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**PHD**

**A mixed-method psychosocial analysis how senior health care professionals recognise dying and engage patients and families in the negotiation of key decisions.**

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A MIXED-METHOD, PSYCHOSOCIAL ANALYSIS OF HOW SENIOR HEALTH CARE  
PROFESSIONALS RECOGNISE DYING AND ENGAGE PATIENTS AND FAMILIES IN  
THE NEGOTIATION OF KEY DECISIONS

A thesis submitted for the degree of Doctor of Philosophy

University of Bath

Department of Psychology

April 2017

Joanne Wilson

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[Signature]

A handwritten signature in cursive script that reads "Joanne Wilson".

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## Abstract

Successive “National Care of the Dying Audit for Hospitals” record that Health Care Professionals (HCPs), are recognising that patients are dying only days before their death, reducing opportunities for patient involvement in decision-making. This PhD, utilizing a mixed and iterative methodology, addresses how senior HCPs in one hospital recognise dying, and negotiate decision-making with patients and families in this process.

In Study One thirteen senior HCPS undertook a Critical Incident Review. These involved the ward based senior HCP who identified dying, and the Hospital

Palliative Care Team (HPCT) HCP(s) subsequently involved in the patient's care. Interviews were recorded, transcribed and themed. In Study Two senior HCPs across the hospital were invited to four consecutive Participatory Action Research (PAR) workshops to critically reflect on the themed data from Study One. Ten HCPs took part (three HPCT HCPs were involved in both studies). The workshops were similarly recorded, transcribed and themed.

The themed analysis yielded a model for decision-making but did not explain why dying was identified so late. A psychoanalytically informed psychosocial approach was taken to examine anomalies and contradictions in the data that pointed to less conscious undercurrents in the personal, professional, educational and institutional dynamics involved in the care of patients who are dying. Through this analysis, it is clear that identifying dying, and negotiating decision-making with the patient and their family at this time, is extremely anxiety provoking. Individual and social psychological defence mechanisms that avoid the recognition of dying come into play. HCPs' experience of learning to care for the dying patient and their family is "chaotic" and anxiety provoking and leaves them ill-equipped. Complicating matters, at the point of recognition of dying, the institution devolves its responsibility for care (requirement for space and time for patient and family conversations, and emotional support for HCPs who sometimes have to deal with angry families) to individual HCPs. The argument is put forward that the HPCT have become part of modern NHS social defence mechanisms.

Sensitively facilitated PAR workshops allow interested HCPs to mutually consider how to identify dying earlier; implications of this for the patient, family and themselves; the organisational resources available; and the role of education. Attention is paid to the HCPs emotional experience and psychological defences, and over time there is opportunity to negotiate sustainable practice change.



## Chapter One - An Introduction And Orientation To The Thesis

I came to this PhD in 2011 with a longing to be able to improve both my own, and other Health Care Professionals (HCPs), clinical care of the dying patient and their family. My experience, as a Consultant Nurse (Palliative Care), of leading change in ward-based clinical practice is that ward doctors, nurses and therapists wanted to care well for the dying patient and their family, and got pleasure from seeing patients having their symptoms well managed and comfortable. However, they often needed assistance to recognise that patients were dying and to work with the patient and their family subsequent to that decision.

Between 2008 and 2014 I based myself for extended periods firstly in Accident and Emergency and the Acute Medical Unit, and then on the respiratory ward at a District General Hospital<sup>1</sup>. In this time, I worked with clinicians in those specialties and together we increased access to palliative and end of life care, and jointly published results at local and international conferences. The practice development used service quality improvement methodology (Maher, Gustafson, & Evans, 2007), and nationally recommended care plans. This was initially the Liverpool Care Pathway (Ellershaw & Wilkinson, 2003) to care for the patient in the last days of life and latterly the AMBER care bundle (Guy's & St Thomas' NHS Foundation Trust, 2012), to care for the patient who was likely in their last six weeks of life and with an uncertain recovery. The understanding though was that this paperwork was only to prompt and record (and it was ultimately used for analysing the intervention); it's the clinician working with the patient and family to achieve meaningful outcomes that is key (Sleeman, Koffman, Bristowe, & Rumble, 2015). Every time I left the clinical area for annual leave, the amount of dying that was recognised dropped, but not the number of deaths. When this was presented to clinicians they were shocked and could not explain the data.

Through this PhD I have become more acutely aware of the anxiety – both my own and others - engendered by caring for dying patients and their families. I have been introduced to psychosocial studies (Frost & McClean, 2014) and psychoanalytically informed ways of thinking about research (Walkerdine, Lucey

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<sup>1</sup> Name not used to promote anonymity of participants in study.

and Melody 2001) and the analysis of research data (Clarke & Hoggett 2009) (Hollway and Jefferson 2013). Psychosocial thinking places the individual HCP at the heart of the study and considers the interconnectedness between the HCP's individual lives – personal (the individual as part of their family and community) and professional - and the external social relationships they maintain with patients, families and colleagues, sited within the hospital as part of the economic and political order that largely governs and shapes the context in which the HCP functions. The pulse of this inter-connectivity is anxiety (Menzies, 1970) (Hoggett, 2009). The psychosocial analysis of data collected in the course of this PhD will be presented in the later chapters but not immediately introduced. The need to take a radical subversive thought (Bibby, 2011), and dive into the consideration of the irrational, psychologically defended HCP, will be considered as the positivist options for practice change are shown to run dry. The marginalised discourse of the lived experience of the HCP in this aspect of clinical care needs to be factored in.

In Chapter Two the necessity for the research is argued. The increasing demographics of an aging and multiply co-morbid population make the care of the dying patient an ever-increasing occurrence in a hospital system whose outcomes are focused on restoration to health and function, and cautioned against early mortality. The positive national policy drives for “good end of life care”, with “care closer to home”, make it difficult to think about less rational influences on identifying dying, and working with patients and families. Yet the evidence has long been present that clinicians are not good at prognosticating, and patients are even worse. This chapter considers why identifying dying is clinically important for both the patient and for preparing the family for bereavement. It considers previous research that has begun to illuminate the challenge of this topic, and considers what was known from the literature ahead of the start of this research. It presents the evidence in a clinically relevant way for what was known about recognising dying and negotiating decision-making for adults with mental capacity, adults without mental capacity due to a long term condition and adults who have temporarily lost mental capacity due to an acute event. It considers the family's role and experience in the decision-making and then thinks about the rapidity and

intensity of the clinical care and decision-making in areas such as the Emergency Department (ED). It shows that identifying dying and negotiating decision-making with patients and families is skilled and emotionally taxing work. Since starting this study, other researchers are interested in the same question, and this chapter considers their research and implications. It then clearly charts how the research question under-pinning this study, has been re-focused from “How senior HCPs, identify dying and negotiate decision-making to improve the patient and family experience. Participatory Action Research explored as a means to develop clinical practice”; to “A mixed-method, psychosocial analysis of how senior Health Care Professionals recognise dying and engage patients and families in the negotiation of key decisions” as findings from this study have emerged. It articulates how the refocused question addresses the gaps in the literature and in clinical practice.

In Chapter Three the two-stage methodology and method are introduced. Whilst writing up this PhD, I knew that the initial themed analysis of the Study One and Study Two transcripts did not fully answer the research question, and I did not have a language to articulate what might be happening. The need for a psychosocial enquiry to illuminate less rational decision-making, and more psychologically defended possibilities at an individual, social and organisation level is articulated. The psychosocial literature review is covered in this chapter.

Chapter Four introduces the reader to the pen portraits of the six patients as described by the 13 HCPs in the Critical Incident Review (Study One), and a summary of the HCPs role in the patient’s care, to help ground the reader in the realities of clinical practice and assist with a “sense of the whole” ahead of the themed and psychosocial analysis.

Chapter Five describes the themed results of the Critical Incident Reviews (Study One), as they were presented to the (mainly) different HCPs who took part in the four Participatory Action Workshops (PAR) of Study Two. The themed data from the PAR workshops (Study Two) is also presented. A four-stage model of recognising dying and engaging with patients is initially described. There was positive evaluation of PAR workshops as a means to facilitate practice development, and so a fifth stage of clinical supervision was added to the model.

What the themed analysis did not facilitate was to explain why the model was not always used, why recognising dying could be avoided, or why there was “blending” between stages or unawareness of stages. With this in mind a psychosocial analysis was undertaken of the workshop transcripts, and two aspects of this – “Families”, and “How HCPs learn to care for the dying patient and family” – are considered in Chapters Seven and Eight. I then considered study one transcripts and this is presented in Chapter Six – “The primary task of the NHS and social defences”.

Chapter Six draws on Menzies-Lyth’s (Menzies, 1970) psychoanalytic study of nurses in a London teaching hospital in the 1950s. In this chapter it is suggested that caring for the dying is both consciously and unconsciously extremely anxiety provoking. In response to this challenge to HCP’s psychological well being there are co-created social defence mechanisms specifically related to dying and these are produced and supported at the level of the personal, the group and the institution. There was evidence of HCPs defending against the anxiety provoked by the task of identifying dying by working to achieve a “cast iron decision”, utilising second opinions and multiple tests. It is no wonder dying is ultimately recognised so late. We saw minimising of anxiety by denial and detachment of feelings. There is evidence of HCPs avoiding the work of identifying dying and subsequent patient and family engagement, by dressing dying up as a treatment – for example “re-x-ray to see if the stent is in place” or leaving the emotional work to other HCPs – writing in the clinical notes “consider Do Not Attempt Cardio-Pulmonary Resuscitation”. It argues that Hospital Palliative Care Teams (HPCT) are the new, but not infallible, social defence mechanism of the modern NHS that relieve others of their anxiety of caring for the dying.

Chapter Seven draws on the concepts of liminality and affectivity to open a space to consider the HCP and patient and family relationships, as news about dying is broken. Dying is a liminal experience for the patient, but the loss of mental capacity to take part in decision-making can and is likely to occur ahead of death and withdraws the patient from the decision-making process. The formal introduction of the family, in a best interests decision-making scenario, is considered. The chapters proposes that recognising dying and engaging with the

family about this has the potential to jettison the family into an experience of liminality where the reality of the death of their family member and the possible personal impact of this upon them becomes a reality. The engagement with the family may also be a liminal experience for the HCP as their protective phantasies of being right and in control can be undermined when their skills to cure or make better have reached an end and they meet the family in a human-being to human-being relationship. This chapter considers anthropological researchers advice that liminal events be structured by ritual for the emotional safety and containment of strong emotions and for people to understand the behaviours of the role.

Chapter Eight presents the current context for medical and nursing education and the importance of the “supervised learning opportunity with reflective debrief” in both the development and assessment of medical and nursing HCPs for professional practice. It evaluates the literature that shows that despite a nationally articulated focus on end of life care, some junior doctors and nurses feel unprepared for this work upon qualification and unsupported by their seniors in their on-going clinical practice (Bowden, Dempsey, Boyd, Fallon, & Murray, 2013; Price & Schofield, 2015). It draws on current psychoanalytic approaches to learning and the data from the workshops to help us understand why. Allowing thought, thinking and moving to learning is inherently dangerous and anxiety provoking, and never more so than when thinking and learning about death. The learning is not just about the clinical situation, but HCPs’ own lives and self. From the workshop data there was evidence that senior HCPs once they are in a psychologically safe environment “discuss the un-discussable”. Instead of the responses from the interviews in Study One, where they expressed the impact of caring for the dying as “part of the job”, they expressed feelings of uselessness and frustration when faced with the reality of a patient whose dying takes time. They thought of their families and imagined their own loss. They had their own phantasies of mastery of death by clinical care and usefulness undermined. Exploring what is un-discussable gives some clues as to why senior doctors may avoid the “supervised learning opportunity” for HCPs. Senior doctors in this study did endeavour to offer junior doctors experiences of watching family meetings take place, but expressed unease at the presence of the junior doctor in the meeting.

There was not evidence that these learning events were debriefed. The chapter considers how HCPs regulate their own learning by seeing and doing and considers that some nurses are the route to safely contain doctors so that they can learn. It was suggested that in contrast to the General Medical Council “Standards and Education for Training” guidance (General Medical Council, 2016) that organisations should provide a good learning environment, that the organisation contributed to a lack of learning by lack of time and opportunity for skilled emotional containment of senior doctors to help them process their own learning and thus better support junior doctors. The national commitment to mandating reflection for judgement and assessment through appraisal and revalidation is unlikely to be helpful. Nurses (apart from palliative care nurses) are educationally unprepared to be the emotional container for doctors at patient and family meeting, or to assist with a reflective debrief in a skilled manner. In this way it is easy to see how troubling experiences and thoughts about dying could be repressed or projected elsewhere and dying patients and families avoided.

The final chapter discusses the nine unique contributions that this PhD makes. The first is to keep the subject of the HCP at the centre of the research question (Frost, 2015), and to introduce the language of the psychoanalytic psychosocial into the care of the dying. I propose it is helpful to name that death and caring for the dying is extremely anxiety provoking and to stop repeating the national rhetoric that “end of life care is everyone’s business”. The purpose of this naming would be to let us pause and stop passing the “emotional hot potato” round long enough to think creatively together about how we might progress this clinical aspect of care in a humane and kind way that is respectful of HCP’s personal histories, professional development, the organisational resource and complexity, and the contribution our educators can make.

The second novel contribution is the use of a five-staged, rather than two-staged (Lamont and Christakis cited in Krawczyk & Gallagher, 2016), model to recognising dying, and then communicate this to the patient and family. HCPs in this study had not previously considered the detail of the process of recognising dying and found it helpful to consider each stage. Giving the process of recognising dying and negotiating decision making a framework means HCPs attention in clinical practice

and teaching can be focused on the detail of each of the stages in a timely rather than rushed manner and there can be pacing of each stage, with spaces open for thought, both for the patient, their family and the HCP, dependent on the clinical situation. Clinical supervision is added as a fifth stage in the model as HCPs valued reflective space to both address the emotional component of their learning, and learn from other HCP's experiences. The addition of this stage allows for future negotiation for organisational support for this aspect of clinical care.

Despite the work of Menzies-Lyth, there is still no language in the NHS for the consideration of co-constructed social defence mechanisms. She herself lamented that her work on social defences had not had more effect (Dartington, 2008). The third and fourth novel contributions are to describe the social defence mechanisms associated with the conscious and unconscious anxiety provoked by the care of the dying and to name palliative care teams as the new social defence of the NHS.

My fifth novel contribution is the detailed consideration of the contribution of families to the raising of the tone of the anxiety and the avoidance of the recognition of dying. Families who are mistrusting, disbelieving and angry at the medical decision-making about dying are particularly challenging. HCPs identified that they felt educationally poorly prepared for family meetings, that the meetings take a long time and that this work is not adequately resourced within current clinical care.

My sixth novel contribution is to highlight that getting the prognostication wrong is hugely impactful for HCPs – this is especially so if the treatment is changed to comfort focused. The experience of HCPs, patients and family of surviving a prognosis warrants further study. In this study HCPs described hours of work getting relationships with patients and families back on track. How HCPs learn from their mistakes has been described as a “marginalised professional discourse” (Vetere, 2007) and the discourse of “learning from getting it wrong”, and “relationship repair” is worthy of further study.

The introduction of the psychoanalytic psychosocial allows new insights about the “supervised learning opportunity”. Whilst the literature highlights that junior doctors and nurses are left to manage dying patients and families alone (Bowden,

Dempsey, Boyd, Fallon & Murray 2013) (Okoye & Arber, 2014), and that when help is asked for not all senior clinicians offer this (Price & Schofield, 2015), it does not explain why this might be the case. This PhD highlights the lack of skilled emotional containment to allow senior doctors to continue to learn from clinical encounters and be able to support junior doctors – this is the seventh novel contribution. The eighth novel contribution that this study highlights is the lack of 24-7 support for emotional containment at the clinical encounter with the dying patient and their family, by those HCPs comfortable and skilled in this work, and suggests that this is in part where the organisation devolves its responsibility for the safe learning environment.

The ninth and final novel contribution is that HCPs, particularly doctors, identify that as they become more senior, they practice more and more in isolation, and have less opportunities to witness and learn from others. This is particularly in relation to patient and family meetings subsequent to the recognition of dying. Senior nurses are both a source of expertise to watch and route to emotional containment and learning. The chapter closes with a critique of the study and with recommendations for practice.



