounds of families.<sup>33</sup> Some healthcare professionals reported identifying a spokesperson for each family to ensure information was effectively communicated to the whole family at a level of detail with which individuals were comfortable.<sup>50,51</sup>

### *Honesty and clarity*

One of the most varied findings was healthcare professionals' honesty and clarity. Healthcare professionals described the need to use direct, simple language to promote understanding.<sup>26,50,56</sup> However, while some families agreed straightforward information was given,<sup>47</sup> others described not understanding information due to technical or ambiguous language.<sup>44,45,48</sup> In observational studies, healthcare professionals' language varied in its level of directness.<sup>30,31,33,40,42,48</sup> In interviews, they highlighted the difficult balance between being honest and allowing families hope, mostly emphasizing the need to avoid false hope and be honest to build trust with families.<sup>49,50,52,54,56</sup> However, nurses reported that doctors sometimes felt the need to 'try everything' and this could lead to false hope for families and unnecessary, aggressive treatments for patients.<sup>52</sup> In line with this, several families reported feeling they had been given false hope because of a lack of honest communication.<sup>44,45,47,48,58</sup> In one interview study, some relatives realized when looking back that healthcare professionals had tried to inform them their relative was dying, but said that they had not fully understood at the time,<sup>58</sup> suggesting possible ambiguity on the part of the healthcare professional. Others felt healthcare professionals had been 'blunt' or 'cold' in their communication.<sup>45,47,48,58</sup>

### *Specific techniques for information delivery*

Various communicative techniques used by healthcare professionals were reported in observational studies and interviews with healthcare professionals, but not interviews with families. Repetition was used both within conversations and across several conversations to ensure families' understanding.<sup>32,33,35,50,53</sup> Healthcare professionals repeated information or asked relatives to summarize what they had been told. Repetition was also used towards the end of conversations, for example, information about patients' deterioration was repeated to justify decisions to remove life-sustaining treatment later on in conversations.<sup>32</sup> However, in a study in older adult hospital wards, healthcare professionals acknowledged the need to repeat information but explained they were reluctant to have this conversation a second time.<sup>58</sup>

Pacing and staging of information were identified as other communicative strategies.<sup>26,33,50,51,53,55–57</sup> This included allowing time for information to be taken in within a conversation, giving smaller chunks of information across several conversations when the family was ready to hear it, or delaying giving information until appropriate support could be provided to families. Healthcare professionals also described postponing decisions to allow parents time to see for themselves their child was dying.<sup>52,56</sup> Staging was not always possible however, especially if the patient had a sudden deterioration necessitating a timely conversation.<sup>53</sup>

## *Roles of different healthcare professionals in communication*

The review looked at a range of healthcare professionals and found different communication roles for different professions. Doctors were often seen by both healthcare professionals and relatives as responsible for conducting prognostic and decision-making conversations with family members,<sup>50,56,58</sup> although when death was imminent, nurses sometimes had these conversations.<sup>35,58</sup> While no observational studies focused primarily on nurse communication, in interviews both physicians and nurses recognized the importance of nurses communicating with families on a more personal, individualized level.<sup>33,35,49–51,54,55</sup> Nurses often reported translating what doctors had said into less technical language.<sup>49,54,55,58</sup> Nurses highlighted their role in giving patients a clearer idea of what treatments would mean for the individual patient and bringing together information from different sources.<sup>46,49,54,55</sup> This role was termed providing ‘the big picture’ in one study.<sup>54</sup> Nurses also reported encouraging physicians to have discussions with families.<sup>49,52,55</sup> These roles of nurses were mostly identified in observational studies and those interviewing healthcare professionals, but in one study families also reported that nurses made things easier to understand.<sup>44</sup> Other allied health professionals, particularly social workers, were identified as playing important roles in communication with relatives,<sup>53,59</sup> but included studies focused primarily on doctors and nurses.

## **Discussion**

### **Key findings and implications**

This review has focused on the content and communicative practices in end-of-life conversations about prognosis and care between healthcare professionals and relatives. We have identified common practices reported in the qualitative literature and variation in these practices within and across studies.

Healthcare professionals used problem listing, including eliciting relatives’ perspectives, to highlight patients’ deterioration. NICE guidelines<sup>14</sup> and Bernacki and Block’s<sup>15</sup> review both suggest prognostic disclosure and exploring patients’ understanding are important elements to be addressed by healthcare professionals. It follows that the same should apply when communicating with relatives. The practice of highlighting deterioration is a collaborative communication strategy that could be used by other healthcare professionals to meet these recommendations.

The involvement of relatives within the decision-making process was varied. Invoking patient wishes was often used for collaborative decision-making. A previous

systematic review found having awareness of the patient’s treatment preferences reduced negative emotional effects for surrogate decision-makers.<sup>63</sup> Therefore, orienting relatives to patient wishes may have long-term benefits beyond the conversation itself. However, references to patient wishes did not occur in paediatric end-of-life care. Healthcare professionals cannot ask parents what their child would want or whether they have had conversations about end-of-life decisions, particularly in neonatal settings. Perhaps, as a result of not being able to refer to patient wishes, most examples of less collaborative decision-making occurred in paediatric settings. However, there was evidence that collaboration could be achieved in these settings by consulting parents whenever decisions were made and providing them with options and time to make plans. Given recent high profile court cases in the United Kingdom involving end-of-life decision-making in paediatric end-of-life care,<sup>64,65</sup> pressure and scrutiny on healthcare professionals communicating difficult decisions to families in these settings is particularly high. The collaborative communicative strategies described in this review could be valuable for these healthcare professionals and should be further researched and put into practice through training.

Other common communicative practices identified, including repetition, pacing and staging, and highlighting continuing care are in line with relative’s preferences for receiving detailed information and time to understand this.<sup>16–20</sup> Healthcare professionals also recognized the need for simple, direct language and honesty, which have been identified as key relative preferences<sup>16–20</sup> and recommended in guidelines.<sup>14,15</sup> However, there was evidence of a struggle to balance honesty and hope. This finding demonstrates that while guidelines are a useful start, training on how to implement them in practice is vital to improve communication. Healthcare professionals have reported emotional support needs relating to end-of-life communication, so any intervention should also consider implementing organizational changes to allow reflective practice in a supportive environment.<sup>66</sup>

Further recommendations from Bernacki and Block’s<sup>15</sup> review include focusing on quality of life and assessing what trade-offs are acceptable to patients when making treatment decisions. The review identified nurses as key to facilitating this individualized decision-making. Doctors were responsible for prognostication and decision-making, while nurses helped families understand their options in the context of individual patients’ lives. A recognition of this important role of nurses is needed, and involving them more formally in decision-making may help promote shared decision-making in line with recommendations. While there was little focus on acknowledging spiritual needs in the included articles, relatives have highlighted this as important<sup>18,19</sup> and the nurse role in

individualized care could put them in a good position to address these needs.

### *Contributions of different qualitative approaches*

Observational studies, those focusing on healthcare professional perspectives and those exploring relatives' perspectives, all provided valuable findings. However, each approach had strengths and weaknesses in addressing the article's aim. Interviews with family members contributed more towards understanding the content of conversations than how communication was actually accomplished. This is unsurprising as relatives are less likely to have considered their communicative practices than healthcare professionals who regularly have these conversations. In comparison, healthcare professionals had insights into how they communicate in this context and provided information about communication beyond a single conversation (e.g. spacing information over several conversations). Different healthcare professionals also had insight into each other's practice, for example, nurses highlighted that doctors sometimes gave families false hope. However, there may be communicative behaviours healthcare professionals are not conscious of. Interviews are also limited by participants' ability to accurately remember these conversations and recollections are subject to their own interpretations.

Observational studies show what actually happened with the most accuracy, particularly those using audio- or video-recording. However, there are limits to what observations can tell us, for example, these studies could not assess whether clinicians were providing honest information or giving false hope. These studies are also unlikely to observe every conversation a healthcare professional has with relatives and therefore can only capture a snapshot of this communication.

These different approaches revealed differing perspectives on the same experiences. For example, healthcare professionals often described giving detailed information clearly and honestly, but this was not always seen in observations or reported by families. Any clinician training should therefore help healthcare professionals recognize when families have not understood them and avoid assumptions of existing knowledge. Each qualitative approach provides its own benefits and should be combined to get a fuller picture of how communication with relatives is accomplished at the end-of-life and inform effective training.

### *Limitations of primary studies and systematic review*

The main limitations of included articles identified through quality appraisal were related to a lack of insight

into the influence of the researchers on the findings. Without stating the study's philosophical perspective or the potential impact of researchers, it is difficult to know how the research team's characteristics may have influenced data collection and analysis. In addition, not all studies reported numbers or demographics for individual healthcare professionals or family members, making it difficult to understand who was involved in these conversations.

The review process also has a number of limitations. The search strategy only included English language articles for resource reasons. As a result, 29 of 31 included articles were from Northern European or English-speaking countries, with 19 from the United States alone. Cultural differences in communication practices are likely and so findings from this review may not be generalizable to other cultures.

The review was limited to qualitative studies to gain in-depth insights into how people communicate not accessible through quantitative methods such as surveys. However, qualitative findings are subject to researchers' interpretations, both in the original studies and during the synthesis. We have aimed to increase rigour in this review through multiple team members independently assessing quality, team discussions during data extraction and synthesis and by reporting our synthesis process transparently.

The search strategy took a broad approach, including studies from a range of patient populations, places of care and methodological approaches. This approach was taken because the review was exploratory and initial scoping of the literature found practices and experiences that applied across different settings. We have highlighted some of the differences between these settings and approaches, but a narrower search strategy would have allowed a more in-depth view of individual settings.

### **Future research**

The majority of studies in this review were in acute care settings. It was not possible to compare the findings from acute settings with palliative care, as there were only three palliative care papers, all in different settings (adult inpatient, adult home hospice and paediatric consultations). However, we can speculate that there are likely to be differences between these settings. The papers in acute settings mostly focused on medical decision-making, particularly withdrawing life-sustaining treatments. In palliative care, these conversations are likely to take place earlier in the disease trajectory and with the patients themselves. By the point of end-of-life care, decision-making conversations will therefore be less common. Family members may have more realistic expectations, particularly in a hospice setting, as hospice inpatient wards generally only admit patients with terminal or life



limiting conditions and do not provide curative treatment. Healthcare professionals in palliative care settings may also have more experience of end-of-life communication and more time with families. This is reflected in higher satisfaction and lower unmet needs of families in hospice compared with hospital settings.<sup>67</sup> Further palliative care research is therefore needed, particularly in hospices at the very end-of-life when patients are likely to have reduced capacity and so conversations will primarily be taking place with relatives. The experience and expertise of hospice clinicians could provide communication strategies that could be applied in other settings.

Interviews and focus groups with nurses provided insights into their roles and communicative strategies. However, no observational studies focused primarily on nurses. This may be due to these conversations being more spontaneous than those held by doctors, and therefore more difficult to capture in a research project. Observational research focused on nurses could provide practice recommendations for all healthcare professionals. Research into the communication of allied healthcare professionals such as social workers is also needed to develop a fuller picture of communication with relatives at the end-of-life.

More focus on how relatives communicate in these conversations is needed. While there were some references to how relatives communicated, the primary focus of existing literature is healthcare professionals' communication. Future research should identify how relatives communicate their perspectives, ask questions and respond to different healthcare professional communication practices. This would provide evidence for which strategies are effective and help healthcare professionals recognize how families might express things such as a desire for further information. This evidence could also be used in interventions to empower families to express their perspectives and ask questions to elicit the information they want and need, for example, using question prompt lists.<sup>68</sup>

## Conclusion

Healthcare professionals use a range of practices that could aid effective communication with relatives at the end-of-life. Key strategies include highlighting the patient's deterioration to aid understanding and decision-making, collaborative decision-making through references to patient wishes and providing options, highlighting continuing care by explaining comfort care, tailoring information to individual understanding and readiness to discuss dying; honesty and clarity to avoid false hope and providing information repeatedly and in small chunks. This systematic review calls for further research to identify the effectiveness of different communicative strategies. This research should be used to develop training for healthcare professionals to help them understand relatives' perspectives and implement

strategies to improve understanding and collaborative decision-making in their practice.

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## Author Contributions

R.A., S.B., P.S. and J.L. were responsible for the study concept and design; R.A., M.A. and J.L. were responsible for the acquisition, analysis and interpretation of the data. R.A. drafted the article; S.B., M.A., P.S. and J.L. revised it critically for important intellectual content. All authors approved the version to be published and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

## Data sharing and management

The full search strategy, inclusion/exclusion criteria, quality appraisal results and example extracts demonstrating the review's themes are available in the Supplementary material. This review is registered on the PROSPERO database (registration number CRD42017065560).

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## Supplemental material

Supplemental material for this article is available online.

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**Supplementary table 1:** Electronic database search strategy

Word Group	MEDLINE (EBSCO)	PsycINFO (Ovid)	EMBASE (Ovid)	CINAHL (Ovid)
Communication	Communication/ Health Communication/ Prognosis/ communicat*.ab,ti. interact*.ab,ti. talk.ab,ti. conversation*.ab,ti. discuss*.ab,ti. prognos*.ab,ti.	Communication/ Health Communication/ Prognosis/ communicat*.ab,ti. interact*.ab,ti. talk.ab,ti. conversation*.ab,ti. discuss*.ab,ti. prognos*.ab,ti.	Communication/ Health Communication/ Prognosis/ communicat*.ab,ti. interact*.ab,ti. talk.ab,ti. conversation*.ab,ti. discuss*.ab,ti. prognos*.ab,ti.	MH "Communication" MH "Discussion" MH "Prognosis" TI or AB communicat* TI or AB interact* TI or AB talk TI or AB conversation* TI or AB discuss* TI or AB prognos*
Relatives	Family/ Caregivers/ Spouses/ Parents/ relative*.ab,ti. family.ab,ti. families.ab,ti. companion*.ab,ti. surrogate*.ab,ti. caregiver*.ab,ti. carer*.ab,ti. spouse*.ab,ti. partner*.ab,ti. parent*.ab,ti.	Family/ Caregivers/ Spouses/ Parents/ relative*.ab,ti. family.ab,ti. families.ab,ti. companion*.ab,ti. surrogate*.ab,ti. caregiver*.ab,ti. carer*.ab,ti. spouse*.ab,ti. partner*.ab,ti. parent*.ab,ti.	Family/ Caregivers/ Spouses/ Parents/ relative*.ab,ti. family.ab,ti. families.ab,ti. companion*.ab,ti. surrogate*.ab,ti. caregiver*.ab,ti. carer*.ab,ti. spouse*.ab,ti. partner*.ab,ti. parent*.ab,ti.	MH "Family" MH "Professional-Family Relations" MH "Caregivers" MH "Spouses" MH "Significant Other" MH "Parents" TI or AB relative* TI or AB family TI or AB families TI or AB companion* TI or AB surrogate* TI or AB caregiver* TI or AB carer* TI or AB spouse* TI or AB partner* TI or AB parent*
Healthcare professionals	Health Personnel/ "Attitude of Health Personnel"/ Practice Patterns, Physicians'/ Medical Staff, Hospital/ Physicians/ Nurse Clinicians/ Nurses/ Patient Care Team/ healthcare professional*.ab,ti. health professional*.ab,ti. doctor*.ab,ti. nurse*.ab,ti. clinician*.ab,ti. physician*.ab,ti. "care team".ab,ti.	Health Personnel/ "Attitude of Health Personnel"/ Practice Patterns, Physicians'/ Medical Staff, Hospital/ Physicians/ Nurses/ healthcare professional*.ab,ti. health professional*.ab,ti. doctor*.ab,ti. nurse*.ab,ti. clinician*.ab,ti. physician*.ab,ti. "care team".ab,ti.	Health Personnel/ "Attitude of Health Personnel"/ Practice Patterns, Physicians'/ Medical Staff, Hospital/ Physicians/ Nurse Clinicians/ Nurses/ Patient Care Team/ healthcare professional*.ab,ti. health professional*.ab,ti. doctor*.ab,ti. nurse*.ab,ti. clinician*.ab,ti. physician*.ab,ti. "care team".ab,ti.	MH "Professional-Family Relations" MH "Nurses" MH "Physicians" MH "Multidisciplinary Care Team" TI or AB healthcare professional* TI or AB health professional* TI or AB doctor* TI or AB nurse* TI or AB clinician* TI or AB physician* TI or AB "care team"

Word Group	MEDLINE (EBSCO)	PsycINFO (Ovid)	EMBASE (Ovid)	CINAHL (Ovid)
End-of-life setting	((Critical Care/ Intensive Care Units/ "intensive care".ab,ti. icu.ab,ti. "critical care".ab,ti. "acute care".ab,ti. AND Terminal Care/ Palliative Care/ palliative.ab,ti. "end of life".ab,ti. palliative.ab,ti. "end of life".ab,ti. terminal*.ab,ti. dying.ab,ti. bereaved.ab,ti.) OR (Hospice Care/ Terminal Care/ Palliative Care/ Hospices/ palliative service*.ab,ti. palliative care.ab,ti. hospice*.ab,ti.))	((("intensive care".ab,ti. icu.ab,ti. "critical care".ab,ti. "acute care".ab,ti. AND Terminal Care/ Palliative Care/ palliative.ab,ti. "end of life".ab,ti. terminal*.ab,ti. dying.ab,ti. bereaved.ab,ti.) OR (Hospice Care/ Terminal Care/ Palliative Care/ palliative service*.ab,ti. palliative care.ab,ti. hospice*.ab,ti.))	((Critical Care/ Intensive Care Units/ "intensive care".ab,ti. icu.ab,ti. "critical care".ab,ti. "acute care".ab,ti. AND Terminal Care/ Palliative Care/ palliative.ab,ti. "end of life".ab,ti. terminal*.ab,ti. dying.ab,ti. bereaved.ab,ti.) OR (Hospice Care/ Terminal Care/ Palliative Care/ Hospices/ palliative service*.ab,ti. palliative care.ab,ti. hospice*.ab,ti.))	((MH "Intensive Care Units" MH "Critical Care" MH "Acute Care" TI or AB "intensive care" TI or AB icu TI or AB "critical care" TI or AB "acute care" AND MH "Palliative Care" MH "Terminal Care" TI or AB palliative TI or AB "end of life" TI or AB terminal* TI or AB dying TI or AB bereaved) OR (MH "Palliative Care" MH "Hospice Patients" MH "Hospice Care" TI or AB palliative service* TI or AB palliative care TI or AB hospice*))
Qualitative methodology	Qualitative Research/ Interview/ Focus Groups/ Observational Study/ qualitative.ab,ti. interview*.ab,ti. focus group*.ab,ti. observation*.ab,ti. audio.ab,ti. video.ab,ti. ethnography.ab,ti. linguistic*.ab,ti. dialectic*.ab,ti. "conversation analysis".ab,ti. "discourse analysis".ab,ti. "sequential analysis".ab,ti. "interpretative phenomenological analysis".ab,ti. "content analysis".ab,ti. "framework analysis".ab,ti. "thematic analysis".ab,ti.	Qualitative Research/ qualitative.ab,ti. interview*.ab,ti. focus group*.ab,ti. observation*.ab,ti. audio.ab,ti. video.ab,ti. ethnography.ab,ti. linguistic*.ab,ti. dialectic*.ab,ti. "conversation analysis".ab,ti. "discourse analysis".ab,ti. "sequential analysis".ab,ti. "interpretative phenomenological analysis".ab,ti. "content analysis".ab,ti. "framework analysis".ab,ti. "thematic analysis".ab,ti.	Qualitative Research/ Interview/ Focus Groups/ Observational Study/ qualitative.ab,ti. interview*.ab,ti. focus group*.ab,ti. observation*.ab,ti. audio.ab,ti. video.ab,ti. ethnography.ab,ti. linguistic*.ab,ti. dialectic*.ab,ti. "conversation analysis".ab,ti. "discourse analysis".ab,ti. "sequential analysis".ab,ti. "interpretative phenomenological analysis".ab,ti. "content analysis".ab,ti. "framework analysis".ab,ti. "thematic analysis".ab,ti.	MH "Qualitative Studies" MH "Interviews" MH "Semi-Structured Interview" MH "Unstructured Interview" MH "Focus Groups" MH "Observational Methods" MH "Participant Observation" MH "Nonparticipant Observation" MH "Ethnographic Research" TI or AB qualitative TI or AB interview* TI or AB focus group* TI or AB observation* TI or AB audio TI or AB video TI or AB ethnography TI or AB linguistic* TI or AB dialectic* TI or AB "conversation analysis" TI or AB "discourse analysis" TI or AB "sequential analysis" TI or AB "interpretative phenomenological analysis" TI or AB "content analysis" TI or AB "framework analysis" TI or AB "thematic analysis"