## Chapter Two – Recognising Dying And The Introduction Of The Research Question

### Introduction

This research study, which started in 2011, has always focussed on addressing how senior Health Care Professionals (HCPs) in one UK District General Hospital recognise dying and engage patients and families in the negotiation of key decisions at this time. It is important to note that my intention with this PhD was to better understand clinical practice and articulate suggestions to improve this area of clinical practice. Subsequent to the first literature review, the research plan was to evaluate Participatory Action Research (PAR) workshops as a means to develop this aspect of clinical practice. Once the first themed data analysis of the workshops was complete, it was clear that on one level the research question was answered and I could evaluate the workshops. However, on another level I could not suggest any novel solutions for clinical practice and the suggestions for practice development would have been “do more of the same”. This was unsatisfactory for me. Thus, from the autumn of 2015, I undertook a psychosocial analysis of the data. The research question has thus evolved from “How senior health care professionals recognise dying and engage patients and families to negotiate key decisions to improve the patient and carer experience. Participatory action-research explored as a means to develop clinical practice”, to “A mixed-method, psychosocial analysis of how senior Health Care Professionals recognise dying and engage patients and families in the negotiation of key decisions”. In order to undertake the psychosocial analysis I undertook a second literature review, which will be introduced in Chapter Three – “Methodology and Method”, and specifically focused in Chapter Six – “The Task of the NHS and Social Defences, Chapter Seven – “Families” and Chapter Eight – “How Senior HCPs Learn to Care for the Dying Patient and Family”.

The chapter below sets out why “how HCPs recognise dying and engage patients and families in the negotiation of key decisions” is such an important question. It sets out the literature on the evaluation of other’s interventions to develop this

area of clinical practice, and how both research questions addressed the gaps in the established research.

### **Why is the care of the patient who is dying in hospital important?**

The care of the dying is hugely important because this is numerically no small issue. There are 460,000 deaths per year in England. Two thirds of those who die are above the age of 75 (National End of Life Care Intelligence Network, 2012a) and 89.6% of all who die have some hospital care in their last year of life (National End of life Intelligence Network, 2013). On average an individual will experience 2.1 admissions in the last year of life and 53% of people die in hospital (National End of Life Care Intelligence Network, 2012a).

The notion of achieving a good death is strongly embedded as an aim of hospital services. Smith (Smith, 2000) names some of the factors that may be important to individuals about a good death. These are having an awareness of death and to understand what can be expected; to retain control; to be afforded privacy and dignity; to choose the place of death; to have access to information and expertise; to be comfortable, and have access to hospice care in hospital; to have control over who is present at the death; to issue advance statement of wishes; to be able to say “goodbye”; as well as have some control over other aspects of dying. Certainly, this is a westernized concept of a good death, and much work still needs to take place to understand the end of life care needs of our black and ethnic minority communities in the UK, and to develop culturally competent staff (Calanzani, Koffman, & Higginson, 2013).

### **Current policy drivers**

There are several drivers currently influencing clinical practice. There is an increasing demographic of a population that is living to a much older age but with multiple long term conditions (Gomes & Higginson, 2008) and these two factors alone are estimated to lead to a 1.7% growth per annum in demand for NHS hospital services (Monitor, 2015) in a financially restricted climate. UK premature mortality is persistently and significantly below the mean of the European Union, Australia, Canada, Norway and the USA (Murray et al., 2013). Thus it is unsurprising that the five primary aims of the NHS are to prevent people dying

prematurely, enhancing quality of life, helping people to recover, ensuring a positive experience of care, treating and protecting patients from avoidable harm (Department of Health, 2016). End of Life Care constitutes only one sub - outcome under the above-mentioned aim of “ensuring people have a positive experience of care”. Surveys previously undertaken in this area have focused on bereaved carers experience as a proxy for the patient’s voice, and to assesses carers experience rather than survey the dying patient (Colvin, 2016).

There is a drive within NHS policy to deliver “care that is closer to home” (Monitor, 2015), to ensure hospital beds are available for those who clinically (rather than socially) need them, and for whom what constitutes hospital care, cannot be provided anywhere else. This policy aligns with Health and Social Care policy that has consistently promoted patient choice and autonomy in decision-making since 2000 (Froggatt, 2005). Choice about preferred place of care and death have been strongly articulated and deaths in the usual place of residence is now being a key performance indicator and used as a marker of quality around patient choice (Public Health England, 2013). This means there is a constant drive in hospitals to discharge patients quickly, and the idea that if patients are in their usual place of residence that this is a good thing. Choice in end of life care is beginning to be recognised as “vacuous” p104 (Borgstrom & Walter, 2015). Choice is limited by the person’s body and mind, supportive familial relationships, the ability to negotiate the NHS to access care, and the disjuncture between physical care being organisationally delivered as part of the NHS market place, rather than delivering compassionate care for each individual (Borgstrom & Walter, 2015). We also know that the dying patient’s health and social care needs may not always be able to be met in their choice of usual place of residence, and this is another of the social losses faced in the run up to death.

There is policy pressure on General Practitioners (GP) by national charities funded by NHS England to identify the 1% of their population likely to be in the last year of life (Dying Matters, 2017), and by the GP contract to identify the 2% of their population who are frail and for whom it is in their best interests to assist in avoiding admission to hospital (NHS England, 2015). This work is supported by the Royal College of GPs (Royal College of General Practitioners, Royal College of

Nursing, 2012). The aim of this clinical work is to progress conversations about preferences for care, treatment plans, end of life care and what patients would want to occur – this is not legally binding and is called advance care planning (ACP). A competent patient can recognise they are dying and both initiate conversations about relevant decisions and make their own decisions to refuse specific treatments. This is called an advance decision to refuse treatment (ADRT), and is legally binding (National End of Life Programme, 2012). Patients, though, tend to discuss their preferences more with family members than HCPs, and expect HCPs to initiate the conversation (Almack, Cox, Moghaddam, Pollock, & Seymour, 2012). However highly experienced clinicians speak of ACP and of being willing to do this with patients, there are almost always reasons not to initiate this conversation. For example clinicians feel the patients are not ready, that they are not the right person to initiate the conversation (Kelley, Mehta, & Reid, 2009), they fear taking away hope (Almack et al., 2012), or that the correct sequence of events has not occurred (all treatment options had not yet been tried) (Drought & Koenig, 2002). In this manner the anticipated hope of the outcome of ACP - that patients and their relatives are prepared and their choices can be actualised if they come into hospital – is rarely materialised. HCPs in hospitals are left initiating conversations with patients and / or their families (dependent on the patient's mental capacity) about their wishes and preferences. A time of acute clinical deterioration is the least preferable time to start this conversation as patients are too unwell to recall them (Seamark et al., 2012).

Despite a publicised focus on improving the care of the dying since the launch of the End of Life Care strategy in 2008 (Department of Health, 2008), and several further publications (NICE, 2013) (Leadership Alliance for the Care of Dying People, 2014) (National Palliative and End of Life Care Partnership, 2015), successive national audits of the care of the dying in hospitals identify that the care of the dying patient and their family is still not adequately resourced. Only 21% of hospital sites surveyed had access to face to face palliative care services seven days a week, despite this being a long standing recommendation (NICE, 2004), and most only provided face to face services on weekdays only. The audits have also identified that HCPs are still only identifying that patients are dying just days

before death and this has been consistently resistant to improvement (Health and Social Care Information Centre, Academy of Medical Royal Colleges, Marie Care Cancer Care, 2014).

Identifying the dying patient has recently been complicated by the national context, where the quality of care offered to seriously ill people in hospital has been the subject of two national reports (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) (Keogh, 2013), as has the care of the dying person (Neuberger, 2013). The possibility of poor care of the dying and its high media profile means patients and families can be worried about the care they might receive and may be more inclined to challenge clinical opinion.

Thus HCPs working in hospitals face both a pressure to identify the dying patient and care well for them, but a simultaneous pressure to prevent premature death or cause avoidable harm. There is a lack of advance care planning, and so hospital HCPs are left working out the decision-making from scratch. They also have to face the potential for families to challenge their decision-making and know that the family's voice is prioritised - the bereaved relatives perspective of the care is evidence of the quality care given to dying patients. HCPs are faced with a constant pressure to discharge patients to care outside of the hospital, as soon as this is possible, to free access to beds for patients in Accident and Emergency. If they recognise that a patient is dying, there may not be access to a seven day a week, specialist palliative care support for assistance with complex symptom management, psychological distress or family support (Health and Social Care Information Centre, Academy of Medical Royal Colleges, Marie Care Cancer Care, 2014).

### **Let's address the confusion - definitions of end of life care, palliative care, death and dying.**

Confusion exists about definitions of end of life care, palliative care, death and dying (Neuberger, 2013). 'End of life' has been defined nationally as being in the last year of life (Department of Health, 2008). The difficulty in identifying in advance if someone is in their last year of life is shown in a retrospective study of all in-patient deaths in a District General Hospital between June 2006 and May

2007. This identified that 56% of patients were not assessed as meeting the criteria for being in the last year of life, at the point of death. Of the remaining 44% only 26% were clearly in the last year of life (Abel, Rich, Griffin, & Purdy, 2009).

Palliative care “is an approach which improves the quality of life of patients and their families facing problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual...it affirms dying as a normal process and intends neither to hasten or postpone death” (Ellershaw & Wilkinson, 2003, P.xi). Palliative Care Teams in hospitals help ward medical, nursing, therapy and social work teams with complex symptom management, psychological distress and care of families, and whilst palliative care is applicable early in the disease process, in hospital care a large proportion of the patients have the potential to be in the last months of their lives and many imminently approaching the end of their life.

Death has been well defined physiologically as the absence of cardio-pulmonary and neurological function (Academy of Medical Royal Colleges, 2008), yet the concept of dying is not well defined. It is acknowledged as a process rather than an event (Academy of Medical Royal Colleges, 2008). For cancer patients, it is often thought of as being the last hours and days of life, when the patient is bedbound, semi-comatose, no longer able to take tablets and only sips of fluid (Ellershaw & Wilkinson, 2003). For patients with non-malignant disease it is less clearly defined, it is usually when the patient is not improving despite best clinical management, and it is recognised when the whole multidisciplinary team identify the patient as dying (Ellershaw & Wilkinson, 2003). Others define it as being in a state of uncertain recovery despite active treatment and at risk of dying (Guy's & St Thomas' NHS Foundation Trust, 2012).

### **Why identifying that a patient is dying is clinically important for the patient**

Identifying that the patient is dying, or is sick enough to die (Krawczyk & Gallagher, 2016) is clinically important. The reason for this is that when a patient is likely to benefit from treatment and improve both clinically and functionally then the aims of care are three fold. The first is to increase survival and reduce

hospitalisation. The second is provide a level of symptom management, but in this case more discomfort is tolerated to minimise any complications from side effects e.g. if analgesia made a patient very sleepy and likely to fall post a hip operation then the analgesia would be changed to one that made the patient less sleepy even though they may be slightly more uncomfortable. The third is the restoration of independence and function. The role of families in the care of patients whose condition will improve as a consequence of treatment is limited and is usually one in which information is imparted either about the patient's condition, or an assessment of their role in the discharge plan.

When the patient is recognised as dying then the aims of care are reorganised. Firstly the aim is to achieve the patient's wishes e.g. preferred place of death. The second is to provide expert symptom management, but in this case side effects of medicines are tolerated and sometimes the drugs are used because of their side effects e.g. if a patient is nauseated and agitated then an anti-emetic drug that sedates would be the drug of choice. The third is to provide holistic care that includes spiritual support, financial and legal preparation for death. Families are involved in the care and there is pre-bereavement support for family and carers, and potential preparation for organ and tissue donation and for care of the body after death. The length of survival time has the potential to become less important and may be traded to achieve patient wishes e.g. a patient with a new untreatable cancer, and with long standing renal failure needing dialysis, may decide that travelling three times a week for dialysis is not how they wish to spend their time and so may choose to stop this treatment knowing their life will be shortened.

Within the district general hospital where this research took place there were approximately 1,500 admissions per week, and there were approximately twenty two deaths per week (55% of all deaths in the locality) (National End of Life Care Intelligence Network, 2012b). Ward based medical and nursing teams were thus required to identify, in amongst a large number of patients moving through the hospital services (from Accident and Emergency, to the Acute Medical or Surgical Unit, to the wards and then to discharge) (Karakusevic & Edwards, 2016), which of the patients may be dying and then manage the patient and the family appropriately. This is very skilled work. In the District General Hospital where this

research took place there was access to seven day a week face-to-face palliative care support.

### **Who can recognise dying and initiate decision-making?**

There are multiple categories of people who can recognise end of life, and that the patient is likely dying. These might be the patient, their family, registered nurses and allied health care professionals, social workers and carers, and the medical team including the consultant. Whilst nurses regularly recognise dying and “plant the seed” of thought with consultants (McMillen 2008, p.254), and they also facilitate communication, and co-ordinate meetings to negotiate end of life decisions (Long-Sutehall et al., 2011), it is though the consultants’ medico-legal responsibility to recognise end of life, in conjunction with the multi-disciplinary team and facilitate appropriate decision-making and clinical care (General Medical Council, 2010).

There are three broad categories of decisions that doctors and patients are required to make at the end of life. The first is what treatment options are and are not in the patient’s best interests and where those treatment options can occur. The second is whether cardio-pulmonary resuscitation is now likely to be futile and a “Do Not Attempt Cardio-Pulmonary Resuscitation” decision needs to be made and communicated by the Consultant. The third is the patient’s wishes for their care including where they would prefer that care to take place.

### **Trajectories of dying**

Murray et al described three trajectories of dying (Murray, Kendall, Boyd & Sheik 2005). Firstly, they described the cancer trajectory where function is maintained at a high level and then there is a rapid, predictable and steady decline and death is easy to predict. Secondly they described the long term condition trajectory where there are rapid dips in function at an acute illness; and where there is recovery with treatment, but the former function is never regained. The third trajectory is the dementia trajectory. This is one of slow decline, where baseline function is low and there are slight dips and slight recovery and death is hard to predict as the person is so close to death at any time. The sudden death trajectory is not included in Murray et al’s work, and for a quarter of our population death, occurs as a



“surprise and unplanned for event” (National End of Life Intelligence Network, 2011). People are living longer and with multiple co-morbidities and so trajectories can combine.

### How good are doctors and nurses at predicting dying?

HCPs are not accurate when predicting dying. In a prospective cohort study of 504 terminally ill patients (the majority of patients had cancer or AIDS) admitted to five out-patient hospice programmes in the USA, and their 365 doctors, it was found that only 20% of the doctor’s predictions were accurate: 63% were over optimistic and 17% over pessimistic. The prognosis was only given to the researcher not the patient. This is important as there is the desire to prognosticate to make good clinical decisions, and the decision to tell the patient – “foretelling and forewarning” (Lamont and Christakis cited in Krawczyk & Gallagher, 2016). These are two different things. Multivariate modeling showed that most types of doctors are prone to error in most types of patients. The greater the experience of the doctor the greater the prognostic accuracy, but a stronger doctor-patient relationship is associated with lower prognostic accuracy (Christakis & Lamont, 2000).

In the UK, a prospective cohort study in four multi-professional palliative care teams in England collected data on 275 consecutive cancer referrals who died. They found that offering a prognosis range had higher levels of accuracy (about double) than traditional estimates, but was still very often inaccurate, except when the patient was very close to death (less than two weeks) (Higginson & Costantini, 2002).

In a UK study that focused on cancer patients, the ability of multidisciplinary teams, doctors and nurses to predict life expectancy were compared. On average all practitioners were correct in a little over 50% of cases. Nurses were less accurate than the Multi-Disciplinary Team (MDT), but were no worse than doctors. Estimates of clinicians and patients were more optimistic, than pessimistic. Nurses’ accuracy increased if they had reviewed the patient within 24 hours. Most patients (61.4%) wanted to know their prognosis, but only 37.1% were willing to offer an estimate regarding their own survival. Patients’ prognostic estimates were

less accurate than health care professionals' (Gwilliam et al., 2013).

It should be noted though that there is evidence that ethnicity, faith and culture of healthcare professionals affect both prognostication and decision-making at end of life (Seale, 2010). In a prospective observational pan-Europe study in Intensive Care Units it was found that a “withholding treatment” decision occurred more if the doctor was Jewish, Greek Orthodox or Muslim and a “withdrawing treatment” decision occurred more often if the doctor was Catholic, Protestant or had no religious affiliation. A possible cultural influence was noted as Jewish doctors withdrew care in 36% instances in the north as opposed to 6% in the south of Europe. Interestingly, religion appears to affect how decisions were discussed with families. There were more discussions with families if the doctor was Protestant, Catholic, had no religious affiliation or were Jewish (Sprung et al., 2007)

The ability to prognosticate accurately remains a concern for clinicians and in specific non-malignant disease groups clinicians have worked hard to generate identifiers of dying (Murphy, Mydin, Fatah, & Antunes, 2010). HCPs retain a desire to be able to be accurate, and are still pursuing a statistical approach to this topic (White, Reid, Harris, Harries, & Stone, 2016) (Taylor, 2012).