**Supplementary table 2:** Full inclusion and exclusion criteria

Abbreviations: HCP, Healthcare professionals; ICU, Intensive care unit

	Inclusion	Exclusion
<b>Study type</b>	Qualitative Peer reviewed	Quantitative Intervention/training studies Reviews Conference abstracts Theses Book chapters Commentaries
<b>Participants/ population</b>	Relatives of patients approaching the end of life (i.e. palliative patients not receiving active treatment, or other patients anticipated to die in the coming days/weeks; no limit on age/illness of patient)  Bereaved relatives  Healthcare or allied professionals who communicate with relatives at the end of life	Pediatric/adolescent relatives
<b>Focus</b>	Communication between HCPs and relatives of patients approaching the end of life  Prognosis and end of life care What and how communication is done	Assisted suicide/euthanasia Organ donation  Hypothetical communication episodes Communication between relative and patient or HCP and patient Communication between different relatives Communication between different HCPs Communication earlier in disease trajectory (e.g. diagnosis) Communication/education needs of HCPs
<b>Setting</b>	Palliative care (home and inpatient)  Acute care (e.g. ICU/ critical care) where patient is not anticipated to recover  Adult and pediatric settings	Non-end-of-life settings (i.e. acute setting with patients receiving active treatment)
<b>Language</b>	English	Non-English language
<b>Date range</b>	All	All



**Supplementary table 3:** Demographic details of study population

Authors (year)	HCP sample (n, profession)	HCP professional background: 1) HCP position 2) Av years of experience	HCP demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Family sample (n of individual family members)	Relation to patient	Family demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Sample of patients being discussed	Details of patients being discussed	Patients' av age (years)
Observational studies									
<sup>a</sup> Aldridge & Barton (2007)	10, physicians (others also present)	1) 6 senior critical care intensivists, 4 surgeons; 2) Not reported	1-3) Not reported	Not reported	Not reported	1-3) Not reported	20	SICU patients	Not reported
<sup>a</sup> Barton (2005)	5, physicians	1) 4 senior SICU intensivists, 1 surgical resident; 2) Not reported	1-3) Not reported	Not reported	Not reported	1-3) Not reported	6	SICU patients	Not reported
<sup>a</sup> Barton (2007)	†Not reported, physicians	1)*Senior critical care intensivists, surgeons; 2)Not reported	1-3) Not reported	Not reported	Not reported	1-3) Not reported	9/20 included in analysis	SICU patients	Not reported
<sup>b</sup> Curtis et al. (2002)	36, physicians	1) Attending, resident & fellow; 2) 12	35/36: 1) 34; 2) 38; 3) 86	214	*Spouse, child, sibling, parent, friend, other relative, other	163/214: 1) 61; 2) 48; 3) 82	50	*Intracranial hemorrhage, end-stage liver disease/ GI bleed, trauma, sepsis, respiratory failure, cardiac failure, other	60
<sup>b</sup> Curtis et al. (2005)	†Not reported, physicians	1) Attending, resident & fellow; 2)†Not reported	1-3)†Not reported	Not reported	†Not reported	1-3) †Not reported	15/51 included in analysis	†Not reported	†Not reported
de Vos et al. (2015)	27, physicians (nurses also present)	1) Intensivist, neurologist, metabolic pediatrician, other pediatric specialty; 2) 12 participants 0-5yrs, 2 participants 5-10yrs, 13 participants>10yrs	1) 44 2) Not reported 3) 96% Western	37	Parents	1) 51 2-3) Not reported	19	Congenital disorder, acute illness, neuro-trauma, sudden infant death syndrome, cancer, perinatal asphyxia	4
Ekberg et al. (2017)	1, physician (others also present)	1) Specialist palliative care consultant; 2) Not reported	1-3) Not reported	Not reported	Parents	1-3) Not reported	8	Severe cerebral palsy, Duchenne Muscular Dystrophy, Metachromatic Leukodystrophy, schizencephaly, & T Cell Lymphoblastic Lymphoma	Not reported

Authors (year)	HCP sample (n, profession)	HCP professional background: 1) HCP position 2) Av years of experience	HCP demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Family sample (n of individual family members)	Relation to patient	Family demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Sample of patients being discussed	Details of patients being discussed	Patients' av age (years)
<sup>a</sup> Engelberg et al. (2008)	6/36 included in analysis, physicians	1) *Attending, resident & fellow physicians 2) 8.7	6/36: 1) 50; 2) 34.7; 3) 83	Not reported	†Not reported	6/36: 1) 68; 2) 48.5; 3) 63	6/51 included in analysis	6/51: Intracranial hemorrhage, respiratory failure, cardiac failure	67.4
<sup>b</sup> Hsieh et al. (2006)	36, physicians (other staff also present)	1) Attending, resident & fellow; 2) 12	35/36: 1) 34; 2) 38; 3) 86	227	*Spouse, child, sibling, parent, friend, other relative, other	169/227: 1) *60; 2) 49; 3) *81	51	*Intracranial hemorrhage, end-stage liver disease/ GI bleed, trauma, sepsis. respiratory failure, cardiac failure, other	60
Kawashima (2017)	†Not reported, physicians (others also present)	1) Doctors 2) Not reported	1-3) Not reported	Not reported	Not reported	1-3) Not reported	19	Patients at risk of imminent death	60-80 (range)
Miller et al. (1992)	16, physicians	1) 7 attending physicians, 5 fellows & 4 residents; 2) Not reported	1-3) Not reported	20	5 spouses, 8 adult children, 7 siblings	1-3) Not reported	15	ICU patients	64.2
Pecanac (2017)	Not reported, physicians (others also present)	1) Physicians 2) Not reported	Not reported	Not reported	Examples included adult children, mother, siblings, cousins, sister-in-law	1-3) Not reported	36	Majority admitted for infection, lung condition, cardiac arrest or neurological condition. Intubated on breathing machine	62.7
Shaw et al. (2016)	6, physicians	1) Consultants 2) Not reported	Not reported	Not reported	Parents	1-2) Not reported 3) 33.3	9	Severe perinatal asphyxia, extremely preterm with neuro complications, threatened pre-term delivery, lethal congenital anomaly	Neonatal
<sup>b</sup> West et al. (2005)	†Not reported, physicians	1) Attending, resident & fellow; 2)†Not reported	1-3)†Not reported	Not reported	†Not reported	1-3)†Not reported	44/51 included in analysis	†Not reported	†Not reported
Family perspective									
Abib El Halal et al. (2013)	N/A	N/A	N/A	15	Parents	1) 60%; 2) 34; 3) Not reported	9	Children who died in PICU in previous 6-12 months	2.6

Authors (year)	HCP sample (n, profession)	HCP professional background: 1) HCP position 2) Av years of experience	HCP demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Family sample (n of individual family members)	Relation to patient	Family demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Sample of patients being discussed	Details of patients being discussed	Patients' av age (years)
Gordon et al. (2009)	N/A	N/A	N/A	†Not reported	Parents	1-3) †Not reported	†Not reported	Children who died in PICU in previous 3-12 months.	†Not reported
Lind (2017)	N/A	N/A	N/A	27	Spouses, adult children, mother & siblings	1) 74; 2) 49.7; 3) Not reported	21	Patients who died in the ICU. Length of stay ranged from <4 days to >1 month	61
Meert et al. (2008)	N/A	N/A	N/A	40/56 included in analysis	Parents	40/56: 1) 65; 2) 35.9; 3) 72.5%	†Not reported	Children who died in PICU in previous 3-12 months	†Not reported
Odgers et al. (2018)	N/A	N/A	N/A	12	Next of kin	1) 83.3; 2-3) Not reported	Not reported	Adult patients who died in previous 3-12 months	Not reported
<b>HCP perspective</b>									
Bach et al. (2009)	14, nurses	1) Critical care registered nurses (10 ICU, 4 CRCU); 2) 13	1) 86; 2-3) Not reported	N/A	N/A	N/A	N/A	Dying patients	60 (Av patient admitted to unit)
Bartel et al. (2000)	22, physicians	1) 12 pediatric residents, 5 pediatric critical care fellows & 5 attending pediatric intensivists; 2) Not reported	1) 64; 2) Not reported 3) 82	N/A	N/A	N/A	N/A	Critically ill children	N/A
Bloomer et al. (2017)	21, nurses	1) Critical care nurses; 2) 13	1-3) Not reported	N/A	N/A	N/A	N/A	Treatment withdrawal in adult patients	N/A
Epstein (2008)	32, 21 nurses; 11 physicians	1) NICU registered nurses, nurse practitioners, attending, resident & fellow physicians; 2) Nurses= 12.6; Physicians= 6.9	1) Nurses= 95; Physicians= 36; 2) Nurses= 36.2; Physicians= 36.5 3) Nurses 84; Physicians 100	N/A	N/A	N/A	21	Infants who died in NICU in previous 6 weeks	71% ±1.5



Authors (year)	HCP sample (n, profession)	HCP professional background: 1) HCP position 2) Av years of experience	HCP demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Family sample (n of individual family members)	Relation to patient	Family demographics: 1) Female (%) 2) Av age (years) 3) White (%)	Sample of patients being discussed	Details of patients being discussed	Patients' av age (years)
Kehl (2015)	19, home hospice clinicians	1) 9 Registered Nurses, 3 Licensed Practical Nurses, 1 Certified Nursing Assistant, 3 social workers, 2 counsellors & 1 chaplain; 2) 11 participants <2yrs; 4 participants 2-10yrs; 4 participants >10yrs	1) 84; 2) 4 participants ≤ 35 yrs; 13 participants 36-50yrs; 2 participants >50yrs; 3) 100	N/A	N/A	N/A	N/A	Hospice home care patients in final days of life	N/A
Liaschenko et al. (2009)	27, nurses	1) Critical care nurses; 2) 15	1) Not reported; 2) 43; 3) Not reported	N/A	N/A	N/A	N/A	Critical care patients at end-of-life	N/A
Peden-McAlpine (2015)	19, nurses	1) ICU nurses comfortable with dying patients and their families; 2) 17	1) 100; 2) 48; 3) 100	N/A	N/A	N/A	N/A	Treatment withdrawal in adult patients	N/A
Rejno et al. (2017)	15, 4 physicians; 11 nurses	1) 7 registered nurses, 4 enrolled nurses; 2) 11	1) Nurses 9; Physicians 25; 2) 41; 3) Not reported	N/A	N/A	N/A	N/A	Acute stroke patients at End-of-life	N/A
Richards et al. (2017)	22, physicians	1) Attending pediatric critical care physicians; 2) 55% ≥5	1) 32; 2-3) Not reported	N/A	N/A	N/A	N/A	Child ICU patients	N/A
Tan & Manca (2013)	11 physicians	1) Family physicians 2) 3-40 (range)	1) 55; 2-3) Not reported	N/A	N/A	N/A	N/A	Dying patients	N/A
<b>Mixed perspectives</b>									
Caswell et al. (2015)	37 interviewed (others observed), healthcare professionals	1) Healthcare professionals; 2) Not reported	1-3) Not reported	13	Not reported	1-3) Not reported	11 discussed (others observed)	Older patients who died during study period (43% had dementia)	81-88 (range of av age at death on wards)
Meeker et al. (2015)	8, 2 nurses; 2 social workers; 4 physicians	1) 2 nurses, 2 social workers, 4 physicians; 2) 8.4	1) 88; 2) 47.8; 3) Not reported	88	Adult children present at 80% of meetings, & spouses 28%	1-3) Not reported	Not reported	Hospice patients	Not reported

<sup>a</sup>Papers using data from Cassell (2005)<sup>50</sup>, <sup>b</sup>Papers using data from Curtis et al. (2002)<sup>22</sup>, <sup>c</sup>Papers using data from Meert et al. (2007)<sup>51</sup>

\*Information gathered from other papers reporting same sample

†Where a sub-sample has been used in the analysis and characteristics are only reported for sample as a whole, this is stated as 'not reported'

Abbreviations: HCP, Healthcare professional; SICU, Surgical intensive care unit, ICU, Intensive care unit; PICU, Pediatric intensive care unit; NICU, Neonatal intensive care unit

**Supplementary table 4:** Quality appraisal results (Corresponding questions are on following page)

Authors (year)	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
Abib El Halal et al. (2013)	No	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes
Aldridge & Barton (2007)	No	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Yes
Bach et al. (2009)	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Bartel (2000)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Barton et al. (2005)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Barton et al. (2007)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Bloomer et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Caswell et al. (2015)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Curtis et al. (2002)	No	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	No	Yes
Curtis et al. (2005)	No	Yes	Yes	Unclear	Yes	Yes	No	Unclear	Yes	Yes
deVos et al. (2015)	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Ekberg et al. (2017)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Engelberg et al. (2008)	No	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes
Epstein (2008)	Yes	Yes	Yes	No	Unclear	No	No	Yes	No	Yes
Gordon et al. (2009)	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes
Hsieh et al. (2006)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Kawashima (2017)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Kehl (2015)	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Liaschenko et al. (2009)	No	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Yes
Lind (2017)	Yes	Unclear	Yes	No	No	No	No	Yes	Yes	Yes
Meeker et al. (2015)	No	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Yes
Meert et al. (2008)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Miller et al. (1992)	No	Yes	Yes	No	No	No	Yes	Unclear	No	Unclear
Odgers et al. (2018)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Pecanac (2007)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Peden-McAlpine et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

Authors (year)	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
Rejno et al. (2017)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Richards et al. (2018)	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Shaw et al. (2016)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Tan & Manca (2013)	No	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
West et al. (2005)	No	Unclear	Yes	Unclear	Yes	No	No	Yes	Yes	Yes

*Questions in Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research (potential responses: yes, no or unclear)*

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of the data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research and vice-versa addressed?
8. Are participants and their voices adequately represented?
9. Is the research ethical according to current criteria, or for recent studies, is there evidence of ethical approval by an appropriate body?
10. Do conclusions drawn in the research report flow from the analysis, or interpretation of the data?

## Supplementary table 5: Extracts from original papers demonstrating themes

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### Highlighting Deterioration

#### *Problem listing from Meeker et al. (2015):*

For family members, changes that were nearly imperceptible on a day-to-day basis would be clarified and placed in the context of illness progression. As reported by one physician, “Recalibrating or reframing the events is very, very, very important so that they can understand that they really haven’t been eating for three months very well. They can’t walk anymore, and that that’s dying” (PR5).  
(p.1287)

#### *Perspective display invitation from Peden-McAlpine et al (2015):*

‘It’s overwhelming, so let’s backtrack to ‘How was he yesterday?’ – and helping them follow the trajectory of what happened to him before he showed up to the hospital, because they’re in shock and they need to go over the story. ‘How has he been in the last two weeks?’ ‘He wasn’t feeling well.’ ‘Has he ever had any kind of situations like this where he ended up in the hospital before?’ (5 3 (26:33).

It is important to note that in the nurses’ narratives the construction of the story is not a one-way process of simply giving information. Rather, nurses reported that they elicit the family’s understanding, identify the need for clear and direct communication about poor prognosis, and modify that understanding as necessary.  
(p. 1153)

### Involvement in decision-making

#### *Medical team’s decision from Abib el Halal et al (2013):*

From the reports it was evident that parental participation was limited to being informed of prior decisions taken by the team. Parents referred to being compelled to accept treatments and interventions defined by the medical PICU staff. They were regularly informed about what was happening, but emphasised they did not decide anything. Decisions regarding the available therapeutic options for their children were not discussed with clarity, especially when they were related to limiting life support or do not resuscitate orders...

‘We received the information of what was to be done or what could be done, without deciding.’ (U12)  
(p. 498)

#### *Collaborative decision-making by invoking patient wishes from Hsieh (2006):*

Clinicians often used recentring to help families consider the situation from the patient’s viewpoint, including patient experience, desires, and preferences. Clinicians urged family members to see their role as the surrogate or advocate of patients.

Physician: You have to exercise what’s called substituted judgment, not what you would want, not what your aunt would want, but what you think your mother would want.

Different conference:

Nurse: If he could sit up right now, what would he say to you. Would he say he wants to go on with all this? Would he say, stop, that’s enough?

(p. 300-301)

### Post-decision interactional work

#### *Emphasizing continued care from deVos (2015):*

At the end of the (last) meeting, all parents expressed their great concern that their child might suffer in the process of dying. In turn, the physicians promised that everything would be done to ensure the child’s comfort and peace. Moreover, several parents asked whether it would be possible to let their child regain consciousness so they could speak with him or her for the last time.

(p. e471)

#### *Justifying the decision as ‘right’ from Barton (2007):*

Reviewing the decision as a family-initiated topic thus merges the voices of the lifeworld and medicine in terms of the decision being warranted from the medical perspective as well as appropriate from the perspective of the lifeworld—the term families use is right, a term that is often used by physicians as well. In the corpus, the lifeworld review of the EOL

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decision was often repeated in Phase 4 of the discussions. In closings, both physicians and families often repeated their satisfaction with the decision, both using the term right:

(8) Fam: If you had known her, you would know that we're doing the right thing.

Dr: And that's important. And again I want everybody to know that from the doctors' standpoint we're doing the right thing. So I don't want down the road people thinking, well you know should we — No.

(p. 135)

### **Tailoring**

*Tailoring to previous experiences of death from Kehl (2015):*

This hospice nurse used both the family's experience in caregiving and the patient's symptoms to tailor the message:

I would first I think ask you if you have ever had experience before taking care of someone who is nearing the end of their life.

And then if you'd say, "No," I'd say, "Well here are some changes I'm seeing, I'm noticing that from last I was here their breathing is different, they're not eating as much, they seem weaker," and just kind of go by the symptoms I'm seeing and explain why that's happening. (RN 1)

(p.133)

### **Honesty and clarity**

*Honesty from Bach (2009):*

One aspect of speaking up was truth telling, which frequently became a contentious issue. The nurses expressed differing approaches with regard to truth telling, including responsibility for information and decisions on how information was to be handled. Some of the nurses supported being straightforward with families, saying that "nurses spend far more time with a family" and "it's the nurse they end up speaking to." As one participant commented, the nurse was "better off telling them... being honest." However, some nurses tempered this direct approach by expressing the need for compassion and not taking away hope. Alice said that although she did believe in honesty, and "although telling [families and patients] this is the worst scenario . . . there's always hope that people can do better."

(p. 505)

### **Specific techniques for information delivery:**

*Pacing & staging of information from Bloomer et al (2017):*

Another consideration was that that families may struggle to cope with information about treatment withdrawal, the impending death and a possible request for organ donation. From this, participants were aware that information needed to be delivered in an incremental way, and in stages:

...they've just had really bad news, so there's got to be a bit of decoupling [emotional processing] with what they do, and I try and give it to them in small amounts so they don't get a big waft of information all at once. (4/2)

(p. 694)

### **Roles of different HCPs**

*Nurses providing individualised care from Bach (2009):*

Providing emotional support and coordinating resources were also significant aspects of this theme. Ben spoke about this as "a supportive role, somebody here to . . . help the family after a family meeting to come to terms with it, answer any questions." For these nurses, coming to terms meant ensuring that all family members understood the health situation and prognoses and that they were all in agreement with the plan of care. This involved the nurses in a variety of roles. Jane described her role as expanding on the implications of a diagnosis and asking questions for the families. She affirmed the importance of detailed information for families to be able to make informed decisions because often once families understood all the information, "they may not have agreed . . . if they'd known all that."

(p. 506)

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**Participant information sheet for senior healthcare professionals**  
**Study Title: Communication with relatives in palliative care (REC 11519/001)**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study before deciding if you wish.