### **Patients and the introduction of their families**

People mainly approach their dying period as part of a network of family and friends. Patients vary, but many do not approach their dying period with mental capacity to take part in decision-making and their care is underpinned by the Mental Capacity Act 2005 (British Medical Association, 2008). Patients may have lost mental capacity as part of a long-term condition, or temporarily lost mental capacity as part of an acute deterioration.

Families can have a formal role in decision-making when a person has a lasting power of attorney (LPA), particularly for health (but it can be for placement issues when the attorney is for finance), as they are responsible for decision-making on behalf of the person when they lose capacity. The Consultant responsible for the medical decision-making can only formally challenge the decision-making of the

LPA on behalf of the patient in the Court of Protection. However, patients can lose mental capacity to take part in decisions, without having established an LPA. In those circumstances families are consulted – in a best interests manner about what they think the patient would have wanted had they been able to express their wishes. The Consultant legally retains control of decision-making.

Ethnicity, faith and culture of patients and families affect decision-making. Deaths in hospital are larger for non-white groups (even when controlling the data for other factors (age, gender, socio-economic group) (National End of Life Care Intelligence Network, 2012a). This may be because there is a more frequent desire for active intervention and life sustaining treatments in African American and Asian groups (Connolly, Sampson, & Purandare, 2012); there are barriers both in terms of relevance and access of community palliative care services to Sikh and Muslim patients and their families, but also Sikh and Muslim patient and family barriers e.g. a reluctance to discuss end of life care and a reluctance to ask for help (Worth et al., 2009); and larger extended networks of families lead to less coordinated help and a fear of dying (Bowling, Iliffe, Kessel, & Higginson, 2010). Families can control information being given to patients for fear of them giving up hope - this can be explicitly done through not translating accurately (Worth et al., 2009) or through asking professionals not to tell the patient everything.

In the current health and social care system, patients and families are mainly interdependent if the patient wishes to die at home (or has previously expressed this wish) (Gomes, 2006). Health and social care agencies can rarely provide 24-hour care at home in a patient's home that can meet the dying patient's care needs. Whilst most patients express a preference to die at home and 80% do not change their mind (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013) (Grande, Ewing, on behalf of the National Forum for Hospice at Home, 2009) care needs to be taken about a discharge decision. The reason for this is that there is a balance between achieving the patient's preference and the impact of this decision for the carer. It is acknowledged that families can decide to care for someone at home without really understanding the implication (Gomes et al., 2013). Carers mental and physical well-being in bereavement was less determined by the achievement of death at home, than by the provision of psychological support to the carer during this time

(Grande et al., 2009). If a patient loses capacity, it should be noted that the tendency is for institutional rather than home death, with the relative feeling the patient died in the appropriate place of care (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005).

In the sections below I will consider what is known about the recognition of dying and the negotiation of decision-making about the three patient groups mentioned above; those who have capacity to take part in decision making, those who have lost mental capacity due to a long term condition, and those who have lost capacity due to an acute deterioration.

### **What the literature tells us about HCP decision-making with patients who have capacity.**

Research into the experience of the older person who has capacity has started to formally articulate what it is like living through repeated hospital admissions. This has relevance for those who are unwell with cancer or a long-term condition where treatment options are becoming limited. There is description of “Living betwixt and between” – a state of imbalance between active living and clinically recognized dying (Nicholson, Meyer, Flatley, Holman, & Lowton, 2012 p. 1426) where people work hard to remain socially connected within and outside of their homes. There is a description of feeling “let down” by the hospital system that sometimes cannot offer a treatment in their best interest, because it would make the clinical situation worse, and thus the person is left with a mind that is able and a body that is increasingly unable. Sometimes though, it is the lack of treatment options that can prompt patients and families to think that end of life might be approaching (Fried & O’Leary, 2008). It is also described as focusing on “trying to keep going”, unable to decide about preferences for death as they have no idea what the dying will look like (Nicholson et al., 2012), and of not wanting to discuss decisions e.g. Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) yet wanting to be involved in the end of life decision-making process, and of personal beliefs and values affecting how decisions such as DNACPR can be made (Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005). There are descriptions of people wanting to live hopefully (Cook, Damato, Marshall, & Salmon, 2011) but

acquiescing previously strongly held wishes at physical crisis points (Drought & Koenig, 2002) when they are staring death in the face.

Lowson has described the older person's view of the role of the family. They are usually the spouse or daughter, and are seen as hugely important and described as the "orchestrators" of care in the patient's home setting (Lowson et al., 2013). Patients are reliant on them and value them as they manage and support everyone who is involved in the older person's care. They are also able to persuade the patient to accept assistance when they might have been resisting such intervention. Lowson has also described families as being relegated to "second fiddle" when the person comes into hospital as their access to the older person is restricted by visiting times and by other paid professionals taking over the care e.g. helping the patient with meals (Lowson et al., 2013). It appears from Hanratty's study, that simultaneously, having taken the responsibility away from family members, that HCPs do not treat the patient with the same amount of listening, detail and care, leading to unhappiness and dissatisfaction with care when the patient is transferred out of the hospital as the handover does not match the patient's needs (Hanratty et al., 2012).

Neither Lowson's nor Hanratty's research identified conflict within families. All patients were positive about their families as carers. Fried has highlighted that some patients and care-givers do not communicate well and that this can cause tension (Fried & O'Leary, 2008). From the experience of clinical practice, it is known that there is the need to remain vigilant to the patient voice separately to the family voice, and a time in hospital can be a time to hear the patient's views and wishes alone. This is particularly relevant when carers who love the patient may have reached the brink of their caring ability and need support to continue. Sometimes a carer only becomes known as a carer when their ability to care breaks down and the patient is admitted to hospital (Joyce, 2006). Patients can be reluctant to burden other family members (Winter & Parks, 2012) and unless the person is carefully heard the relatives can want more treatment than the patient wants. Patients do not always want the treatment options available to them – they can be tired of living (Fried & O'Leary, 2008).

Patients can make brave decisions about their dying care and face their dying where it is known and expected (Clinch & Le, 2011). This can be helped by mutually informing the patient and family of the patient's prognosis and the way forward (Heyland et al., 2009). However, there is evidence that patient's wishes can be abrogated when they ultimately become unconscious. This is because it is hard to watch someone who has chosen that they do not want life prolongation at the point when they deteriorate to unconsciousness, and especially if there are treatment escalation options open to them (Abadir, Finucane, & McNabney, 2011). The importance of this is that professionals can negotiate and stand for a patient's wishes against the family if the professional knows the patient and their wishes well. This is further complicated as there is evidence that patients can subjugate their previous wishes for end of life care, when their families long for life prolongation (Abadir et al., 2011).

Patients, who are competent but cannot communicate verbally, form a particularly vulnerable group with respect to decision-making. In an ethnographic study in ITU, Sorensen found that doctors avoided talking to competent dying patients because it was time consuming, and a very difficult conversation for the doctor, especially if the patient is not ready to die. There was evidence that when doctors speak with family members and ignore patients it does affect nurses and doctors working relationships. Sorensen describes professionals as living with "guilty knowledge" (Sorensen & Iedema, 2011, p.13).

### **What the literature tells us about decision-making with patients who have lost capacity through long term illness**

Decision-making in the context of the patient who has dementia is always complex. Mental capacity is decision specific – clearly the requirement for capacity to decide whether sugar is wanted in a cup of tea is different to the capacity required to make an informed decision about place of care. The question then remains as to whether the person's wishes are as they were when they were competent or as they are currently.

It is argued that the decision making for the person with dementia is not a one off event but a continual and on-going process evidenced within the interaction of the

patient with their physical care environment and through the relationships the patient has with their clinician, family and carers (Muramoto, 2011). Some family members have made decisions with and for the patient (and sometimes despite the patient, when the person with dementia cannot safely manage at home and has required placement in a care setting which not have been their choice). These decisions may have been about access to dementia related health and social care, legal and financial matters, and non-dementia related health care. End of life decision-making can thus be the last of many decisions a families will have to make and it is identified as being “very difficult” (Livingston et al., 2010, p.8).

Families of patients with advanced dementia identify being unprepared for decision-making at end of life – they did not know what was expected of them, they were not given any explanation of their role by the medical team, but they did very much want to be involved in the decision-making (Caron, Griffith, & Arcand, 2005). Families have described five different ways they make decisions (they are not mutually exclusive). These are previous conversations, reliance on written documents, shared experience and life values, family’s own beliefs, values and preferences and involvement of other family members (Vig, Taylor, Starks, Hopley, & Fryer Edwards, 2006).

It is important to recognise that not all families work harmoniously together, and family conflict is identified as an impediment to decision-making (Livingston et al., 2010) (Klager, Duckett, Sandler, & Moskowitz, 2008). It is also noted that generically solving family conflict is unhelpful but giving families resources to address specific challenges is useful (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007).

### **What the literature tells us about decision-making with patients who have lost capacity through acute illness**

The key role of the family in decision-making about the care of the acutely unwell patient is recognised (Truog et al., 2008). Usually this takes place in the form of formally organized “family meetings” once it is recognised that significant decisions need to be made. These meetings are usually only instigated about treatment withdrawal or withholding and rarely about the decision to escalate

treatment (Kryworuchko, Stacey, Peterson, Heyland, & Graham, 2012). The significant point about having the rare meetings to consider a decision to escalate treatment is that families may experience false hope that their loved one might recover.

Facilitating these meetings is skilled work. Family members can have different information requirements, and play differing, informal roles. Several roles have been identified although one family member may play more than one role. The roles are primary caregiver, primary decision maker, family spokesperson, out-of-towner, patient's wishes expert, protector, vulnerable member, and health care expert. The lead clinician may need to spend time helping the family decide who is to be the primary decision maker (Quinn et al., 2011).

The meetings are not about shared decision-making but the clinician increasingly taking the responsibility for the decisions and for ascertaining the preference for the family about their role in such a meeting (Curtis & Vincent, 2010). They are about taking all opportunities to empathise (Selph, Shiang, Engelberg, Curtis, & White, 2008) and to provide understandable and consistent information (Kryworuchko et al., 2012). It is vital to pay close attention to the language used by families and reframing this where needed e.g. 'letting die' rather than 'killing' (Hsieh, Shannon, & Curtis, 2006), and to listen and respond to families and address their emotions, to provide reassurance that the family will not feel abandoned and to address medical ethics (Curtis et al., 2005). When these features do not occur, families can be dissatisfied (Selph et al., 2008) (Curtis et al., 2005). Family meetings take time to set up and there is evidence that some particularly proactive families "chase doctors" (Limerick, 2007) to gain information.

The process of decision-making by families has been described as "arriving at a new belief that active care is futile; retreating into oneself to make a decision and communicating the decision to the health care team" (Limerick, 2007, p. 335). This process can take time (Kryworuchko et al., 2012) and has been described as a "turning point" (Hiltunen cited in Limerick, 2007). Families do not have to make a decision but they must agree the decision that the consultant and team have made.



The turning point can be influenced by a variety of factors including assessment of quality of life, family and friends' opinions and such factors as personal beliefs.

### **How quickly does a decision need to be made about the potential of a patient to be dying?**

The process of becoming physically unwell enough to require admission to hospital can mean that patients can give up their wish or their choice to be at home. At the point where the patient comes into hospital (usually through the Emergency Department (ED)) they will likely not be known to HCPs there, and an immediate clinical decision will need to be made about whether the patient is a candidate for life prolonging treatment; life prolonging treatment, but with acknowledgement the patient is likely dying and there will be a low threshold to care for the dying patient; or the patient is dying immediately and needs all comfort. It may not initially be possible to decide whether this admission represents an admission for end of life care and this might only become clear if the patient does not recover despite the medical treatment offered.

The trajectories of dying identified by Murray et al (Murray et al, 2005) are unhelpful in the ED as they are over too long a time frame and do not illuminate the complexities of decision making that have to be made very rapidly at an imminent "end of life" decision-point. Trajectories of dying have been described specifically for Emergency Departments (ED) to help HCPs recognise the clinical situation and initiate conversations with patients (if possible), the family and wider healthcare team (Chan, 2011). The trajectories described by Chan are that the patient is dead on arrival; the patient is admitted to the ED with subsequent death there; the patient has a pre-hospital resuscitation with survival until admission and death pronounced in the ED; the patient is terminally ill and comes to ED; the patient is frail and hovering near death; the patient is alive but arrests in the ED; or the patient has a potentially reversible death by omission or commission

The categories related to the patient who is terminally ill or frail and hovering near death in the ED are particularly relevant. These dying periods and deaths have been described as "subtacular", and contrasted with the "spectacular" dying periods and deaths where all staff efforts are concentrated on resuscitation

(Bailey, Murphy, & Porock, 2011) (the majority of ED deaths). In a year-long study which involved ethnographic observation of care within a UK ED department and interviews with staff, patients and carers, Bailey identified that staff within the ED department segregate those dying “subtacular deaths” to different areas of the ED, and offer them lesser standards of care. Bailey suggests that the relatives of patients who are dying the “subtacular deaths” are present for much longer periods than the spectacular deaths and thus require information and support for a longer period. She observed staff protecting themselves from building a therapeutic relationship, and suggested they did this in order that they did not experience loss themselves (Bailey et al., 2011).

### Previous research to develop clinical practice

#### At the start of this PhD

There had been three research projects (Curtis et al., 2011; Jacobowski, Girard, Mulder, & Ely, 2010; Quenot et al., 2011), which have trialled an intervention to see whether end of life practice can be developed by that intervention. Curtis targeted clinicians in ITU in twelve hospitals and introduced education, local champions, academic support, and feedback of clinical data. Outcomes were assessed for patients within 30 hours of death and their families were surveyed too. There was no measurable change in the quality of dying or family satisfaction with the care. The authors proposed that future work should focus on direct contact with patients and families (Curtis et al., 2011). Jacobowski evaluated the outcome of allowing the family to be present for consultant ward rounds on ITU. For families who were bereaved on ITU the inclusion on the ward round did not improve their satisfaction with care and it was found that some families felt rushed to make a decision (Jacobowski et al., 2010). Neither study evaluated the effect of the intervention on the well being of staff.

One research project (Quenot et al., 2011) trialled a range of supportive interventions for staff who cared for patients in ITU over a two year period (integrating palliative care into ITU, focusing on communication, psychological support of staff, teaching about ethical decision-making, promoting staff meetings) and the incident of staff ‘burn out’. Depression in staff was markedly reduced

indicating that facilitating communication on a unit that cares for patients has a positive effect on staff well being. This study did not evaluate the impact for patients and carers.

### Current research

Since starting this PhD the interest in recognising dying and sustaining practice change has continued to appear in the literature. Professor Kennedy has undertaken a literature review, following a PRISMA standard for reporting (Moher, 2010), about how dying is recognised (Kennedy et al., 2014) – the very question I am interested in answering. She, in collaboration with eight other researchers, surveyed 576 papers from 2001 to 2012 and ultimately included 23 papers and following a themed analysis generated a conceptual map which she suggests needs further testing. The concept map highlighted the uncertainty of decision-making, and factors that affected the decision-making. These included professional factors such as fear, and doing the wrong thing, the local context and the patient's illness trajectory. These have similarities with the findings of this PhD. She suggests strategies to help decision-making. These are education, integration of palliative care, and defining roles and responsibilities, and have parallels with where I anticipated at the start of the PhD that I would have answers.

In another evaluation of practice development in end of life care, Dr McConnell interviewed twenty HCPs and two policy makers about their experience of implementing the Liverpool Care Pathway (LCP)<sup>2</sup> in an acute trust (McConnell, O'Halloran, Donnelly, & Porter, 2014). The results of the first set of interviews were themed and integrated with the literature review to present theories about how to implement and sustain change in good clinical care of the dying patient, and these and were re-presented to the same participants. This is a similar methodology to that which I initially used. She identified that facilitation of the use of the pathway was important and when the funding for the facilitator had stopped the recognition of dying and use of the paperwork decreased too. This had been my own experience of clinical practice. The methodology used to investigate the

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<sup>2</sup> The LCP was designed by Dr Ellershaw to transfer best practice in the care of the dying from a hospice setting to the hospital setting. It required that dying was identified so the care pathway paperwork could be used.

question was similar to my own. She identified that key enablers were: consistent senior management support; on-going education and training that was profession dependent; audit; and an organisational change in the hospital to embrace end of life care. The findings of her study resonated with Dr Susi Lund's literature review which identified that the ability of HCPs to engage patients in advance care planning is impeded by competing demands of other work, the emotional nature of the HCP-patient work and challenges in sharing decisions and preferences within and between health care organizations (Lund, Richardson, & May, 2015). Both studies identify that a clinical facilitator, with responsibility for practice development about the end of life care initiative (advance care planning or end of life care), is essential to sustained practice change. Whilst acknowledging the practical resource and the physical presence of a skilled HCP to drive change, neither author has a language to explain why, when the role disappears, that engagement with the care of the dying also disappears.