This information sheet answers a number of questions you may have, but please ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part.

**1. What is the purpose of the study?**

This study aims to improve our understanding of communication between healthcare professionals (HCPs) and relatives and friends of inpatients approaching the end of life. Previous research is limited as the focus has more often been limited to conversations earlier in the patient's disease, for example at diagnosis. We hope that by recording and analysing conversations between expert HCPs at [REDACTED] and relatives and friends of inpatients approaching the end of life, findings can help to develop guidelines and teaching materials for inexperienced doctors to improve their communication skills in similar situations.

We hope to combine the data from recorded conversations with focus groups of HCPs discussing what you consider to be a good conversation and what difficulties and barriers you may face. We will also interview relatives and friends who take part in order to gain their perceptions of communication at the end of life.

The project will be looking at these communication practices across the HCPs involved, and will not be evaluating individual HCP performances.

**2. What aspects of communication will you focus on?**

We intend to use the recordings to look at sequences of communication between HCPs and relatives or friends of inpatients at [REDACTED] who are approaching the end of life and have lost capacity. We are particularly interested in discussions about prognosis and end of life care. As this is a relatively new area of research, we cannot be certain which aspects will prove important for our analysis, however we anticipate that we are likely to focus on certain aspects including: (1) how prognostic talk arises, (2) making plans for end of life care and how decisions are made, and (3) how empathy is conveyed and responded to.

**3. Why have I been invited?**

We have invited senior doctors and nurses considered who have considerable experience of having these sorts of conversations with relatives and friends of patients. We are inviting all consultants, senior nurses (band 7 or above) and specialist trainees with at least 3 months experience at this level to take part. We hope to capture 30 such conversations between HCPs and relatives or friends of patients in which prognosis and/ or end-of-life care is discussed.

#### **4. Do I have to take part?**

It is up to you to decide whether or not to join the study. We appreciate that not all relatives or healthcare professionals will feel that participation is right for them. We will describe the study and go through this information sheet with you. If you do agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason. Not participating will not affect your professional standing or employment.

#### **5. What will I have to do?**

At the start of the study, a researcher will ask you for some basic information about yourself and for your contact details. You will be asked to sign a consent form agreeing to participation in the study generally, and will later be asked to consent to the use of each individual recording. We anticipate that the recruitment period will be around 14 months, but we will let you know when we have received enough recordings.

##### **5a) Recruitment and recording**

We will provide you with a digital voice recorder to carry with you during the recruitment period of the study. When you have a conversation with a relative or friend of an inpatient who you believe is approaching the end of life and lacks capacity, we would like you to ask for their permission to record the conversation (unless you judge them to be too distressed to be approached for participation). We will provide you with a guide to use to decide who to approach and when, and to guide how to seek verbal consent. If they agree, we would like you to record the conversation. If at any point you or the relative/friend participant are concerned that recording may be negatively affecting the conversation, you may halt the recording without giving a reason. You are also free to halt the recording at any time if you change your mind.

Following the recording we would like you to give the relative a participant information sheet and take their contact details so that we can contact them to seek full written consent. If you judge at the end of the conversation that it would be in their best interests not to be contacted for consent, the recording will be deleted.

Each patient who provides written consent will be asked to complete a brief consultation and relational empathy (CARE) measure. They will also be invited to take part in an interview about their experiences of communication at [REDACTED] at a later date. Neither of these will be used to judge your individual performance.

We are aware that there may be times when other healthcare staff will be present during the recorded conversations. Their communication will not be a focus of the analysis, but we will ask you to provide their details so that we can obtain consent from them for the use of the recordings. We will only transfer the recording to our database once we have permission from you, the relative/friend, and any other person present on the recording. If we do not obtain all of these permissions the recording will be deleted.

##### **5b) Focus group**

In addition to the recording of conversations, we would also like to carry out a focus group in order to gain your and other HCPs' perspectives on what makes a good



conversation with relatives about prognosis and end of life care, and what barriers you face during these discussions. This focus group would be audio-recorded, transcribed and analysed by the research team. If you are unable to attend the focus group we may ask you to take part in a one-to-one interview. Consenting to the first part of the study does not commit you to taking part in the focus group, and we will ask you to complete a separate consent form prior to the focus group, should you choose to take part.

#### **6. Why are conversations being audio recorded?**

We need to audio record the conversations because the data we need cannot be obtained simply through observing and taking notes, or through interviews. The results will be analysed using a technique called conversation analysis in order to identify key patterns in communication. This technique requires the detailed recordings of conversations that occur naturally. This method sometimes uses video recording, but we have decided to limit the recording to audio in order to avoid disrupting the conversation. However if at any point you or anyone else present feels that the conversation is being adversely affected by the audio recording, you can halt it at any time.

#### **7. Who will listen to the recordings?**

The recordings will primarily be listened to, transcribed and analysed by the research team. The recordings will also be used for future research studies aimed at improving understanding communication in healthcare. We will also ask for your permission to use the recordings (with person and place names removed) in the following ways:

- A. Data analysis in closed sessions with other communication researchers to help strengthen the research results.
- B. Presentations about the research to professional audiences of researchers, health and social care staff and trainees
- C. In the future, recordings may be used to design communication skills training and used as training materials in these sessions. This would involve playing audio recordings to restricted audiences during face to face and/or online training by professionals who teach communication to NHS staff and health and social care trainees.

Following each recording you will be given the choice of which of these uses you consent to the specific recording being used for, and whether you would like your voice to be altered for uses outside of the research team (i.e. A, B & C above).

#### **8. What are the possible disadvantages and risks of taking part?**

We will make all efforts to reduce minimise the effects of recording conversations, but it is possible that you will find that your communication or that of the relative/ friend participant is affected by the presence of the audio recorder. If you or anyone else present believe this to be the case, please halt the recording immediately.

If you consent to your recordings being used outside of the research team in the ways described in section 7 of this information sheet, there is a small possibility that someone you know may be participating and may recognise your voice. At the time of consent you will be given to option to have your voice altered for such uses. If your



voice is not altered, we will make it clear to participants not to use your name or discuss your personal details during the meeting or afterwards.

**9. What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get from this study may contribute to training less experienced healthcare professionals and improving their communication skills in a palliative care context. Additionally, our analysis will look at the different communication techniques used by clinicians and what responses they elicit. We would be happy to provide general feedback to you based on our conversation analysis of the recordings if you would like it. If you wish, you will have the option to listen to your recording, by request, any time before the end of the study (February, 2020). You may find that this feedback enhances your reflective practice.

**10. What if there is a problem?**

If you have any concerns or questions about the study you can speak to the research team in the first instance, contact details are provided at the end of this information sheet. If you are not happy with the response and wish to make a formal complaint you can do so by contacting [research-incidents@ucl.ac.uk](mailto:research-incidents@ucl.ac.uk).

**11. Will my taking part in the study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All information collected about you, including contact details, recordings and consent forms, will be held securely, in a locked room, or locked cupboard or cabinet at UCL or on a password protected electronic database.

Contact details will be removed from any databases at the end of the study and all other data will be pseudonymised and kept securely for 20 years following the end of the study. After this time the research data will be disposed of securely.

Other researchers, health and social care staff and trainees may hear your recordings with person and place names removed (detailed in section 7 of this information sheet), depending on which uses you consent to. The recordings and transcripts will not be made available to the public. Pseudonymised quotes may be used in study reports.

**12. What will happen if I decide to withdraw from the study?**

We understand that after consenting initially you may change your mind about taking part. Your participation is completely voluntary and you are free to withdraw at any time without your professional standing or employment being affected. You are free to give different levels of consent for different recordings, as detailed above, or to withdraw completely. If you withdraw and ask for recordings to be deleted before we have completed the reports for the study, your information and recording will not be used in the analysis.

**13. What will happen to the results of the research study?**

The research team will analyse the recordings of conversations with relatives and the focus group. The results of the study will be available after it finishes and will be published in journals and presented at conferences. The study will also be published as part of a PhD thesis. The data will be anonymous and none of the participants involved in the study will be identified in any report or publication.

Should you wish to see the results, or the publication, please inform the research team whose contact details are at the end of this information sheet.

**14. Who is organising and funding the research?**

This project is a collaboration between the Marie Curie Palliative Care Research Department (MCPCRD) at UCL and [REDACTED]. The study is a PhD project as part of a larger grant funded by Marie Curie looking into prognostication in palliative care.

**15. Who has reviewed the study?**

The research has been reviewed by a Research Ethics Committee to ensure it is high quality, safe and ethical. This study has been reviewed and given a favourable opinion by UCL Research Ethics Committee (ref 11519/001).

**16. Further information and contact details**

You are encouraged to ask any questions you wish, before and during the study. If you require any further information or have any concerns while taking part in the study please contact Becky Anderson at MCPCRD on [REDACTED]  
[REDACTED]

If you decide you would like to take part we will give you a consent form for you to read and sign. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed at UCL.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

#### Appendix 4. Senior HCP consent form part one

### Informed consent form for senior healthcare professionals PART ONE

#### Study Title: Communication with relatives in palliative care

REC Ref: 11519/001

Participant number \_\_\_\_\_

#### To be completed at least one day before any conversations are recorded

Please  
initial if  
you agree

1. I confirm that I have read the information sheet dated 06.06.17 (version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my professional standing or employment being affected. ☐
3. I understand that I will be asked to audio-record my conversations with consenting relatives and friends of patients, that these recordings will be heard and transcriptions seen by members of the research team, and that anonymised quotes may be used in study reports. ☐
4. I understand that there will be an opportunity for me to indicate the details of my consent after each individual recording has been made. ☐
5. I agree to take part in the above study ☐

\_\_\_\_\_  
Name of HCP participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Two copies – one to HCP participant, one to TMF*

## Appendix 5. Senior HCP consent form part two

### Informed consent form for senior healthcare professionals PART TWO

**In addition to this, where I have initialled, I agree to the following use(s) of this recording (person and place names will be removed from recordings and transcripts, but your voice will not be altered unless requested):**

Please  
initial each  
use you  
agree to

5. I agree that this audio recording and resulting transcripts may be shown to other communication researchers in closed sessions in order to strengthen the research results.
6. I agree that this audio recording and resulting transcripts may be used in presentations about the research to professional audiences of researchers, health and social care staff and trainees.
7. I agree that this audio recording and resulting transcripts may be read by and played to stakeholders, research advisors and research teams to help the design of communication skills training materials.
8. I agree that this audio recording and resulting transcripts may be used in communication skills training. I understand that these will only been shown to restricted audiences during face to face and/or online training by professionals who teach communication to NHS staff and health and social care trainees.

☐☐☐☐

I would like my voice to be altered for the above uses of the audio recording (5-8)

Please tick YES ☐ NO ☐

\_\_\_\_\_  
Name of HCP participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Two copies – one to HCP participant, one to TMF*

**Appendix 6. Senior HCP consent form part three**

**Informed consent form for senior healthcare professionals PART THREE**

**Study Title: Communication with relatives in palliative care**

REC Ref: 11519/001

Participant number \_\_\_\_\_

To be completed prior to the senior HCP focus group/interview

Please  
initial if  
you agree

1. I confirm that I have read the information sheet dated 06.06.17 (version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason (including throughout the focus group/interview), without my professional standing or employment being affected. ☐
3. I understand that the focus group/ interview will be recorded, that recordings will be heard and transcriptions seen by members of the research team, and that anonymised quotes may be used in study reports. ☐
4. I understand that the current project aims to improve understanding about communication with relatives in palliative care. I agree to the use of my anonymised focus group/interview data for future research aiming to improve understanding of other areas of communication (subject to approval from the data custodian). ☐
5. I agree to take part in the above study ☐

\_\_\_\_\_  
Name of HCP participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Two copies – one to HCP participant, one to TMF*

**Participant information sheet for relative & friend participants**  
**Study Title: Communication with relatives in palliative care (REC 11519/001)**

We would like to ask you to take part in our research study looking at how doctors and nurses communicate with relatives and friends of patients in hospices. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will contact you to make an appointment to go through the information sheet with you and answer any questions you have. Talk to others about the study before deciding if you wish.

This information sheet answers some questions you may have, but please ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part.

**1. What is the purpose of the study?**

We hope that by recording conversations between experienced hospice doctors/nurses and relatives and friends of inpatients at [REDACTED] we can understand how important, sensitive discussions about the care of patients happen. By looking in detail at these conversations we hope that the findings can be used in the future to improve the communication skills of other doctors and nurses.

As well as looking at what happens in these conversations, we also would like to find out what relatives' and friends' think about these conversations. We would like to know about what was helpful, whether you felt information was made clear to you in a sensitive way, and how much you felt listened to. All of this information will help us to consider how discussions with friends and relatives can be improved.

**2. Why have I been asked to take part?**

You have a relative or friend who is a patient at [REDACTED] and you recently had a conversation about their care with a doctor or nurse who is taking part in this project. The doctor or nurse asked you for your permission to record the conversation, you said yes and so now we would like to check whether or not you are happy for us to use this recording in our research.

**3. Do I have to take part?**

No, it is up to you to decide to join the study. Just because you agreed to the conversation being recorded at the time does not mean you have to let us use it for our research. We will only use the recording if you, the doctor or nurse, and anyone else present agree. Otherwise we will delete the recording without listening to it. If you do agree to take part, we will arrange a meeting to go through this information and then ask you to sign a form which says you are happy to take part. Even if you agree to take part and sign this form, you are free to leave the study at any time without giving a reason. Not taking part will not affect your care or the care of your relative or friend.

#### **4. What will I have to do?**

A doctor or nurse should have already explained the study briefly, asked for your permission and recorded a conversation they had with you. What happened during that conversation will have been no different to what would have happened if they were not taking part in the study, the only difference was that it was recorded.

At least a day after the recording was made, once you have had chance to read this information sheet, Becky who is one of our researchers, will contact you to arrange a time to meet to talk about whether or not we may use the recording. You can decide where and when you would like to have this talk. At this meeting, Becky will go through the information in this sheet and you will have the chance to ask any questions. If you decide that you are happy for the recording to be used she will ask you to sign a consent form, take some basic information and ask you to complete a short questionnaire about your experience of the conversation with the doctor or nurse. The consent form allows you to choose what the recording will be used for and who will be able to hear it.

We will also ask you if you would be happy to be contacted in 3-6 months' time for an interview about your experiences of conversations at the hospice. If you agree to this we will call you later on to give you more information. This does not mean you have to do the interview and you can change your mind at any time. If you do not want to be contacted for an interview that's ok and this will be the end of your involvement in the study.

#### **5. Why are conversations being audio recorded?**

We need to audio record the conversations because we cannot get the data we need simply by watching and taking notes, or from interviews. To get the information that will be the most helpful in improving our understanding of this communication, we need to study conversations that happen naturally. Sometimes people use video recording, but we have decided to just use audio recording in order to avoid causing any distraction.

#### **6. Who will listen to the recordings?**

The research team will listen to recordings and write them up in order to analyse them for the research project. With your permission, the recordings will also be used for future research studies aimed at improving understanding communication in healthcare. We will also ask you if we can use the recordings (with person and place names removed) in the following ways:

- A. Looking at the recording and written copies in private sessions with other researchers to help strengthen the research results
- B. Presentations about the research to audiences of researchers, health and social care staff and trainees
- C. In the future, recordings may be used to design communication skills training and used as training materials in these sessions. This would involve playing audio recordings to private audiences during face to face and/or online training to teach communication to NHS staff and health and social care trainees

You will be given the choice of which of these uses you are happy for the recording to be used for, and whether you would like your voice to be changed for uses outside of the research team (i.e. A, B & C above).

**7. Will I be able to listen to the recording?**

As long as everyone in the conversation agrees to take part in the study, you can ask to hear the recording at any time up until the end of the study (February, 2020). To do this please contact Becky Anderson whose contact details are at the end of this information sheet. Because other people will be on the recording, you will not be able to keep a copy.

**8. What are the possible disadvantages and risks of taking part?**

The doctor or nurse should have told you at the time of the recording that you could stop the recording if you felt uncomfortable. We therefore do not expect that your conversation will have been changed by the audio recording.

If you agree to your recordings being used outside of the research team in the ways described in section 6 of this information sheet, there is a small possibility that someone you know may be participating and may recognise your voice. You will be given the option to have your voice changed for these uses. If your voice is not changed, we will make it clear to participants not to use your name or discuss your personal details during the meeting or afterwards.

We realise this is a difficult time for you and that taking part in this study may bring up some difficult issues. If you would like any information about support services available to you, please ask the research team (contact details at the end of this information sheet) or the MCHH care team.

**9. What are the possible benefits of taking part?**

We cannot promise the study will help you directly, but the information we get from this study may help to train less experienced healthcare professionals and improve their communication skills for good care of people in similar situations to yours.

**10. What if there is a problem?**

If you have any problems or questions about the study you can speak to the research team whose contact details are provided at the end of this information sheet. If you are not happy with the response and wish to make a formal complaint you can do so by contacting [research-incidents@ucl.ac.uk](mailto:research-incidents@ucl.ac.uk).

**11. Will my taking part in the study be kept private?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All information collected about you, including contact details, recordings and consent forms, will be held securely, in a locked room, or locked cupboard or cabinet at UCL or on a password protected electronic database.

Contact details will be removed from any databases at the end of the study and all other data will be changed so that you cannot be identified and kept securely for 20 years following the end of the study. After this time the research data will be destroyed securely.



Other researchers, health and social care staff and trainees may hear your recordings with person and place names removed (detailed in section 6 of this information sheet), depending on which uses you agree to. The recordings and written copies will not be made available to the public. Quotes may be used in study reports or presentations, but your name will not be used and others will not be able to identify you from reports or presentations.

**12. What will happen if I decide to leave the study?**

We understand that after agreeing to begin with you may change your mind about taking part. Your participation is completely your choice and you are free to leave the study and ask that the recording is deleted at any time without your care or the care of your relative/friend being affected. If you leave the study before we have completed the reports, your information and recording will not be used in the analysis.

**13. What will happen to the results of the research study?**

The research team will analyse the recordings of conversations between doctors/nurses and relatives/friends of patients. The results of the study will be published in journals and presented at conferences. The study will also be published as part of a PhD thesis. The data will not include your name and you will not be identified in any report or publication. If you would like to see the results, or the publications, please tell the research team.

**14. Who is organising and funding the research?**

This project is being carried out by the Marie Curie Palliative Care Research Department (MCPCRD) at UCL and [REDACTED]. The study is a PhD project as part of a larger project funded by Marie Curie looking into assessments and communication in end-of-life care.

**15. Who has reviewed the study?**

The research has been reviewed by a Research Ethics Committee to ensure it is high quality, safe and ethical. This study has been reviewed and given a favourable opinion by UCL Research Ethics Committee (ref 11519/001).

**16. Further information and contact details**

Please ask any questions you wish, before and during the study. If you would like any further information or have any concerns while taking part in the study please contact Becky Anderson at MCPCRD on [REDACTED]

If you decide you would like to take part we will give you a consent form for you to read and sign. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed at UCL.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

**Appendix 8.** Relative/friend consent form for recorded conversations

**Informed consent form for relative & friend participants**

**Study Title: Communication with relatives in palliative care**

REC Ref: 11519/001

Participant number \_\_\_\_\_ Recording number \_\_\_\_\_

To be completed at least one day after the conversation has been recorded

Please  
initial if  
you agree

1. I have read the information sheet 06.06.17 (version 1.0) for the above study. I have had the time to think about the information, ask questions and have had these answered fully.

☐

2. I understand that taking part is my choice and that I am free to leave the study at any time without giving any reason, without my care or the care of my relative/friend being affected.

☐

3. I understand that a conversation I had with a doctor or nurse at [REDACTED] was recorded, that this recording will be written-up and seen/heard by members of the research team, and that quotes from it may be used in study reports. I understand that my name will not be used and others will not be able to identify me from these reports.

☐

4. I agree to take part in the above study

☐

**HOW THE RECORDING MAY BE USED.** When we use your recording for the following purposes (5-7), person and place names will be removed from recordings and written copies.

5. I agree to allow the research team to listen to the recording in order to create a written copy, read, analyse, and take notes about it.