The concept of working with uncertainty around the recognition of dying has been more firmly introduced (Krawczyk & Gallagher, 2016), with evidence from working with bereaved family members that they would have preferred to have known the prognosis was uncertain, even if they would have resisted this information at the time. The challenge here is that the group surveyed had all been bereaved, and patients had not survived the prognosis of dying.

Other researchers have identified that lead HCPs (not palliative care) are recognizing their own lack of skills at being able to prognosticate for patients who have diseases that particularly affect low socio-economic groups e.g. liver cirrhosis (Low, Vickerstaff, Davis, & Bichard, 2015). Other researchers (Parry, 2016) are endeavoring to understand how experienced palliative care specialists talk about end of life in a sensitive manner, in order that this can be taught. Interestingly this has echoes of what I had initially hoped to achieve through this PhD, namely that best practice could be embedded into teaching practice.

In the time since the PhD has started there is a renewed interest in the well being of HCPs' emotional functioning with NHS organisations. The relevance of this to this PhD is that the spoken and unspoken anxiety of the NHS has been publically

named, as has the tension when families demand care, that doctors and nurses do not believe in the best interests of the patient (Wren, 2016). 'Schwartz rounds' have been gradually introduced into UK clinical practice since 2009. The premise of the 'Schwartz round' is that in a carefully prepared one hour meeting (led by an organisational clinical psychologist and medical consultant) held once a month, HCPs are invited to present a case that has meaning to them and likely to others in the organisation. Attendance is voluntary, but in my current trust approximately one hundred HCPs attend per month. In this hour, there is a space created for the telling and hearing, and sometimes the processing of emotionally impactful experiences, whilst acknowledging the creativity and meaningfulness of clinical work. In the book *"True Tales of Organisational Life"* (Wren, 2016) seven case studies are presented – three pertain specifically to death and loss, one to misplaced anger from a patient, one about a complaint regarding communication when the doctor was under the most extreme personal pressure from both a respected senior colleague and his father dying, and the final one was about the loss of a long standing source of expertise (Nurse Consultant in Palliative Care) after 27 years in clinical practice. HCPs are themselves, independently highlighting, that the topic of this PhD is something that is unusually challenging for them, their colleagues, patients and families and the organisation.

Other practitioner-researchers are realising the benefits of paying attention to the emotional impact of learning. Dr Jo Hockley has evaluated the learning subsequent to de-briefing care home staff after the death of a resident (Hockley, 2014). She held a reflective de-brief at the start of an afternoon shift five to ten days after a resident had died. The aim of the group was "to use the experience of caring for a resident who had died as a basis for learning about end of life care; to be a place where death and dying could safely be discussed and to construct knowledge about caring for frail, older people who were dying" (Hockley 2014, p120). She found the groups facilitated learning at three different levels, - being taught, developing understanding and critical thinking. Staff also felt supported and valued.

## Summary and rationale for research question

Recognizing that a patient is dying is vitally important to ensure that there is potential for a “good death”, the patient can be involved in decision-making if they can and wish to be, that the patient is not subjected to futile and painful investigations or treatments, and there is some potential to think about care outside of a hospital setting, putting affairs in order, and preparing the family.

Whilst there is a national strategy for excellent end of life care, this chapter has covered the many policy drivers that in hospitals have the potential to confound this. In the context of the District General Hospital where this study took place, HCPs are required to identify dying in the enormous volume of patient care, and where the number of deaths is only 1.5% of the patients admitted in a week. Also, in the hospital there is the policy drive to rapidly discharge patients for “care closer to home” to ensure flow of patients through the hospital and availability of beds for other patients. Even if GPs made advance care plans with all the 1% of their population who they anticipated being in the last year of life, this would still be a small percentage of those who die in hospital every year, and so hospital HCPs bear the responsibility for decision-making and care.

It appears from the literature on prognostication and disease trajectories that HCPs have been interested in accurately prognosticating, and recognising dying for many years, but it continues to be a very challenging area of clinical care that is resistant to accuracy. It appears from the literature on advance care planning that HCPs are supportive of the idea of introducing conversations about the future with patients and yet these are difficult to realise. We know from repeated national audits that HCPs in hospitals are identifying dying in a range of only hours to a short number of days pre-death and this is resistant to change. This is challenging clinical work worthy of a through understanding.

The care of the dying patient is under-pinned by the Mental Capacity Act (2005). Since patients rarely retain capacity to engage in decision-making until they die, this introduces the family in a formal way into the decision-making regarding dying either as a Lasting Power of Attorney or in a best interests manner. The literature review indicated that even when the patient retained capacity to take

part in decision-making, they may not wish or be ready to do this, they might have complicated feelings about their experiences of care that could affect the conversation, but some could make decisions. There was evidence that the HCP could avoid discussing dying with the patient, preferring to speak with the family. The literature about HCPs experience of working with families is limited. The literature indicates that patients view their families' role in their care in a positive manner, and that the NHS marginalises families from the patient's care whilst they are in hospital. There were hints from a number of papers that families do not always agree, or support patient wishes, and that they could influence HCPs to not follow what the patient previously wished. Also this work with patients and families could occur in a very time compressed manner in such places as the ED, and that those patients who were dying from frailty or terminal illness could be segregated and they and their family receive a poorer standard of care. Thus the interaction of the HCP with the patient and family is challenging clinical work and worthy of study.

It is important to note that decision-making about dying and care is affected by culture, faith and ethnicity, both on the part of the HCP and the patient and family. This study was mindful of this but the intention was not to focus on this.

Thus in this study I specifically wanted to ascertain:

How senior HCPs actually recognise dying. This includes what underpinned their decision that the patient was dying and their personal response to this. Also whether the dying was initially recognised by the healthcare professional or pointed out by another member of the team, patient or family.

How senior HCPs engaged with patients and families to progress decision-making.

How senior HCPs continued to maintain the relationship with the dying patient and their family.

How senior HCPs learnt to identify dying and support patient and family care

Whether senior HCPs could identify any gaps in service provision, training and support that impede the identification of dying.

The literature review of interventions to improve clinical practice in this area of care both indicate the length of time this has been a concern in clinical practice – the first paper was published in 2010 – and the ramping up of research in the last seven years with increasing attention being paid to the emotional consequences for HCPs of undertaking this work. I was, at the start of this PhD and remain, very interested to investigate how senior healthcare professionals actually recognise dying and engage patients and families in the negotiation of key decisions. I want to be able to move practice on. I recognise that since starting this PhD, key tenets of my interests are replicated in studies undertaken by others – the research question is replicated (Kennedy et al., 2014), the methodology similarly replicated (McConnell et al., 2014), the recognition that sustained practice facilitation is key to sustainable change (Lund et al., 2015), my hopeful desire of a “teachable outcome” (Kennedy et al., 2014), and the key role that paying attention to the emotional impact of clinical care has on the ability to learn and keep engaged in clinical care (Hockley, 2014; Wren, 2016). Wren and Hockley’s work on safely contained emotion debrief after a significant event, yield a helpful, if time intensive approach to learning from clinical practice. None of the other authors though have novel or creative solutions that help reframe clinical practice in a way that is helpful to HCPs, patients, and families. Alongside the plea to National Institute of Health Research to fund evidence based care in the care of the dying (Higginson, 2016), the research of the past six years keep HCPs where they currently are – doing more of the same, and probably in this current economic climate with less resource.

Initially, I evaluated how senior HCPs utilised and evaluated PAR as a means to develop clinical practice. Without disclosing the results, there were though things that kept occurring in the data that didn’t make sense to me e.g. the time where dying was not identified, the level of distress when HCPs felt with hindsight they had made a wrong decision, and when they expressed taboo wishes to break ethical principles, but with good intent. In order to understand the data and generate new solutions for clinical practice I then moved to a psychosocial analysis of the data to place the HCP at the centre of the study and consider whether



identifying dying, and negotiating decision-making with the patient and family was influenced by less than rational, and psychologically defensive processes.

## Chapter Three – Methodology and Methods

### Introduction and reminder of research question

In Chapter Two the necessity for the research was clarified. The increasing demographics of an aging and multiply co-morbid population mean the care of the dying patient is an ever-increasing occurrence in a hospital system whose outcomes are focused on restoration to health and function, and cautioned against early mortality. The positive national policy drives for “good end of life care”, with “care closer to home”, make it difficult to think about less rational influences on identifying dying, and working with patients and families. The evidence showed that clinicians are not good at prognosticating. The chapter considered what was known about recognising dying and negotiating decision-making for adults with mental capacity to take part in decision-making, adults without mental capacity due to a long-term condition and adults who have temporarily lost mental capacity due to an acute event. It considered the family’s role in the decision-making, and then highlighted the rapidity and intensity of the clinical care and decision-making in areas such as the Emergency Department. The chapter articulated how the first part of the research question had not changed over the course of the research. Thus in this study I specifically wanted to ascertain:

How senior HCPs actually recognised dying. This included what underpinned their decision that the patient was dying and their personal response to this. Also whether the dying was initially recognised by the Health Care Professional (HCP) or pointed out by another member of the team, patient or family.

How senior HCPs engaged with patients and families to progress decision-making, and how they continued to maintain the relationship with the dying patient and their family.

How senior HCPs learnt to identify dying and support patient and family care, and finally, whether senior HCPs could identify any gaps in service provision, training and support that impede the identification of dying.

Chapter Two then considered the research that previously endeavoured to develop clinical practice. In response to the gaps in the literature I initially researched how

senior HCPs utilised and evaluated Participatory Action Research (PAR) as a means to develop clinical practice. Then when the themed analysis yielded a result that left clinical practice doing more of the same, a psychosocial enquiry approach was taken to the data.

### Research Paradigm

The PhD utilised a transformative and pragmatic paradigm (Mackenzie & Knipe, 2006) to hang the research on (top down approach). The methodology was iterative, and reflective, careful conduct of the research (bottom up approach) was required to yield new observations of clinical practice. A considered approach has been taken to the manner of the research (Frankfurt, 1998). I have been concerned that the research is helpful for HCPs and clinical practice, both in its conduct at the time and in the writing up. Senior HCPs can be emotionally exhausted from clinical practice (Pereira, Fonseca, & Carvalho, 2011), and I did not want to be an “expert” that took part in the current culture of “naming, measuring, acting, blaming” (Bibby, 2011). I used the premise that it was “faster and more straight forward to go through the front door of enthusiasm” then to use “the back door of low morale” (Ludema, Cooperrider, & Barrett, 2006, p.158) and thus framed the research within an appreciative, enquiry manner (Ludema et al., 2006). Reflection is now mandatory for medical and nursing revalidation (Nursing & Midwifery Council 2014; General Medical Council 2012), and so evidence of reflection was captured by individual HCPs through this study to add to their professional portfolios.

This research has taken a psychologically safe approach. The continual process of researching practice is part of the professional’s role (Dadds, 2005). Most professionals use others’ research to influence their practice, rather than research their own practice. In this research I, and other participants, were the researchers and the researched. The need for ethical sensitivity and courage were recognised in advance, as it is hard to separate the person from professional clinical decision making and care (Dadds, 2005).

## Orientation to the research process

Ahead of explaining the methodology and method in detail, the overall research process is introduced for the orientation of the reader. In Study One, thirteen senior HCPs undertook a critical incident review. These involved the ward based senior HCP who identified dying, and the Hospital Palliative Care Team (HPCT), who are the HCPs subsequently involved in the patient's care. Interviews were recorded, transcribed and themed. In Study Two senior HCPs across the hospital were invited to four consecutive PAR workshops to critically reflect on the themed data from Study One. Ten HCPs took part (three HPCT HCPs were involved in both studies). The interviews were similarly recorded, transcribed and themed.

The themed analysis yielded a model for decision-making but did not explain why dying was identified so late. A psychoanalytically informed psychosocial approach was taken to examine anomalies and contradictions in the data that pointed to less conscious undercurrents in the personal, professional, educational and institutional dynamics involved in the care of patients who are dying.

The consent forms, participant information, interview schedule for (Study One), and sample of posters as they went to the ethics department in the hospital are all located Appendix 2. A copy of the poster is included in Appendix 3. A copy of the participant feedback form is included in Appendix 4.

## Why Qualitative Research?

It is known from repeated national audits of clinical practice in the care of the dying in hospitals, that dying is being recognised less than two days from death (Health and Social Care Information Centre, Academy of Medical Royal Colleges, Marie Care Cancer Care, 2014; Marie Curie Palliative Care Institute Liverpool Health and Social Care Information Centre, Academy of Medical Royal Colleges, 2011). In the 2011 audit it was 29 hours from death, and in the 2014 audit it was 35.5 hours from death. From quantitative research we know the HCPs are inaccurate at prognosticating (Christakis & Lamont, 2000), although it does become more accurate nearer to death (Higginson & Costantini, 2002) and we have statistical evidence about the relative strengths of the accuracy of doctors,

nurses and even patients (Gwilliam et al., 2013). We have statistical evidence that the better a doctor knows their patient, the more inaccurate the prognosis (Christakis & Lamont, 2000). There is also evidence that doctors' prognosticating that the patient is dying and how they interact with the patient's family is affected by religious affiliation and culture (Sprung et al., 2007).

Doctors continue to want to hone their prognostic skills. Recent quantitative research has looked at physiological parameters e.g. blood results to see if they can assist in predicting dying more accurately, but the researcher still concluded that "the fluid, iterative and on-going nature of the decision and use of intuition are key factors influencing the recognition of dying" (Taylor, 2012, p.3). So quantitative data tells us some of the answers, but it cannot answer, "how do clinicians identify the dying" in order to begin conversations with patients and families or help us understand how HCPs learn to undertake this aspect of care, or progress clinical practice.

### **Why a Critical Incident Review?**

A 'critical incident review' is "one which causes a person to pause and contemplate the events that occurred to try and give them some meaning" (Elliott, 2004). It is a widely used exploratory research tool. It was originally developed by Flanagan in 1954 to analyse people's jobs with the aim of identifying the critical factors for job success and is recognised to be the start of a qualitative approach to a research question in a time in the social sciences that was inherently positivist (Chell 1998 cited in Spencer-Oatey, 2012). A critical incident review is a process that clinicians are familiar with (Mahajan, 2010) (General Medical Council, 2012) and I anticipated this would aid recruitment to the study.

The incident was the care of a patient referred to the HPCT by ward based HCPs, and the HPCT's assessment and understanding of the same clinical situation. The plan was to have a sample of six incidents (patient referrals) and thus twelve HCP interviews. The aim was to draw senior HCPs back to "how they made the decision in that circumstance about the recognition of dying" rather than talking generically about how they identified dying. The link between a referral to the HPCT and the identification of dying was based on the commonly misheld perception by a

majority of generalist HCPs that palliative care teams see all dying patients. Please note that HPCTs see all patients referred to them with palliative care needs and not all patients with palliative care needs are at end of life, they can occur pre diagnosis onwards (World Health Organisation, 2013). For each incident (patient referral), I invited the HCPs to be interviewed by me, and aimed to complete the interview in seven days, with the clinical notes present to prompt their memory recollection<sup>3</sup>. Since, I identified the incident I anticipated that it would not necessarily have the emotional impact or personal meaning for the HCP as per some definitions (Kirby, 2010).

### **Study one - critical incident review**

The aim of the 'critical incident review was ensure a) there was analysed data about the research question for the PAR workshops to reflect on. Also it was anticipated that HCPs were used to attending workshops with an element of didactic learning and having evidence to critique would be familiar to them and reduce anxiety. b) As researcher and facilitator I was informed ahead of PAR workshop of factors that were relevant and could refine facilitation of the workshops. c) I was also keen to ensure my unconscious unknowing, or any unconscious biases were exposed. Please note that at this stage this was not a psychosocial knowing but a more mainstream psychological way of knowing such as in the notion of fast clinical practice that becomes unconscious, and needs to be reconsidered (Stratton & Hanks, 2016).

### **Participants**

The study was open to all senior HCPs employed in one district general hospital<sup>4</sup>. For this study a senior HCP was defined as nurses, therapists, chaplains above band 6 (agenda for change<sup>5</sup>) and doctors who were in core and specialty training,

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<sup>3</sup> When considering the interview schedule for Study One in Appendix 2 – section one, question one - please recall the HCP had made the referral to palliative care and consideration was requested in the interview to “this specific case”.

<sup>4</sup> This was my place of employment

<sup>5</sup> Agenda for Change (AfC) is the current National Health Service (NHS) grading and pay system for NHS staff, with the exception of doctors, dentists, apprentices and some senior managers.

and consultants. Based on the literature that data saturation occurs at about twelve interviews I anticipated interviewing the six senior HCPs responsible for the referral of the six patients and also the corresponding palliative care specialist who contributed to the on-going patient and family care for each patient (Guest, Bunce, & Johnson, 2006). In reality I interviewed thirteen HCPs as two palliative care HCPs contributed to the care and decision-making of one patient.