☐

6. I understand that this project aims to understand communication with relatives in palliative care. I agree to the use of non-personal data for other future research if approved by the data custodian (the person in charge of the security of the data).

☐

7. I understand that I may ask to listen to this recording any time before February 2020 but that I will not be given a copy to keep.

☐

**In addition to this, where I have initialled, I agree to the following use(s) of this recording. When we use your recording for the following purposes (8-11), person and place names will be removed from recordings and written copies.**

Please  
initial each  
use you  
agree to

8. I agree that this audio-recording and written copies may be shown to other communication researchers in private sessions in order to strengthen the research results. ☐
9. I agree that this audio-recording and written copies may be used in presentations about the research to audiences of researchers, health and social care staff and trainees. ☐
10. I agree that this audio-recording and written copies may be played to and read by researchers and others involved in the design of communication skills training. ☐
11. I agree that this audio recording and written copies may be used in communication skills training. These will only been shown to limited audiences during face to face and/or online training to teach communication to NHS staff and health and social care trainees. ☐

Would you like your voice to be changed for the above uses of the audio-recording (8-11)?

Please tick YES ☐ NO ☐

\_\_\_\_\_  
Name of participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Two copies – one to participant, one to TMF*

**Participant information sheet for relative & friend participants (interview study)**  
**Study Title: Communication with relatives in palliative care (REC 11519/001)**

Thank you again for taking part in the earlier part of this study by letting us use a recording of your conversation at [REDACTED] in our research to improve communication in palliative care. We would now like to ask you to take part in an interview in order to find out more about what you thought about discussions you have had at [REDACTED]. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study before deciding if you wish.

This information sheet answers some questions you may have, but please ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part.

**1. What is the purpose of the study?**

We have already recorded a conversation you had with a doctor or nurse at [REDACTED] and you have given your permission to use this in our research. Our analysis of this recording will give us an understanding of how these discussions happen, but we would also like to know what you think about communication at [REDACTED]. We will use the information from an interview with you and from the recordings to try and understand what types of conversations are helpful to improve care for patients, relatives and friends. We hope that this can lead to advice for less experienced doctors and nurses in similar situations.

**2. Why have I been asked to take part?**

You have been asked because you previously agreed to let us to record a conversation you had with a doctor or nurse at [REDACTED] and told us you were happy to be contacted about taking part in an interview.

**3. Do I have to take part?**

No, it is up to you whether you would like to take part in this part of the study. Just because you agreed to be contacted about an interview does not mean that you cannot change your mind. Choosing not to take part will not disadvantage you in any way and you can change your mind at any time.

**4. What will I have to do?**

We will make an appointment with you at the time and place of your choosing to carry out an interview. We will ask you to sign another form to say that you are happy to take part and for the interview to be recorded. We will then have a conversation where we will ask you about your experiences of communication at [REDACTED]. This conversation will last around an hour and will be with Becky, the researcher who you met with previously to discuss agreeing to let us use your recording. This is all you will be asked to do.

**5. What are the possible disadvantages and risks of taking part?**

Due to the sensitive conversations you may have had at [REDACTED] some people may find this a difficult or upsetting topic to talk about. You do not need to answer any questions that you don't want to and can stop the interview at any time without giving a reason. If you would like any information about bereavement support services, you can ask Becky before, during or after the interview. Her contact details are at the bottom of this sheet.

**6. What are the possible benefits of taking part?**

We cannot promise the study will help you directly, but the information we get from this study may help to train less experienced doctors and nurses and improve their communication skills for good care of people in similar situations to yours. This interview is about your experiences and so if there is anything that you think could have been improved or that you found particularly helpful this will be part of the research results and recommendations for future practice.

**7. What if there is a problem?**

If you have any problems or questions about the study you can speak to the research team whose contact details are at the end of this information sheet. If you are not happy with the response and wish to make a formal complaint you can do so by contacting [research-incidents@ucl.ac.uk](mailto:research-incidents@ucl.ac.uk).

**8. Will my taking part in the study be kept private?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All information collected about you, including contact details, recordings of the interview and consent forms, will be held securely, in a locked room, or locked cupboard or cabinet at UCL or on a password protected electronic database.

Contact details will be removed from any databases at the end of the study and all other data will be changed so that you cannot be identified and kept securely for 20 years after the end of the study. After this time the research data will be destroyed securely. Quotes may be used in study reports or presentations, but your name will not be used and others will not be able to identify you from reports or presentations.

**9. What will happen if I decide to leave the study?**

Your participation is completely your choice and you are free to leave the study at any time, including during the interview without giving a reason. If you leave the study before we have completed the reports for the study, your interview will not be used in the analysis.

**10. What will happen to the results of the research study?**

The research team will analyse the interview alongside the recordings of conversations at MCHH. The results of the study will be available after it finishes and will be published in journals and presented at conferences. The study will also be published as part of a PhD thesis. The data will not include your name and you will not be identified in any report or publication.

If you would like to see the results or any publications, please tell the research team whose contact details are at the end of this information sheet.

**11. Who is organising and funding the research?**

This project is being carried out by the Marie Curie Palliative Care Research Department (MCPCRD) at UCL and [REDACTED]. The study is a PhD project as part of a larger project funded by Marie Curie looking into assessments and communication in palliative care.

**12. Who has reviewed the study?**

The research has been reviewed by a Research Ethics Committee to ensure it is high quality, safe and ethical. This study has been reviewed and given a favourable opinion by UCL Research Ethics Committee (ref 11519/001).

**13. Further information and contact details**

Please ask any questions you wish, before and during the study. If you would like any further information or have any concerns while taking part in the study please contact Becky Anderson at MCPCRD on [REDACTED]

If you decide you would like to take part in the interview we will give you a consent form for you to read and sign. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed at UCL.

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

## Appendix 10. Relative/friend interview consent form

### Informed consent form for relative & friend participants (Interview)

#### Study Title: Communication with relatives in palliative care

REC Ref: 11519/001

Participant number \_\_\_\_\_

#### To be completed prior to the relative/friend participant interview

Please  
initial if  
you agree

1. I confirm that I have read the information sheet dated 06.06.17 (version 1.0) for the above study. I have had the time to think about the information, ask questions and have had these answered fully. ☐
2. I understand that taking part is my choice and that I am free to leave the study at any time without giving any reason (including throughout the interview), without any disadvantage to me or others. ☐
3. I understand that the interview will be recorded, that recordings will be written-up and seen/heard by members of the research team, and quotes may be used in study reports and presentations. I understand that my name will not be used and others will not be able to identify me from these reports and presentations. ☐
4. I understand that this project aims to understand communication with relatives in palliative care. I agree to the use of the recording for other future research, if approved by the data custodian (the person in charge of the security of the data). ☐
5. I agree to take part in the above study ☐

\_\_\_\_\_  
Name of participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Two copies – one to participant, one to TMF*

## Appendix 11. Topic guide for interviews with relatives

### Topic guide for relative interviews

#### Study title: Communication with relatives in palliative care (REC 11519/001)

Thank you again for agreeing to talk with me about your experiences of conversations you had during your relative's time at the hospice. I'll be asking you about the times when you spoke with [REDACTED] staff and your views on how they gave information to you and your family. I understand that some of these things might be quite difficult to talk about, so if there is anything you don't want to answer that is absolutely fine. If you decide at any time that you don't want to continue with the interview, just let me know, you don't need to give me a reason. Do you have any other questions?

**Research question:** what are relatives' perceptions of how information about the care of their relative was communicated to them and their involvement in decision making?

#### Background

*To begin with, it would be helpful to know a bit about your relative's time at the hospice if that's ok.*

1. How did your relative come to be admitted to the hospice?

*Prompts: did they come in from home/hospital etc.? some people stay at the hospice at several different times or come to the day care unit, had your relative ever been to the hospice before? how long were they there for?*

2. How would you rate the quality of your relationship with hospice staff?

*Prompts: were there people you could comfortably speak to about your relative? were there any specific members of staff that you spoke to the most/ about different parts of your relative's care? how much were your concerns listened to? how much time were you given to discuss your relative's care? did anyone talk to you about how you were feeling/getting on?*

#### Delivery of information about prognosis and care

3. What information were you given about your relative's care?

*Prompts: were you kept up to date with all the information you needed? did you feel you were given information at the right time?*

4. Were you told when the staff looking after your relative thought that they were likely to die soon?

4. a) *If no:* How did you feel about not being told?

*Prompts: why do you think this didn't happen? was your relative's death unexpected? were you able to be there when your relative died? were there any times when staff told you they thought that your relative was dying but they did not?*

4. b) *If yes:* What do you remember about that conversation?

*Prompts: who did you have this conversation with? how well did you feel they handled it? did they explain what changes to expect? did they tell you when they thought it was likely to happen? were you able to be there when your relative died? were there any times when staff told you they thought that your relative was dying but they did not?*



5. How clear was the information that you were given at the hospice?

*Prompts: what sort of language did the doctors/nurses use? did you always understand it? did you ever feel they weren't telling you everything you needed/wanted to know? did you ever feel like you were given too much information in one go?*

6. How well did you feel the staff understood your individual situation?

*Prompts: did you feel like they genuinely cared about you and your relative? how much did you feel you were being listened to? were you treated as an individual? what made you feel that way? can you give me any examples?*

### **Decision making**

7. Were there any times when staff discussed with you a decision that needed to be made about your relative's care? *(if unclear, e.g. the use of medications such as pain killers or antibiotics, whether your relative should be cared for at the hospice or elsewhere)*

7. a) *If no:* Were there any decisions made that you felt should have been discussed with you?

7. b) *If yes:* How did you and the doctor/nurse make the decision?

*Prompts: did the doctor/nurse ask for your opinion? did you feel you had enough time and info to make the decision? were you aware of their preference? how involved did you feel you were in decisions? how much did you want to be involved? did they discuss what your relative would want to happen?*

8. Once decisions had been made, what information were you given about what would happen next?

*Prompts: what sorts of things did they discuss with you? did you have time to ask questions? did things then progress as you expected? did you know where to go if you had any questions?*

### **General**

9. What was helpful/comforting about the conversations you had with staff at the hospice?

10. What could staff members have done to improve the way they spoke with you?

*Prompts: what difficulties did you have when trying to talk to staff about your relative's care?*

11. What else you would like to add that we haven't spoken about?

## Appendix 12. Topic guide for focus group/ interview with HCPs

### Topic guide for HCP interviews

#### Study title: Communication with relatives in palliative care (REC 11519/001)

Thank you for agreeing to talk about your views and experiences of communicating with relatives of patients at the end-of-life. I'll be asking you about what you think is important about communication with relatives and friends, particularly the sorts of conversations you recorded for the study when patients lack capacity and are approaching the end-of-life. Feel free to speak up at any time and to each other not just me, but please try to talk one at a time.

**Research question:** What do HCPs think is important for good communication with relatives at the end-of-life? What are the barriers and facilitators to good communication?

#### Content/ Process of conversations

*To begin with it would be good to know what you think is important to discuss with families and friends at the point when their relative no longer has capacity and is approaching the end of life...*

- What do you see as the main purpose of these conversations?
- *Prompts:* what is important for them to know at this point? how do your roles in this communication differ with each other and with (doctors/nurses)?

*Order of/ time spent on the following topics depends on what HCPs say is important:*

#### *Prognosis:*

- How is prognosis usually raised?  
*Prompts:* who raises the question of prognosis more often- you or relatives? If they don't raise prognosis, do you- how? do you check what they want to know- how?
- How do you explain the prognosis?  
*Prompts:* what sort of language do you use? do you often refer to death or use euphemisms- why? how do you communicate uncertainty? how precise are you in your estimates?

#### *Dying process*

- Do you explain what to expect from the dying process- how?  
*Prompts:* what do you think they need to know about this? when is this conversation appropriate?

#### *Relative wellbeing:*

- How do you see your role in relation to relatives' wellbeing?
- How do you respond to emotional reactions from relatives/friends?  
*Prompts:* do you feel comfortable responding to this? so you refer people to other services?

#### *Decision making*

- What sorts of decisions about care need to be made at this point?
- How much do you involve relatives in these decisions?  
*Prompts:* How much do you think they usually want to be involved? How do you assess this?
- What situations have you encountered where you disagreed with the relative's care preferences?- how do you deal with this?

#### *General*

- How do you know if someone has understood what you have told them?
- Are there any non-verbal strategies you use?  
*Prompts:* body language, physical contact, any written information, allowing silence
- Do you have any strategies to bring these sorts of conversations to a close- what are they?

#### **Barriers/facilitators:**

- What factors can impact on how difficult these conversations are?  
*Prompts:*
  - patient factors (e.g. disease- more uncertain trajectory, fluctuations in state, previously known to hospice, demographics etc.)
  - relative factors (e.g. previous conversations/ relationship with, demographics, level of knowledge etc.)
  - context (e.g. privacy: are there certain conversations you prefer to have at the bedside vs in a private room; time: ward rounds vs more informal; others present- nurses, med students etc.)

#### **Study related:**

*(If time allows)*

- What did you find difficult about participating in the study?
- Were there times when you chose not to approach a potentially eligible family member- why?
- How do you think you would have felt if the conversations were video recorded?

#### **Closing:**

- What do you think could be done to improve communication at the hospice generally?  
*Prompts:* not just your own practice but things that would make communication better for relatives on a day-to-day basis
- What else do you think is important for us to know about good communication with relatives at the end-of-life?

### Appendix 13. Transcription symbols

Symbol/ example	Explanation
[word] [word]	Overlapping speech
(0.4)	Silence in seconds
(.)	Micro-pause (under 0.2 seconds)
<u>word</u>	Emphasis
wo::rd	Elongation of prior sound. No. of colons indicates length of elongation
wo:rd	Rising intonation contour
wo_r:rd	Falling intonation contour
↑    ↓	Marked pitch change up or down (multiple arrows for sharper pitch changes)
WORD	Speech that is louder than surrounding speech
°word°/ °°word°°	Speech that is quieter than surrounding speech (double degree signs indicate whispering)
word= =word	Latching of successive speech (no silence between turns/ parts of one turn)
hhh	Out-breath (number of h indicates length)
.hhh	In-breath (number of h indicates length)
.shih	Wet sniff
,	Slightly rising intonation
?	Strongly rising intonation
.	Falling/ stopping intonation
>word<	Speeded up talk
<word>	Slowed down talk
word-	Cut-off of preceding sound
heh/ huh/ hah	Laugh particles
wo(h)rd	In-word laugh
huhh .hhhih	Can be used for sobbing- combinations of 'hhs', '.hh's and vowels
#word	Rasping/ creaky voice
~word	Wobbly voice
\$word	Laughing voice
£word	Smiling voice
(word)/ (    )	Possible hearings/ inaudible
((comment))	Transcriber's comments

Adapted from Jefferson (2004) and Hepburn and Bolden (2017)

## Appendix 14. Initial interview and focus group coding

Relative initial codes	HCP initial codes
Able to be present at death	Bring up concerns before family do
Availability of staff	Can seem like have understood but haven't
Availability of staff lacking	Agree with doctors, then object to nurses
Complaint	Check understanding
Consistency and knowledge of situation across staff	Compromise
Consulted in decisions	Dealing with aggressive relatives
Didn't focus on DNACPR	Dealing with multiple family members
Difficulty of numerous relatives to communicate with	Different communication for different families
Difficulty of staff changing, lack of consistency esp weekend or nights	Disagreements more difficult when patient has lost capacity esp if no ACP
Dr knows best	Look for cues
Emotional support	Don't always raise prognosis
Environment and privacy	Family often already aware
Explained symptoms	Prepare for possibility of not being there
General style of communication e.g. compassionate, calm	Often raise prognosis for practical reasons- is a way to initiate
Got to know relatives' situation	Prompted by changes to initiate prognostic talk
Honesty	Try not to let prognosis be the focus
Hospice as major transition	Don't leave stuff for another conversation
Inclusion of patient views, personalised care	Environment: room vs private
Info second hand from relative	Experience important
Informal and non-medical conversations with staff	Explain change of treatment focus
Lack of info on what to expect	Explain what to expect from time at hospice
Language barrier	Explain why symptoms are happening
Level of info good	Explore psychological impact
Needed to persuade HCPs of decision	Allow silence
Negative, unspecified	Let people talk
No major decisions to be made	Some don't want to talk
No need for info at v end of life	Giving options
Not enough info	Humour
Not listened to	Some have over-optimistic view of prognosis
Not patronised	Sometimes have not accepted prognosis
Not present at death	Language barrier
Not updated	Language of prognosis
Nurses gave prognosis	MDT
Positive unspecified	Pauses to allow end of conversation
Prefer to get informal emotional support from elsewhere	Need to tell people what to expect in advance rather than explain after
Presence of staff helpful	Preparation for conversation
Prognostic info for practical reasons	State uncertainty
Reassurance	Prognosis unpredictable
Knew without being told that was imminently dying	Rapport important to encourage questions
Relatives organising to see consultant on ward round	Remove as much uncertainty as possible
Relatives' role in care	Self-care
Religious support	Acknowledge difficulty of situation
Social worker for own wellbeing	Signposting to emotional support
Some staff better than others or knew patient and family better	Prognosis as a changing process not just one conversation
Staff who genuinely care	Summarising, stating availability, final concerns
Timing of info	Tell family to be normal around patient
Uncertainty	Allow families to make place feel like home
Welcoming, open atmosphere	Try to make it ok to ask questions
What to expect	What to expect
Unsure still on certain issues e.g. if meds contributed to death	Working out what they know
	Ask what has happened so far
	Ask why they think it has happened

#### Example coding from relative interview

Extract	Initial coding
so normally ask whoever the allocated nurse was, and the nursing assistants knew quite a lot because they used to spend quite a lot of care, quite a bit of time there – and some knew my mum, some, you sort of connected more with on a personal level and I think some knew my mum a bit more, and then they so I think I would ask them more (R01, Daughter of patient)	Level of info good  Informal and non-medical conversations with staff  Some staff better than others or knew patient and family better

#### Example coding from HCP focus group

Extract	Initial coding
The key is acknowledging that the person is dying, and then the time scales around that are very uncertain. But I think, from my experience anyway, if a family know that somebody is dying, they know the seriousness to that. So they will call family. Like Bridget I don't really have a tick to say I need to now talk about days, weeks, whatever, unless there's specific. Really common is my daughter or son has got a holiday or a flight booked tomorrow (R09, Registrar)	Family often already aware  Often raise prognosis for practical reasons  State uncertainty

## Appendix 15. Features of prognostic discussions reproduced from published paper

Feature	Example
Uncertainty alluded to in time estimate request	<p>"how long, time <b>do you think</b> he <b>could</b> go on before death" (HCP07, R17, R18)</p> <p>"in terms of a timeline <b>do you, do you feel</b> there's a timeline here?" (HCP05, R61, R62)</p>
Qualifying language in response	<p>"<b>at the moment</b> I would say it <b>could</b> be hours it <b>could</b> be days" (HCP05, R51)</p> <p>"I <b>think</b> hours to days I <b>think at the moment</b>" (HCP07, R27, R28)</p>
Account for time estimate relating to changes accessible to family	<p>"because <b>her colour's completely changed</b>... and it's actually <b>hearing it from some of the members of your family</b>" (HCP01, R04, R05)</p> <p>"there's a <b>clear change</b>... on Wednesday sitting in a chair, still <b>able to talk</b> and knew, <b>knew who we were</b>" (HCP02, R52, R53)</p>
Explicit statement of uncertainty that alludes to experience	<p>"I <b>don't think any of us actually know... throughout my years in palliative care I've sort of learnt my own lessons</b>" (HCP01, R09)</p> <p>"I've been surprised <b>so many times that I've just learnt</b> that I <b>don't really know</b>" (HCP05, R11, R12)</p>
Absolute categorical time estimate	<p>"I think we've now changed from <b>weeks</b> to <b>days</b>" (HCP05, R34)</p> <p>"I think it would be <b>days</b>" (HCP02, R10)</p>
Descriptive time estimate	<p>"we're anticipating that <b>time</b> might be <b>quite short</b> now" (HCP09, R13)</p> <p>"<b>time</b> could be getting <b>short</b>" (HCP05, R19, R20)</p>