Participants were asked for basic demographic data including the length of time since qualification on the professional register (GMC, NMC), role, band of role, area of clinical practice, and frequency of exposure to dying. HCPs were also asked for a perception of their comfortableness with caring for the dying. The aim was to match staff to the workforce groups identified in the National End of Life Care Strategy (National End of Life Care Programme, Skills for Health, Skills for care, Department of Health, 2009) i.e. Group A staff - working in Specialist Palliative Care, Group B – staff who frequently deal with end of life care and Group C – Staff who infrequently deal with end of life care.

**Table 1.** Summary of study one showing the participant’s length of time in clinical practice, their experience of end of life care and self rated comfortableness with dying. Each interviewee was labelled HCP 1 – HCP 13.

Interviewee (HCP)	Years practice in	Experience	Comfortableness with dying
1	26	Group A	At ease
2	Didn't answer	Group A	At ease
3	22	Group B	At ease
4	3	Group B	At ease
5	31	Group A	At ease
6	Didn't answer	Group B	Moderately at ease
7	13	Group B	At ease
8	23	Group A	At ease
9	6	Group A	At ease

10	15	Group A	At ease
11	14	Group B	Moderately at ease
12	27	Group A	At ease
13	Not returned	Group B/C	Not returned

It can be seen that for those HCPs who answered, that the staff had been in clinical practice for an average of 18 years (range 3-31). Seven described themselves as working in palliative care, 5 described themselves as frequently dealing with end of life care, and 1 did not return their form, but from my knowledge of their clinical practice would have been working between frequently and rarely dealing with end of life care. All working in palliative care described themselves as “at ease” with dying. Of the 5 who rated themselves as frequently working with end of life care 3 were “at ease” with dying, and 2 were “moderately at ease”.

### **Inclusion and exclusion criteria**

The inclusion criteria for the study related to the staff who initiated the referral to the HPCT, (rather than the person who completed the referral form as this can be delegated to a junior member of staff), and the HPCT HCP who subsequently reviewed the patient. HCPs from outside the District General Hospital were excluded because this research was about developing clinical practice within the hospital. Families who called the team for help with a patient were excluded as the research question pertained to how HCPs undertook this clinical work.

### **Recruitment**

A poster containing study information was posted on the intranet, in strategic places in corridors in the District General Hospital, and the HPCT intranet site. Senior HCPs were informed about the study via e-mail, with the support of the Director of Medicine and the Director of Nursing. When referrals came into the HPCT, I reviewed the patient’s medical notes to see who initiated the referral. The referrer and the HPCT HCP were approached and e-mailed an invitation pack that included an information sheet, consent form and demographic questionnaire about



the study. The referrer and HCPT HCP had 48 hours to decide whether to take part in the study. The aim was that the individual interviews would take place within 7 working days of the referral. At the interview the patient's notes were available. This did not require NHS ethics approval as the patient's notes did not leave the Trust and were only viewed by healthcare professionals who are already caring for the patient.

**Table 2** A summary table of the date of referral of a patient to the palliative care team, and the range of diagnosis and wards.

Critical incident (Patient referral to Pal Care team)	Date patient referred to Pal Care team	Patient Diagnosis	Referring Ward	Date ward HCP Interview & Interviewee number	Date Pal care HCP Interview & Interviewee number	Date pal care HCP Interview & Interviewee number <sup>6</sup>
1	03.04.2014	Cancer	Intensive care	09.04.2014 HCP 4	04.04.2014 HCP1	
2	04.04.2014	Congestive cardiac failure	Medical ward	08.04.2014 HCP 3	08.04.2014 HCP 2	
3	12.04.2014	Lymphoma	Oncology Ward	24.04.2014 HCP 6	22.04.2014 HCP 5	
4	22.04.2014	Stroke	Acute stroke Unit	29.04.2014 HCP 7	02.05.2014 HCP 8	01.05.2014 HCP 9
5	12.05.2015	Surgery / dementia	Surgical Ward	26.06.2014 HCP 11	22.05.2014 HCP 10	
6	16.06.2015	Surgery / cancer	Surgical Ward	18.08.2014 HCP 13	15.07.2014 HCP 12	

<sup>6</sup> Column 5 and 6 are the same, but Patient 4 had two palliative care HCPs associated with the recognition of dying.

### *Issues with recruitment and sampling*

Study one opened on 2<sup>nd</sup> April 2014 and closed on the 16<sup>th</sup> June 2014 and between these dates the HPCT received 217 referrals. On discussion with the PhD supervisors it was agreed that successive referrals would not be interviewed as it was not possible to combine this level of interviewing and clinical commitments without compromising patient and family care. It was decided to purposefully sample across different specialties and patient conditions. Thus, HCPs who cared for patients with a range of malignant and non-malignant conditions were sampled from surgical and medical wards, and from areas of extremely high intensity of care, namely the acute stroke unit and intensive care.

Several recruitment and practical issues were experienced. Firstly, once the decision was made to sample across specialties, it took time to wait for a dying surgical patient to be referred to the palliative care team. Secondly, some participants required more time and chasing, after they had consented to take part in the study to agree a mutually convenient interview date. A potential pair of interviews was omitted from the study, as there was no mutually convenient time to interview the referring HCP, due to leave, within a reasonable timescale. Repeated attempts had been made to set up the interview, and a point had occurred, that despite verbal consent, that it felt more respectful to let the interview lapse. A different decision was made to proceed with interviewing referring HCP 11 after 7 days. This participant was proactive about re-arranging the interview, the doctor had the notes available, and the participant was aware from the start that they would be interviewed about decision-making with respect to this patient. I did this to ensure that the time and data from the palliative care interview that had already been undertaken, was fully utilised.

### **Consent**

Participation was voluntary. This was made explicit on the recruitment poster and in the accompanying information. All participants were given the relevant participant information sheet and consent form which the Trust and University of

Bath approved. Participants were free to withdraw any time but I could use any data up to this point.

### **Data Collection**

The interviews were recorded via Dictaphone onto an encrypted disc and transcribed. The original recording was stored in a protected electronic file on a password-protected computer in a locked office. The files were then transferred to the University database for safe storage and will be disposed of in three years i.e. the end of 2017. Prior to the recording the participant was reminded not to use patient identifiable information and transcripts are anonymised so that the HCP is unidentifiable.

### **Interview Schedule**

HCPs were asked a series of questions, about the identified patient (for the full interview schedule with prompts see Appendix 2), which focused on five specific areas. The first questions explored the HCP's experience of recognising dying in that particular patient's case, their personal response to this, and whether they were the first person to recognise dying. The second area explored how the HCP had engaged with the patient and family, how they knew when to do this, and what the process looked like and what decisions were made. The third area concerned how the HCP maintained their relationship with the patient and family after the meeting. The fourth set of questions explored the HCP's experience of training to equip them for this aspect of clinical practice. The final set of questions explored their current experience of reflection as a means to develop their practice. They were then given an opportunity to reflect on the interview and say whether there was anything they felt was important to add. The interview schedule was used for every interview to ensure that there was consistency. The interviews were fully transcribed and submitted to a thematic analysis (Braun & Clarke, 2006) across the data set to address the research question.

## Why a themed analysis of Study One?

Braun and Clarke summarise ten benefits of a themed analysis, and three stood out as particularly relevant. The first was that thematic analysis can usefully summarise key features of a large body of data and offer a “thick description” of the data set – this is one that can explain behaviour and context. The second is that it can generate unanticipated insights, and the third is that it allows for social as well as psychological interpretation (Braun & Clarke, 2006). Through the themed analysis the data was organised and this allowed the description of the interviews for consideration by HCPs in the PAR workshops. Reicher and Taylor caution that thematic analysis needs to be clear and explicit, and rigorous in devising a systematic method (Reicher and Taylor, 2005 cited in Braun & Clarke, 2006). This will be attended to in the sections below.

## Themed analysis

### Coding decisions

The transcripts were read and re-read. Iteratively, and inductively from the data an excel spreadsheet was built with codes and the quote associated with this. These were ultimately subsections of themes (see Appendix 5 and 6). When in a subsequent reading a new code was found, that was undiscovered in other transcripts, this was taken as a prompt to return to the beginning of the transcripts and re-read them to see if the code was present or not. Inductive analysis is a process of coding the data without fitting it into a pre-existing coding framework (Braun & Clarke, 2006), but as a clinician and researcher I recognise I had an active role in identifying patterns and identifying them as themes, which were informed by my experience of clinical practice (Braun & Clarke, 2006)). Braun and Clarke (Braun & Clarke, 2006) state that an important question to address in terms of coding is what counts as a theme? As an example from this study, the theme “recognising the potential for dying” was made up of the codes, “HCP has a gut feeling the patient is dying”, “HCP did not recognise the patient as dying”, “patient raises the topic of dying”, “family raises the topic of dying” and “other members of the health care team recognise dying”. HCPs described a mixture of the codes in

each individual case, but across the 13 interviews there were codes attributed in this theme for each individual case. The analysis of the data and thinking about how best to describe this for fellow HCPs in Study Two was undertaken in discussion with PhD supervisors and clinical supervisor.

The level of the theming in Study One is broadly semantic (descriptive) rather than latent (interpretist) (Boyatziz 1998 cited in Braun & Clarke, 2006)) as the plan was to present the whole data set for participants in study two for their consideration. It is recognised this is important when a subject is under-researched and when the views of participants are unknown (Braun & Clarke, 2006).

### **Memos and theoretical sorting**

Memos and notes about the process of sorting that linked the codes to theory were kept in a diary. In the diary it was possible to see an emerging interest in the “gaps” between the analysed themes from Study One. An excerpt from the diary is included below in Figure 1. In the research question there are three small words “and” “to” and “to” and they are highlighted in green in the table below. They represented a significant movement in the evolution of my thoughts. It was at this point that I realised that senior HCPs could recognise dying but ignore this or did not think through the varying approaches to managing the dying period, that they could ignore the need to engage with patients and families, or they could be unable to manage the emotional and practical fall out. It suddenly struck me that these small words indicated the need to manage uncertainty in all dimensions e.g. prognosis, families’ viewpoints, and the possible need for significant amounts of emotional work. Also these words indicated the ownership of the “fluid, iterative and on-going nature of the decision” and what a responsibility that was (Taylor, 2012, p.3). This then informed how I structured the workshops to allow the discussion of the emotional work HCPs are engaged in.

**Figure 1.** Exert from research diary

2<sup>nd</sup> March 2015

**Title:** How senior HCP recognise dying and engage patients and families to negotiate key decisions to improve the patient and carer experience. PAR explored as a means to develop practice.

**How Senior HCP recognise dying** - Duty / Gut feeling;

**And** - Shades of grey in decision-making - going to die / dying; staging versus escalation approach, courage and bravery including educational preparation

**Engage patients and families** - Pass the hot potato - Meeting, pacing of information dependent on clinical scenario.

**To** Emotional work in family meetings including educational preparation

**Negotiate Key Decisions** - Key Decisions

**To** improve the patient and carer experience - Managing the emotional fall out.

## Diagramming

In line with others (Charmaz, 2006) diagrams have regularly been generated as a concrete image of researcher ideas. They have been useful in the workshops to succinctly describe the findings of Study One and to prompt discussion with others.

## Negative Cases

Whilst the patient's clinical record was available for all HCPs at the time of the interview in order that they could remind themselves of the patient's care if they needed, as a researcher I did not examine these notes. I was only interested in the HCP's narrative. The scenario of Patient 2 (HCP 2 and 3) caused me further on-going reflection. The dying was missed in this patient's care by one HCP and I wanted to look at the clinical notes to try and understand the decision-making, but discussed this in supervision. It was strongly recommended that the clinical notes were not accessed as other patient case notes had not been similarly accessed. With hindsight this was a wise decision as instead of judging the HCP and decision-making in this case, it moved me to really engage with the data and consider why the recognition of dying might be missed.

## Why PAR?

Action research is described as a “participatory, democratic process concerned with developing practical knowledge, which brings together action and reflection, theory and practice in participation with others, in the pursuit of practice issues of pressing concern to people and to the flourishing of individuals and their communities” (Heron & Reason, 2006). Action research recognises that the inquiry and the change are not separate moments but the inquiry is the intervention (Ludema et al., 2006) and ethically this was important, as the intervention needed to be helpful for clinical practice.

Action research, as a method, was planned to articulate the knowledge gained from study one and to allow others to jointly reflect on it, balance it with known theory, and their experience of clinical practice. It was to facilitate co-operative generation of an action to test out and reflect on in clinical practice in the intervening weeks between workshops and evaluate the impact of the action. This could be “psychological” action, rather than physical action (Baldwin, 2006).

### Study two – PAR workshops.

The overall aim of the four PAR workshops, held monthly for four months, was for senior HCPs to co-operatively generate new knowledge by considering the data from Study One, commenting about whether they recognised the narratives I had determined, and adding detail to how they recognise dying, negotiate decision-making, and cope with the physical and emotional fall out of decision-making. At the end of each workshop the group was challenged to document what they had learnt from the workshop and over the next two weeks to reflect on influences on decision-making to bring these back to the next workshop for discussion and to evaluate the workshops as a route to learning i.e. a “psychological action”. I also wanted to ensure that any biases I had and may have inadvertently brought into the research process were also exposed.

## Participants

As per Study One, this study was open to all senior HCPs employed in one District General Hospital. The study was voluntary and 3 HCPs who took part in study one also took part in study two. PAR group participants were asked to complete the same short demographic questionnaire that was requested in Study one.

**Table 3.** Summary of study two in respect of the participant's length of time in clinical practice, their experience of end of life care and self rated comfortableness with dying

Participant	Years in practice	Experience	Comfortableness with dying
1	32	Group A	At ease
2	6	Group A	At ease
3	15	Group B	Moderately at ease
4	20	Group B	At ease
5	24	Group B	At ease
6	30	Group B	Moderately at ease
7	19	Group B	Moderately at ease
8	27	Group B	At ease
9	15	Group B	Moderately at ease
10	30	Group A	At ease



HCPs had been in clinical practice for an average of 22 years (range 6-32). Three described themselves as working in palliative care, and 7 described themselves as frequently dealing with end of life care. All working in palliative care described themselves as “at ease” with dying. Of the 7 who rated themselves as frequently working with end of life care, 3 were at ease with dying, and 4 were moderately at ease.

### **Inclusion and exclusion criteria**

As per study one.

### **Recruitment**

HCPs were invited to take part through a consultant medical colleague advertising the study at a medical academic half day. This was done through the PowerPoint projection of the poster and by verbal support. The poster about the workshops (which included the intention of the workshops and the expectations of the HCP’s commitment) was publicised on the trust intranet, and by word of mouth. Both doctors and nurses are required, as part of their appraisal and professional re-validation process, to demonstrate reflective practice and this was highlighted as a key way to achieve this. An application had been made to the Royal College of Physicians, Surgeons and Nursing for Continuing Professional Re-validation points for attendance at the workshops. The colleges were interested to award these, but required a payment of greater than £1000, and since this study had no funding it was not possible. A sheet was designed that HCPs could use for their portfolios and allocate their own professionally recognised study time. The Directors of Nursing and Medicine were new in post and informed about the research study, and were verbally supportive.

Expressions of interest were received from 14 HCPs, and they were asked to commit to attending three of the four sessions. Ten HCPs joined the study. They were e-mailed an information pack, consent form, and a demographic questionnaire and they confirmed their interest in taking part in the study. These documents were collected at the start of Workshop One.

## Consent

As per study one

## Workshops

The workshops took place between April and July 2015, between 12.45 and 14.00 in a quiet room in the hospital. The content of the workshops was based on the analysis of Study One (Example of PowerPoint – Appendix 7), and the topics are listed in the table below.

**Table 4.** PAR workshop dates, attendees and topics for discussion

<b>PAR Workshop Dates</b>	<b>Number of attendees</b>	<b>Topic for discussion</b>
29.04.2015	9	Identifying dying
13.05.2015	10	Engaging with the family to negotiate decisions
03.06.2015	8	Coping with the fall out decisions
15.07.2015	8	Evaluation of the workshops as a means to practice development

### *Forward planning of workshops and plan for safe containment*

Ahead of every PAR workshop I went through the presentation with a colleague who was present in the group (not a participant). The role of the colleague was to keep me on track with timing, as I knew it would be challenging to bring the discussions together within one hour, and all HCPs would need to return promptly to clinical practice. I also knew that they would be able to assist if anyone became distressed. This is a common practice for educators in palliative care as unexpected distress is common (Lillyman, Gutteridge, & Berridge, 2011).

### *Privacy and Anonymity*

A working agreement was negotiated at the start of the first PAR workshop, which clearly identified expectations of group behaviour, and the roles the group members could take e.g. that they could challenge each other. This was in line with other working agreements for groups that some participants will have been familiar with i.e. the National Cancer Action Team Connected Advanced Communications Course. As part of this, in order to protect patient and family confidentiality, they were asked not to use patient names or patient identifiable information; they were also asked to agree that information about a colleague's practice also be kept confidential to the PAR group. They were also asked to commit to full attendance if possible. All transcripts were anonymised so the HCP was not identifiable.

### *My own learning from reflection owned and presented*

Every session, the same slide on reflection was presented, and I briefly stated what I had learnt from the HCPs' contribution as I transcribed the workshop recording. I was very mindful from Study One, and my own clinical practice, how much we learn from others (Perry, 2009), and I wanted to role model an open minded, reflective approach to clinical practice, and thank the participants for helping me learn.

### **Data capture**

PAR workshop data was recorded, transcribed, as per Study One.

### **Feedback from group regarding relevance, quality and effectiveness of workshop**

The group were given a hand out to document their evaluation of the delivery of the session, document their learning and their reflection on their practice over the intervening two weeks. They were able to use this to put in their professional portfolios to evidence their continuing professional development (Nursing and Midwifery Council, 2014; General Medical Council 2012). They were asked to rate the relevance, quality and effectiveness of the workshop on a scale of 0 to 5 where

0 is not relevant to 5 is highly relevant. Those that attended rated the workshops highly.

**Table 5.** HCPs rated perception of relevance, quality and effectiveness of the PAR workshops

<b>Workshop</b>	<b>Relevance (Average)</b>	<b>Quality (Average)</b>	<b>Effectiveness (Average)</b>
<b>One</b>	5	4.8	4.7
<b>Two</b>	4.7	4.3	4.6
<b>Three</b>	5	4.75	4.6
<b>Four</b>	5	4.8	4.7

### **Why an initial thematic analysis of Study Two?**

Initially the transcripts of the workshops were themed for the same reasons and in the same manner as undertaken for Study One.

### **Negative cases**

During the workshops the group highlighted what Study One had missed, namely the patient that survived the prognostication of dying, and the subsequent impact that had on the relationship of the HCP with the patients and their families subsequently had with HCPs. However, rather than negative cases, the workshops greatly added to the depth and understanding of the themes generated from the themed analysis of the Critical Incident Review (Study One).

### **A study in transition**

Without describing the results here, the themed analysis facilitated articulation of a four-stage model for recognising dying and negotiating decision making with patients and families. It also allowed description of how HCPs have learnt to deliver this aspect of care, and their positive evaluation of PAR workshops as a means to facilitate practice development. Following consideration of this

evaluation a five-stage model was ultimately developed that includes clinical supervision of this aspect of care. The themed analysis is presented in Chapter 5.

What the methodology did not allow to happen was to explain why the model for decision-making was not always used, why dying could be avoided, or why there was “blending” between stages or unawareness of stages. For example, HCP 11 (Study One) was able to state that after recognising dying she would normally engage with the family, but in this instance she had not. She could not explain further why, but her impression was that palliative care team were going to be involved and that they would do that. Through the analysis of the data I have become more acutely aware of the anxiety – my own and others – engendered by caring for dying patients and their families and have been introduced to psychosocial studies (Frost & McClean 2014), and psychoanalytically psychosocially informed ways of thinking about research and research data (Clarke & Hoggett, 2009; Frost, 2015; Hollway & Jefferson, 2013; Walkerdine, et al 2001).

At this point here, I want to highlight that I have considered whether death anxiety, and terror management theory (TMT) would be a helpful framework with which to consider the data from this study. Death anxiety – a concept generated by Ernest Becker in 1973 – is identified as the basic motivation for human behaviour. In his Pulitzer Prize winning book he describes how contemplating one’s own death is inherently anxiety provoking. He argues that management of this anxiety is so crucial to our own well being that it is mainly controlled at an unconscious level (Becker 1973). Terror Management Theory (TMT) was generated in 1986 by three social scientists, Jeff Greenberg, Tom Pyszczynski, and Sheldon Solomon, based on Becker’s work (Greenberg and Arndt 2011). TMT suggests that humans are unique in their ability to realize that death is inevitable and can occur at any time, and that this awareness engenders a debilitating terror that is contained by the development and maintenance of cultural worldviews. These worldviews may be through, for example, constructing a life that offers symbolic immortality. This is the sense that we are part of something greater than ourselves that will continue after our death e.g. our intellectual or physical work. Similarly, but not necessarily separately, it may be through the comfort of a faith

that guarantees immortality in some form after death. There are two central tenants of TMT. The first is our need to maintain faith in our cultural worldview. This is an act of work as our worldview is a fragile construction, which takes time and energy to maintain and defend. The second is the drive for self-esteem, and personal significance (Solomon, Greenberg & Pyszczynski 2015). Multiple tools to measure death anxiety have been generated: death anxiety is viewed as an internal construct that can be quantitatively captured. Greenberg and Arndt in the Handbook of Theories of Social Psychology (2011) cite how over 400 studies in 16 countries provide empirical support for TMT. Recent researchers interested in end of life care have started to use TMT as a route to explain cultural and moral disagreements in end of life care (Johnstone 2012), and death avoidance strategies in health care workers (Mckenzie, Brown, Mak & Chamberlain 2016).

Initially TMT was an appealing theory with which to consider the data from this study, as this PhD is about identifying dying, and therefore there is a definite link to contemplating death. As I reflected on the data in supervision, it became clear that the anxieties expressed by HCPs were much more complex than an anxiety purely about the death of the patient, or the HCP being forced to consider their own mortality. There was fear of “getting the recognition of dying wrong”, survivor guilt, the impact of other colleagues on the HCP and patient relationship, the impact of the family on the HCP and patient relationship, the lack of organisational resource to undertake patient and family meetings and lack of educational preparation for these meetings. My assessment is that death anxiety in the context of healthcare is not something that can be individually measured, but is influenced by interactional relationships and the complicated organisational contexts of both health care and the educational preparation for the HCP roles.

Psychosocial thinking then places the HCP at the heart of the study and considers the inter-connectedness between the HCP's individual lives - the intra-psychic, the individual in relationship with their family and community - and professional. It involves considering the external social relationships HCPs maintain with patients, families and colleagues, sited within the hospital, which are governed by the economics and policies of NHS England. It involves consideration of the influence

of Higher Education Institutes educating future HCPs for whom the individual HCP bear responsibility for practice placements.

With this in mind a psychosocial analysis was undertaken of the workshop transcripts, and two aspects of this – families, and education – are considered in Chapters Seven and Eight. I then considered Study One transcripts and this is presented in Chapter Six. I would describe this secondary analysis of the data as a “light psychosocial analysis”. I use the term “light” to describe the analysis, as this research did not start off with a psychosocial ontology and epistemology. The analysis though was systematic and thorough.

## **Psychosocial analysis**

### **What it means to take a psychosocial approach to the research?**

I am going to briefly describe some of the key ideas and concepts that underpin a psychoanalytically informed psychosocial approach. In the UK different disciplines have attempted to engage with this approach – notably psychology, especially social psychology, psychoanalysis, sociology and cultural studies (Woodward 2015). It needs to be said that psychoanalysis is a complex field, with a specialist language, and its own academic history, development and politics. I have found the language challenging to understand, the concepts slightly terrifying to sit in the field of health care (as it fundamentally challenges the dominant discourse of rationality which somehow I have absorbed over my life and career), and yet when reframed, and contextualised within this study gives an alternative lens and possible new ways of thinking.

Broadly speaking I have worked with a theory that accepts:

- We possess a dynamic unconscious that we can never access directly or know completely.
- Our psychological heartbeat is “anxiety” and that we are made with our psychological defences.
- As well as affecting us, our unconscious affects those around us and we are affected by others. Thus we are psychosocial beings.

- As psychosocial beings, our social currency is anxiety and we co-make and co-use socially constructed psychological defence mechanisms.
- As psychosocial beings we are affected by, and affect the wider social “milieu”. This is not just teams and professional groups, but the institutions that HCPs work in, and the economic and policy drives that affect these institutions.

It is recognised that psychosocial research is “more an attitude, or position towards a subject, rather than a methodology” (Clarke & Hoggett, 2009, p.2), and in our shared humanness I am not immune to my own “self deceit” (Alexandrov cited in S. Clarke & Hoggett, 2009, p.43), and need for external challenge. This analysis has been regularly supervised.

### **The dynamic unconscious**

The concept that our mind is split into the part that is conscious of ourselves and the part that we are unaware of, is described as “the radical suggestion at the heart of all psychoanalysis” (Bibby, 2011, p.6). Other people may get glimpses of it through our mood / affect / slips of the tongue; I may be aware of my own unconscious through my forgetting and remembering (Trustringham, 2016), of my dreams. Freud separates the pre-conscious, that which is “latent and capable of becoming conscious” (Freud 1923 cited in Bibby, 2011), from the unconscious, repressed and properly unknowable. The unconscious though is dynamic. It is like our psychological immune system. It represses, “holds back” that which is too dangerous to know, and is generative in terms of dreams, wishes and aspirations. It can be known in part through observing its effects in analysis, although this changes it.

### **Anxiety and individual psychological defences.**

The concept of anxiety, as is understood by psychoanalysts, is not necessarily a conscious anxiety as defined by the Cambridge Dictionary “an uncomfortable feeling of nervousness or worry about something that is happening or might happen in the future” (Cambridge Dictionary, 2016), nor the pathological anxiety described in the ICD 10 codes (World Health Organisation, 2016) requiring



medical psychological intervention, but rather the tone of our psychic life. Melanie Klein argued that we are born with this, and as we are usually unaware of our heartbeat, so we are usually unaware of our anxiety. This anxiety is the provider of the impetus to engage and to learn, but when that “tenor” cannot be managed it escalates into distress. Thus “at the conscious level”, anxieties may be named and talked about. But at the level of the unconscious, rather than being “out of sight, out of mind”, anxieties continue to wield their considerable power beyond the rationalising influence of language” (Walkerdine et al., 2001, p.89).

Our range of psychological defences develop as a way to manage the anxieties provoked both by life and by the challenges of managing our conscious and unconscious lives. Klein, in the early twentieth century, described how psychological defences operate in detail to protect the self from all that is unbearable to our psyche. It should be noted however that whilst Klein formulated her theories of mental functioning in terms of child development, “most contemporary Kleinians use them to understand mental functioning in the child and adult” (Roth in Riesenberg-Malcolm, 1999, p.3).

From the perspective of this study, it is helpful to understand Klein’s “object relations” theory, as I have drawn on the research of Isabelle Menzies-Lyth (a Kleinian psychoanalyst) (Menzies, 1970) to underpin the psychosocial analysis of Study One. Klein developed “object relations theory” from her observations of how children play and their preoccupation with what went on inside themselves and their experience of the world. She described an “internal object” as a term to represent an inner mental or emotional image of an external figure (external object), and she saw the inner world as populated by these. The state of an internal object is linked to the development of the mental health of the individual and she argued that the introjection of and identification with a stable good object is crucial to the ability to psychologically integrate an experience, and that damaged or dead internal objects cause enormous anxiety. It should be noted that internal objects can be more or less unconscious and more or less primitive. Infantile internal objects – the mother’s breast is widely quoted (Frost, & McClean 2014) - are experienced initially concretely within the body and mind. Klein postulated that early childhood experiences of care, relationship and vulnerability,

“constitute a primitive level of the adult psyche, adding emotional influence and force to later perceptions, feelings and thoughts. Internal objects may be represented to the self in dreams, phantasies and language” (Melanie Klein Trust, 2016, p.1). This concept is linked to Klein’s theory of life and death instincts (developed from Freud), her ideas of unconscious phantasy and her ideas of the infant’s development from part object to whole object functioning, which is linked to a movement from the paranoid-schizoid position to the depressive position (Melanie Klein Trust, 2016). I will consider this below.

Klein postulated that we have unconscious defence mechanisms, which allow the individual to ‘down regulate’ anxiety. This is often accompanied by splitting. Splitting is seen as a way of protecting what is experienced as good (loving, affirming etc.), from that which is seen as bad (anger, hate etc.) (Bibby, 2011). We can split and project the good onto the other e.g. in the form of envy and “safely experience our own negative emotions” (Bibby, 2011); or project the bad on to others and “can deny the feelings are inside us and instead assert they belong to the other person” (Walkerdine et al., 2001, p.91). Denial is defined as “a refusal to recognise or appreciate the inner significance of an experience” (Walkerdine et al., 2001, p.91). However, splitting and projection are not unidirectional, and unconscious communication (like conscious communication) is received. We take in, sometimes gladly, other’s projections onto us. In Kleinian psychoanalytic terms this process of splitting and projection may lead to the paranoid-schizoid position whereby the good and bad, in others and ourselves, must be kept separate. For example, in this study, medical HCPs repeatedly named “surgeons” as a group (accompanied either with an emotional response of anger or with laughter), when they talked about other HCPs who did not want to address dying. The medical HCP was seen as “good” and surgeons as “bad”. Klein described a less defended psychological position called “depressive”. This is where the person is able to accommodate the good and the bad within themselves. This occurred in the fourth workshop when the medical HCPs acknowledged they could not physically undertake a surgical job, and saw their previous view of surgeons being “bad” at recognising dying in a new, and more tolerant light. The positions of paranoid-

schizoid or depressive are not “final”, and we move between the positions throughout our lives.

### **Anxiety and social psychological defences**

Bibby describes how in everyday life, there is a tendency to split the internal and individual from the external and social much in the way one could specialise in psychology or sociology. In this manner splitting misses the “ways in which the internal and external, the private and public, the individual and social are deeply and mutually implicated” (Bibby, 2011, p.9). This concept of a deep and mutual implication for the personal and social is not just at a conscious level, but unconscious too. Walkerdine, Lucey and Melody describe a “collective unconscious, intertwined with the collective conscious having the ability to profoundly influence the structures of life, state, education, family and work; and the lived experiences of class, race, femininity” (Walkerdine et al., 2001, p.84). In this manner we can recognise the collective unconscious, alongside the conscious potential to affect the healthcare system and roles. Anxiety is named as the “psychological currency” not only of the individual, but also of society seeping into the “foundations, of social, economic and political life” (Hoggett, 2009). We are psychosocial beings and others have proposed ways that culture is acquired and non-verbally conveyed (Egyed, Kiraly, & Gergely, 2013).

Isabelle Menzies-Lyth in the late 1950s undertook the seminal psycho-analytic study of nurses working in a large London teaching hospital (Menzies, 1970). She was invited into the hospital because the morale of the nursing workforce was low, and the hospital was having trouble retaining nurses. Menzies-Lyth observed and described the primary task of the NHS. She felt that this was to care for those with ill health that could not be nursed at home. She proposed that anxieties (conscious and unconscious) – linked to nurses earliest experience of care and vulnerability - were raised in response to the primary task of caring and she felt that nurses (not nurse managers) took the stress of providing this care (Menzies, 1970). Menzies-Lyth noted that the nurse’s own personal biography added another layer of complexity, and that nurses projected their own childhood phantasies into the clinical situation, and when it was not “too close to home” they achieved a sense of

conquering their fear. When the clinical situation resonated too closely then it could prompt nurses to leave the profession.

She witnessed what she called unconscious social defence mechanisms being used to down-regulate anxiety. A social defence mechanism describes a process and gives a visible representation of how we unconsciously or consciously place part of our emotional life outside of our self and into the life of the group, and in this case, of the institution, to alleviate anxiety. The social defence mechanisms she identified were the splitting up of the nurse-patient relationship, depersonalisation, detachment and denial of feelings, eliminating decisions through ritual task performance, checking and counter checking to alleviate individual responsibility, obscurity in the allocation of final responsibility, reduction of personal impact by delegating upwards, and avoidance of change. In this study she specifically built on the work of Elliott Jacques – a “social scientist who was the first to use the term social defence in a scholarly publication” (Bain, 1998 cited in Kraemer (2015), p.148). Jacques had formulated<sup>7</sup> that social defences were imported into the organisation from the outside, specifically from the psychological states of its members. To take this one step further, nurses “make the defended organisation” subsequent to their individual psychotic anxieties (Armstrong and Rustin 2015). Menzies-Lyth formulated that the social defences were in response specifically to the nursing task. Taking this one step further, she formulated that nurses do not import the defensive structure of the organisation, but that the social defences are generated within the organisation. Social defence mechanisms are “bittersweet”. Menzies-Lyth recognised that splitting the nurse-patient relationship into “tasks” allowed down-regulation of anxiety from the total responsibility for patient care. However, it also meant that nurses were deprived of knowing patients and gaining pleasure from taking responsibility for care and building therapeutic relationships. Social defence mechanisms are often unconscious, and become embedded as organisational culture. New members of staff are required to sign up to the culture when they join the organisation and, they “have to swallow the systems of defences already present” (Auestad, 2011, p.

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<sup>7</sup> To formulate is a theoretically based explanation obtained from a clinical assessment.

400). In this manner embedded social defence mechanisms can add to an individual's anxiety, rather than alleviating it when they contradict the new recruit's own personal methods of containing anxiety.

Whilst more recent researchers consider that Menzies-Lyth's work has "stood the test of time" (Lawlor 2009, p.529), it has both been heavily critiqued, and yet still built upon. It is to this literature that I wish to pay attention to now. Modern authors consider her research would not meet "current theoretical frameworks that guide good qualitative research" (Tutton and Langstaff 2015, p.113); that the focus of her report is clearly about her findings, with only basic information about her observations and interviews (Whittaker 2011) and that she focused very much on nursing rather than medical or lay subsystems. Whittaker highlights how Menzies-Lyth latterly critiqued her own methodology and recognised a serious limitation to her study was that she had only been able to gain access to nurses, rather than doctors and the administrative and support sections of the hospital (Menzies-Lyth cited in Whittaker 2011).

The importance of this is that it gives rise to the second critique which claims that Menzies-Lyth's study is an "under socialised account" (Hoggett 2015) that focuses the attention on the individual nurse's psychological defences, rather than consider wider societal factors, or organisational and cultural factors. Let's consider what authors have said. Paul Hoggett (2015) argues that Menzies-Lyth's focus on the "task" of the organisation, and the definition of this "task" being the direct clinical care that nurses offered patients, ignored the role of society in the making of that task. For instance there was a gendered split at that time, with nursing a predominantly female profession, and medicine predominantly male. Hoggett argues that therefore there can be no such thing as the "primary task" that stands as a definable phenomenon. The task can only be seen in the context of the time period, with its concomitant social and cultural milieu. Hoggett uses Ronald Britton's development of Bion's thinking (that if an experience cannot be held in the mind, then it is somaticized and embodied, hallucinated, projected or enabled) to consider how nursing was trapped in a rigid, tight and anxious organisational body. In this manner nurses denied the emotional impact of their work, and thus at this hospital nursing was organised to create a "thick skin" through its rules,

systems and procedures (Hoggett 2015, p.55). He then argues that whilst some feelings are pertinent to the individual (this would be in line with Jacques' formulations), societal anxieties are taken from society and lodged in the organisation. In the research that constitutes this study, I argue that currently, we can see that the public fear of dying has leaked into current NHS organisations through the media outcry and the withdrawal of the Liverpool Care Pathway (Neuberger 2013). Participants in this study (Chapter Five) identified that the introduction of the Liverpool Care Pathway through national policy introduced an unrealistic expectation that death could be accurately prognosticated and communicated to patients and families. In line with other clinicians (Roeland et al 2014) HCPs have started to question whether the change from paternalistic care early in their career, to patient and family involved care later in their career, had been a helpful one for themselves, patients or families.

Papadopoulous (2015) too considers that Menzies-Lyth's study is an under-socialised account and that an organization's strategy, culture and leadership culture limit the opportunities and constraints on individuals working within the organization. He argues that because Menzies-Lyth confined her study to junior nurses she sidestepped the larger challenge of seeing how the wider hospital structure contributed to the design of the nursing service and the drop out rate. Like Hoggett he recognises that anxieties and defences were due to wider pressures in the nursing service rather than just clinical care. Indeed, like other authors, he argues that the modern NHS creates anxieties all of its own, separate to the many anxieties generated by direct patient care. Boxer (2015) argues that the turbulence of the modern NHS, with its demand for constant improvement, and the fact that good individual patient care can only now be delivered by multiple partner organizations, means that clinical staff working the transition between organisations, on behalf of patients, are caught between different organisational cultures and with expectation of service improvement which can leave them with a vague existential anxiety. Tutton and Langstaff (2015) argue that the ever-increasing volume of patient care leaves staff feeling constantly in crisis. Evans (2015) argues that the current climate of cuts, doing more for less, alongside outcome measures and targets, mean that senior managers are themselves so

anxious and insecure that they cannot provide the “containment and reverie” that clinical staff need (Evans 2015, p.137). Evans claims that the lack of empathy shown by managers for clinical staff may be one of the reasons nurses display a lack of empathy for their patients.

Menzies-Lyth continued over her career to express empathy and support for junior nurses and her frustration with nurse managers (Menzies-Lyth, 1999) who she identified as responsible for the inability to change the culture of care to benefit patients and nurses. She was disappointed that so little progress had been made despite her papers (Barnett, 2008). Latterly, she was strong in her viewpoint that nurse managers did not effectively manage, and left situations unmanaged to the detriment of patients and nurses (Menzies-Lyth, 1999). In a more modern NHS she observed that nurse managers practiced “denial and deception” (Menzies-Lyth, 1999, p.208), splitting the elements of “good caring nurse” and “hard manager” causing themselves internal conflict, but also damaging relationships when they retained the “good caring nurse” and projected the “hard manager” onto other colleagues.

Armstrong and Rustin argue that giving inadequate recognition to social forces can explain why psychoanalytic interventions such as Menzies-Lyth’s fail. Her hope was that naming the social defences meant that nurses could begin to change the organisation through changing themselves and how they organised patient care. Indeed this was seen in the development of the Nursing Development Units in the late 1980s. Alistair Bain (1998) though explains how organisational defences can be so embedded that any new change is short lived as defensive structures return to swallow the new initiative that is perceived as threatening and therefore anxiety provoking.

Despite the limitations of Menzies-Lyth’s work and later critiques of it, she has nevertheless contributed extremely important ideas. These ideas developed existing research and triggered critical thinking and reflections about the internal life of organisations that are still on going half a century later (Obholzer & Roberts 1994), Armstrong (2005) and Armstrong & Rustin (2015). From the perspective of this study, the ideas of value that Menzies-Lyth have offered to this study are to

really consider the humanness and psychological strengths and vulnerability of all working within the NHS; to have captured and benchmarked the “essence of the NHS” in the 1950s in order that a comparison can be drawn with today’s NHS; to consider what of the clinical role may be consciously and unconsciously anxiety provoking given the task of caring for the dying patient and their family, in an organisation charged with preventing people from dying prematurely (Department of Health 2014); and the detailed consideration of social defences to protect clinicians from unbearable anxiety.

## Method

To undertake this approach I initially read key texts and discussed them with my supervisors. I then took three key texts in psychosocial analysis to ground my analysis. They were *“Doing Qualitative Research differently”* (Hollway & Jefferson, 2013); *“Researching Beneath the Surface”* (Clarke & Hoggett, 2009) and *“Growing up Girl”* (Walkerdine et al., 2001). From closely reading *“Researching Beneath the Surface”* and *“Doing Qualitative Research Differently”*, I directly extracted, and listed in a word document the key tenets of what the authors identified constituted a psychosocial analysis. From closely reading *“Growing up Girl”*, and specifically Chapter 4 – “working with emotions” – I learnt that to research effectively required “a willingness to engage (way beyond the point of comfort) in what are difficult emotions” (Walkerdine et al., 2001, p107). Understanding this I re-ordered the key tenets of a psychosocial enquiry into three sections in a new word document (See Appendix 8). The sections were “questions to ask of myself” (this contained 33 questions), “questions to ask of participants” (this contained 48 questions), and “questions to ask of “us as a partnership” (this contained 13 questions). I then put the questions into an excel spread sheet and systematically went through every transcript of the four PAR workshops, seeing if those questions could be answered, and evidencing this with the relevant quote. In the table below I give two examples for each section of the reference, the question generated from the evidence and an example of evidence from the workshop transcripts.

**Table 6.** Example of how I moved from the question identified in the key texts to evidence from the workshop transcripts



	Reference from three main texts	Question generated from reference	Example of evidence
Questions to ask of me <sup>8</sup>	“Clinicians interpret into the encounter, whereas researchers save their interpretations for later”(Hollway & Jefferson, 2013, p.72)	Look at where I interpreted into the interviews.	I clarify the degree of ethical principle that allows negotiation of treatment to broker psychological adaptation: INT JW so there is a balance between not doing harm and doing good. Group agrees; INT JW So the fluids aren’t doing good but they have to stop when they are doing harm. Is that what I am hearing? Group yes" (L538-542 Workshop Three)
	“The leader of the team viewed this exchange as an example of an undefended, courageous researcher, but more than that I was conscious of wanting to explore issues for my own satisfaction, and was saved from myself by...”(Clarke & Hoggett, 2009, p.113)	Am I a courageous undefended researcher or wanting to explore issues for my satisfaction. How do I manage the boundaries? When do I feel fear?	I was really shocked at this...kept quiet...best I could do..."PART 9 I see this in a lot of cases, and honestly I’m not really...sighs...distressed and sad to see people stay stuck in the bed for 4,5,6,7,8,9,10 days. Just waiting for that moment there, our patients suffer. I get very frustrated and would really like to be able to kill them (nervous laugh); it would, can’t really explain it, its a when you know there is nothing else to do and you see just all the family there just waiting for that moment, sometimes it is very very long, or maybe the patient is so distressed and even if you put on drip, syringe driver or whatever they are still distressed and you are just nothing else we can do and it makes me feel pretty uncomfortable. Sometimes also the family say can you kill them can you stop?" (L577-585)

<sup>8</sup> Structure of analysis underpinned by understanding Chapter 4 – “Working with emotions” (Walkerdine et al., 2001)

			Workshop Three)
<b>Questions to ask of them</b>	Klein - we spilt objects into good/bad...paranoid/schizoid position...can be past /present or us /them...(Hollway & Jefferson, 2013, p.18)	Look for splitting / Look for accommodation.	<b>Surgeons being seen as "crappy" with regards to communication...</b> "PART 7 yeah that very much strikes chords with how I recognise; your taught very factual stuff on how to do this and processes; the softer aspects - and I think that is quite a nice term - are learnt from seeing people do it poorly, badly but also recognising people who are skilled; and we are fortunate enough to be attached to a palliative care team and you come away and feel that was done well; its quite difficult when you are a junior to put your finger on why but it just felt better than a crappy old surgeon standing at the end of the bed (L177-184" Workshop Four)
	"Respondents frequently played down or laughed off distressing losses they sustained"(Clarke & Hoggett, 2009, p.155)	Explore the role of humour and when humour occurred.	<b>Some can smell death, and this causes the group to laugh... this is a shocking truth"</b> PART 9 He's dying, it's a look. Maybe with experience you see the other stuff. Another thing I can smell when a patient is dying PART 5 yeah we had a conversation in the office the other day about the smell PART 9 yes I can smell. Group (laughter)" L217-221 (Workshop One)
<b>Questions to ask of us.</b>	"To understand why the "hard man" discourse (and not some other way of acting out invincibility) comes to be the vehicle of his unconscious investment"... (Hollway & Jefferson, 2013, p.129)	Are some discourses more available to some than others?	<b>Nurses feel silenced and it is personally difficult...</b> "PART 1 Think the difficulty can be personally that you see it yourself but nobody is seeing it with you, and that's quite hard as you think "they are dying" and no one can hear me" (L226-228 Workshop One)

	<p>“Interpretive knowledge is synthetic and integrative, rather than analytic and reductive” (Park 2001, p83 cited in S. Clarke &amp; Hoggett, 2009)</p>	<p>Look for this.</p>	<p>I am learning and this in turn affects my questions as I do go on to ask about impact...INT JW "I think my learning was that, actually, the emotional work we do is really large and that we don't really get trained for this, its not anything we are prepared for or trained how to manage; um and that all patients in Study One that I interviewed people about had died; patients had all died and that you raised the consequences of predicting dying and then what meant for you if patients lived, survived your predication of dying and what some of the consequences were for both patients and families (you'd mentioned a bit about sometimes anger or) and then what the consequences are for us. Those were the things that really stuck out for me from last time as an initial thing and that made me think more over the last two weeks. One of the things I wanted to ask you is how you manage the impact of the patient surviving the identifying dying. So when we get it wrong (I don't know there is a right and a wrong 'cos we are doing it, we are just doing the best that we can to predict something that is uncertain); but when the patients survives it how do you manage the impact on yourselves and the relationship with the patient?" (L38-49, Workshop Two)</p>
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Looking at the excel spread sheet was like looking at a contour Ordnance Survey map. It gave a physical representation of the volume and depth of emotion and

experience, and the areas these pertained to. In line with Hollway (2013) it is importance to note that a) I cannot tell a story of all HCPs, but I can tell individual stories and b) I can note themes that re-occurred. The narrative is set in the context of the workshops and research question. This psychosocial analysis is my endeavour to not compromise the truth by my motivations (to only research according to methods I am familiar with, with previously acquired knowledge (rather than new knowledge), or memory (the transcripts were typed reliably and conscientiously). For the PhD write up it is necessary to focus on significant aspects of the data, and I have chosen key topics pertinent to the research question.

After I had undertaken the psychosocial analysis of the workshops, I wrote an initial chapter considering the data about families, and how HCPs learnt to care for the dying and their family, and presented this at the 2<sup>nd</sup> Association of Psychosocial Studies Conference. Writing is a way of knowing (Richardson & St. Pierre 2005) and of analysis and synthesis (Rolfe, 2000). Reading work from a related field (Harvey, 2010), (Bibby, 2011) and undertaking a written reflection on the “negative case” where the recognition of dying was missed, enabled me to return to with some distance from the data: it levered me into a different place. Richardson describes that validity is not triangulation of data, but the central imagery is the “crystal, which combines symmetry and substance with an infinite variety of...angles of approach” (Richardson & St Pierre, 2005, p.963).

#### *Return to Study One*

I then returned to the transcripts of Study One and asked the same questions of them as I had of Study Two. I could only “see” the social defence mechanisms utilized by HCPs in Study One with the lens of what I had understood of Study Two.

**Table 7.** Example of how I moved from the question identified in the key texts to evidence from the interview transcripts

	Reference from three main texts	Question generated from reference	Example of evidence
Questions to ask of me <sup>9</sup>	“It can be argued, that by asking the questions, we ask, notably by asking about anxiety, we produce the anxiety we are seeking to produce empirically (Hollway & Jefferson, 2013, p.35)	Did my questions provoke anxiety?	INT JW So thank you. Did you meet them [family] on the ward? Did you set up a meeting or did it just happen because it was part of the assessment? Where did it take place? “Can’t remember”...HCP 13 [My note] - Interesting as he could remember detail of patient but not family...
	“There were constant invitations to explain actions & feelings, motivated by our pursuit of contradictions, inconsistencies and the “irrational explanation”. (Hollway & Jefferson, 2013, p.25)	Look at how I question...am I bothered by irrational explanations...or my agenda / blind spots?	I did explore inconsistencies -" I realise that I have missed one thing; um can I go back to it and then go to section 5 I am really sorry HCP2 yes INT JW you know when we talked about the decision that you made that when you went to assess the patient and um you had made the decision that he was not dying at this time and he was being appropriately acutely managed and it was not a rapid decline it was a gradual decline; HCP2 yes INT JW can I ask what is the emotional impact on you of that kind of decision-making? HCP2 Ok so – pause – so - pause- in his case it wasn’t so in this patient’s case it wasn’t particularly difficult as I felt that the treatment he was receiving felt justifiable. Um (pause) so that was ok – the emotional, what impacts on me much more dramatically emotionally is when I am faced with

<sup>9</sup> Structure of analysis underpinned by understanding Chapter 4 – “Working with emotions” (Walkerdine et al., 2001)

			situations where I am can't see the justification for the treatment that is being done" L191-207
<b>Questions to ask of them</b>	The concept of anxiety is employed at individual level (Hollway & Jefferson, 2013, p.148) but it also exists at organisational level (Menzies-Lyth) & into groups (Bion).	Look for how anxiety is managed within an organisation	<b>Takes a nurse in for family meetings. Is the nurse part of emotional safety?</b> "When I am speaking to patient families I tend to have a nurse with me and I tend to ask them you know how they think it went and whether they thought you know and if they had any suggestions for improvement" L200-203.
	"As I was carrying out the interviews... I became intrigued by the use of metaphors..." (Clarke & Hoggett, 2009, p.244)	Look at metaphors (meaning - provide a visual picture of a word or thought) used by participants.	<b>HCP describes gut instinct</b> - "I became aware through some sort of gut instinct that I have tried to reflect on that this patient might actually be dying;" L33-35
<b>Questions to ask of us.</b>	Concepts of recognition & containment" (Hollway & Jefferson, 2013, p.45)...also a becoming through the process (in part what action research is...a psychological becoming rather than a physical doing / becoming). (Hollway & Jefferson, 2013, p.49)	Look at evidence of becoming	<b>HCP starts to reflect on actions...</b> "I am thinking, if I just think about it now; I didn't ask anyone what his wishes were, or did anyone know what the family wishes were or expectations; erm you know because we always pick up a lot non verbally don't we about the situation and I think we all thought that it was clear to everyone that this person was not going to live and survive this and so probably a lot of that kind of stuff I had thought that maybe that was already done. I don't know, just thinking about it now why didn't I stop and think about those things; but it is easy to forget to do things like that so maybe that is something that we can definitely improve on is, erm thinking about the patients wishes and relatives. But usually, especially on our own ward we know we are kind of thinking behind it".

			L248-259
	<p>"Interpretive knowledge is synthetic &amp; integrative, rather than analytic &amp; reductive" ...its also transformative. (S. Clarke &amp; Hoggett, 2009, p.36)</p>	Look for this.	<p>She starts to recognise dying and communication with family as a series of steps...needn't all be done by one person ..."and I haven't really thought about it like this but when I think about it that's what we were doing the nurses had done step one - they had stood at the end of the bed and gone "oh you look really sick" and come to me for step two, that what they had done, and then we had set up the stroke consultant for step 3 we then came down and finished the work and had the conversation with the family and out of that conversation was quite interesting; it was not possible to remove the TPN at that point; they weren't ready it was too; so the pace at which we withdraw treatment and take an end of life approaches it depends where the family are and where the patient is". HCP 8 L266-276</p>

### The psychologically defended researcher

The focus on researcher subjectivity and its place in the research process can be traced back to Jennifer Hunt (1998) - *"The psychoanalytic aspects of fieldwork"*. The work of Valerie Walkerdine, Helen Lucey, and June Melody (2001), and particularly Chapter 4 of *"Growing up girl"* is recognised as one of the most pioneering and most influential pieces of work with respect to the concept of the psychologically defended researcher. Dr Helen Lucey, who co-supervised this PhD in its latter stage, and her colleagues were among the pioneers who generated a methodology for considering how the researcher may be affecting the research process and accounting for this (Lucey, Melody and Walkerdine 2003). Examining how researchers work with their own and others' conscious and unconscious processes

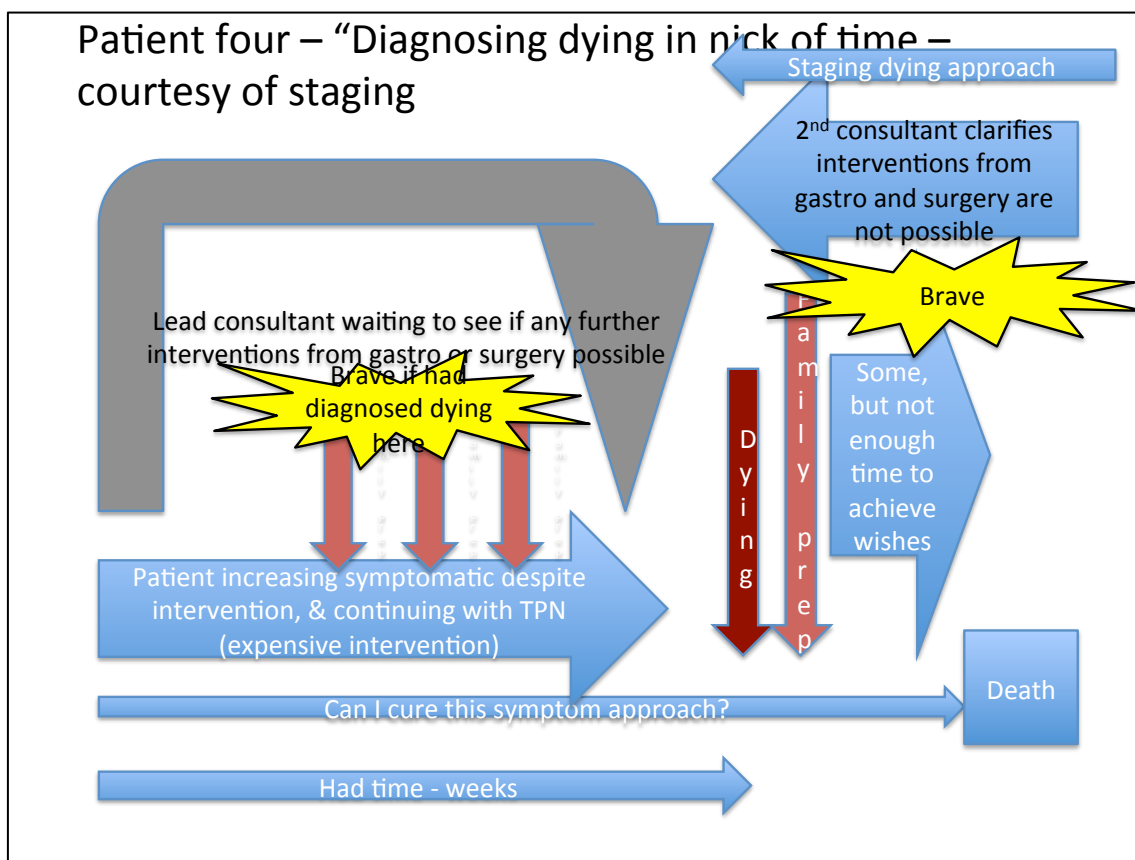
is an essential part of offering an interpretation of the data which is not set on a single agreed answer but an interpretation that is “historical, personal, social, cultural and psychic” (Lucey et al 2003, p.283). It also alleviates the reader of concern that the research is more about the researcher than the researched, or that the data has been misinterpreted or over-interpreted (Hollway and Jefferson 2013). The important point for this PhD is that my own unconscious psychological defences had the potential to affect the study design, questioning of Study One participants, transcription of the interviews, themed analysis, facilitation of the workshops, transcription of those interviews, and the themed analysis. My unconscious psychological defences had the potential to influence the psychosocial analysis.

An important part of this PhD was the supervision of my interpretation of the data, and the arguments I was making. The recorded interviews were not listened directly to, as recommended by some authors (Garfield et al 2010), but in line with many psychosocial research approaches, the transcripts of the interviews and workshops were treated as raw data (Urwin 2007). I presented to the supervisory team, at that stage Dr Smith and Dr Baldwin, the initial interview transcripts (Study One) and we independently coded them and discussed the similarities and differences between our codes. If they identified a code that I had not, I went back and looked for this in all of the interview transcripts. I then presented the supervisory team, who by now had changed as Dr Baldwin had retired and consisted of Dr Smith, Dr Lucey and Dr Dack, with the initial themed data from the Study One. These were large spreadsheets with the codes and quotes. Once the workshops were transcribed, and as I undertook the themed and then the psychosocial analysis, the supervisors saw all of these spreadsheets with the coded data on. Thus, while the supervisors did not read entire transcripts, they did see a large amount of the raw data at each stage of data collection. Typically, in supervisions, carefully looking at sections of raw data alongside my initial interpretation of the data were the foci of discussion. With Dr Lucey on board the supervisory team, I was encouraged to look at data in ways that I was quite unused to. Often, my original interpretations were closely questioned.



In the sections below, I will give two examples where my analysis of the data was challenged in supervision. The first is from Study One, and relates to the period of time after I had coded the data from Study One, and at a point where I had moved quickly into “model making” to describe my interpretation of the data. I started to identify points in the decision-making process at which HCPs were either brave in decision-making, or could have been braver. My use of the notion of “bravery” as an interpretation, and my use of model making were strongly critiqued.

**Figure 2.** Example of early data analysis



**Figure 3.** Example of Supervision notes.

**Supervision notes 14<sup>th</sup> Jan 2015:** Is it braveness? Is there a link to anxiety? Is there a link to defensiveness? Black and white thinking instead of grey... “black and white moments are few and far between – don’t get stuck with binary arguments”. Think through why I had introduced the concept of bravery and why? It’s not a good enough concept. Consider institutionally how practices and position are supported. Insider research – can’t ignore my perspective. Need to critique what is important to my thinking. **Reflexive diary:** “felt upset” was told – “if you do not move beyond diagram to academic debate its not more than a third year project”. I have been working so hard; still have to face it is not enough. I have to stop (my early interpretation of the data and model making) and allow myself to immerse myself in the themes”.

Despite, my supervisors intention to provide supervision in a supportive manner, and to hold a space where we could all enter the irrational and think about our thoughts (Doyle 2012), it is clear in this diary entry that I was upset by supervision. Indeed the subsequent diary entries on the 19<sup>th</sup> Jan indicate that I shared the model, and my upset, with my clinical supervisor who was encouraging and I note, "Gave me the inspiration to keep going". Over the next month until supervision on the 25<sup>th</sup> February 2015 I specifically recorded the hours that I worked on the PhD. For example, on the 7<sup>th</sup> February 2015 I have written "did good one and half hours yesterday. Did two hours today". Working hard when I am psychologically challenged is one of my defence mechanisms. It also allows me to read which allows me to process new information in a manner that is controlled.

There is no reason to think that supervision should not be a place for the intersection of university norms and protocols, and the messiness of human beings working together (Lucey and Rogers 2007). What I perceived as a disregard for model making as my route to learning and the PhD supervisors' drive for written academic debate floored me, and I was on-goingly angry at times. Without being able to make a model I temporarily lost my coping strategy for independent thinking and discussion. My anger has been contained by many people e.g. friends in, or with experience of higher education, and colleagues. My clinical supervisor helped me re-frame my thinking, and suggested I try a cognitive strategy of thinking about writing differently. The challenge to myself was to make my thoughts understandable in words instead of pictures. While others have engaged in therapy and found it helpful for their research (Walkerdine, Lucey and Melody 2001) I have valued clinical supervision to process the impact of the PhD on my life and its impact on my clinical practice.

The need to produce my learning in a written manner that is considered academically acceptable has consistently rattled my defences, and left me feeling really vulnerable. As Bibby (2011) highlights, learning in and of itself is anxiety provoking and difficult and tied to feelings of frustration. It is only by surviving the frustration, and learning to live with "not knowing" that we can develop our knowledge. It is impossible to say whether I project and blame the "writing" to defend myself against the anxiety of a lack of knowledge about psychosocial

thinking, or the critique of the accuracy of my model making, or the removal of model making, and the replacement of this with writing as a way to think (Richardson 2000). At the end of supervision I often feel really alone, and I am mindful that this aggravates personal feelings of aloneness from bereavement and divorce. I have no desire to project blame onto the supervisors. Our personal lives play out in all relationships including those within the PhD supervisory relationship (Lucey and Rogers 2007). I have psychologically moved myself to a position where I, mostly now, value the personal time and work it takes to produce knowledge in a written manner that is acceptable to the University. How the anger, frustration and sometimes depression about the time and work it takes, subsequent to this psychological shift, ebbs and flows in my life. Reflecting on why I did not strongly express my anger in supervision, I think it is in part personal, as I do not like to express anger. However, I also recognise that the feedback from supervision represents something more than the supervisors themselves, and represents the power of the university to judge my academic work through written text alone (Bell and Birch 2007). I want to pass the PhD. Since February 2015 I have been learning how to write in order to convey my learning, and find it very anxiety provoking, as I am never sure how the analysis or the writing of it will be received. The diary entry on the 2<sup>nd</sup> March 2015 states, "I have written out fall out decisions and emailed Paula (Dr Smith) and Helen (Dr Lucey). Fingers crossed re response". What has been really helpful for me, to contain my distress about learning to write is the prompt written feedback from Dr Lucey and the repeated correction of my grammar and text, and prompts to take time to explain my thinking. Through this on-going containment I am learning to write.

Additionally, through PhD supervision, I have had a dawning realisation that I am at the crux of a clash of cultures – the NHS, academic life, and my life. Being on this crux has left me always with a vague feeling of anxiety. Examining this vagueness (Boxer 2015) has made me realise that model making is a social defence in medicine and nursing to make complex, anxiety provoking situations simple and teachable. This is evident in the generation of the "map of medicine", and its pathways of care (Brennan 2011) and is evident in Kennedy's paper about decision making in end of life care (2014). As clinicians we use models, and pathways to

think about our thoughts, and to discuss them. It may be that I am so comfortable in clinical practice as my way of learning lines up with others around me - thinking in pictures and colours is mainly how I learn (See mind map in Appendix 12). It was through categorising the literature using this mind map that I was able to gauge the gap in the literature that this study addressed. Model making also allows clinicians to think quickly and recognise the gaps in models, and thus clinical practice. Reflecting on this I realise that the pace of clinical and academic life is also a clash of cultures. The time needed to think about my thoughts, and the slowness, and learning through a written explanation (Richardson 2005) has also challenged both my understanding of myself and has challenged my self worth. I recognise the speed at which I think and act in the clinical situation (and my ability to pace this to the clinical situation) is valued professionally by others and myself. This speed though is acquired through years of clinical practice and study, and is required for the professional grade I am appointed to. Translating the speed I have in clinical practice (where I am expert), to an expectation for the PhD study (where I am a novice), alongside the fact that University life anticipates that thinking can take time, discussion and safe containment, has brought me to my knees. For this research the ability to sit with the data, and allow a range of thoughts, rather than proceed with the first thought (which is also often an ill informed thought as I have been learning about psychosocial studies) has been critical. I have had to manage the conscious anxiety as best I can about the slowness of progress of the PhD, and live with the experience of irrational thoughts bubbling up, and feeling out of control. PhD supervision has been part of this painful process. Through the PhD I have more learnt to understand the differing socio-cultural expectations of personal fluency and functioning by the university and NHS, and from my own internal values. At times the irrational thoughts and feelings result in my hating the PhD for all its impact, yet I understand at some level this is splitting and projection to alleviate myself of anxiety at the demands of the PhD on me. I oscillate between this and depressive accommodation when I realise the benefits of learning through the PhD.

At the February 2015 supervision I specifically asked for feedback, from Dr Lucey, about my understanding of bravery and courage. The fact that I asked indicates

the level of support I felt to think the unthinkable regarding learning. I did have a safe container to hold my unknowing re the data in PhD supervision (Salzberger-Wittenberg 1999). In this supervision I was again prompted to think about my interpretation of the data.

**Figure 4.** Example of Supervision notes.

**Exert from supervision notes 25<sup>th</sup> February 2015.** Bravery / courage. What particular kinds of feeling affect courage? What connects me to the data versus what can be a defence? In the face of something that frightens you – yet we function and function well. Say more about my starting point. Elaborate more on how we might understand courage and bravery and how data might show different ways of understanding it. What about lack of courage? Complexity includes unconscious. NB. There was no record of upset after this supervision.

Academically, it was these challenges about my interpretation of bravery in supervision that made me return to the themed analysis and present it directly, rather than my interpretation of it, to the workshops for consideration. I made a commitment to really let the HCPs in the workshop speak and to hear what they said.

The second example relates to where I was challenged regarding my interpretation of the data from Workshop Three (Study Two). By way of explanation, in this workshop I found myself completely panic-struck when HCP 9 talked about euthanasia and considered the death of her mother to justify her decision-making (this is discussed in Chapter Eight). At the time, the best I could do was to be silent. I was terrified I was going to have to breach the HCP's confidentiality if the euthanasia overstepped a professional boundary (it did not). My Mother died when I was eight, and I could not ever imagine wishing your mother dead. Jervis (2009) highlights how one way to examine the unconscious defences of the researcher is to utilise the embodied response of the researcher. The caution offered though is for the researcher not to interpret those feelings evoked in them in the research without supervision, as it can compromise the results and discussion. Over time I have written about this portion of the workshop three times in the write up of the PhD. The first time I wrote a reflection about my

learning and identifying what my distress was. PhD supervisors felt it was well written but did not add to the PhD. The second time I wrote about it in the education chapter, and again analysed why I was distressed. Again I was asked by my supervisor to think again as my distress and shock was preventing me from engaging with the data. I was writing about me, and not what I could interpret from the data. It was on the third attempt that I was able to sit with my very uncomfortable and distressed feelings and really represent what the data represented for the HCP and education. It had required the containment and support of supervision, as per Bion's concept of containment, and emotional containment of myself to get my own distress out of the way in order to really see the data. The education chapter remains the one I feel was hardest to write.

In this section I have described my experience of being a psychologically defended researcher in the conduct of this research, and a little of my experience of supervision, and of having my defences challenged. It is supported by reflexive diary excerpts. I am also mindful that conscious thoughts and processes slip away, into forgetting and unconscious processes all the time (Doyle 2012). Additionally this is only one side of a supervision narrative. Drawing on Bibby (2011) it is clear that the time and psychological space *in supervision* [my words] is necessary to think the unthinkable about the data and the researcher, and for that thought to find a resolution, *if only a temporary resolution* [my words], for communication about that thought, for un-thought thoughts to be verbalised and considered, for new connections to be made. After supervision this learning is further challenged, developed and sometimes avoided through the reading and understanding of books and papers and re-consideration of the data. The learning is ultimately transcribed into and through text to feed into the next experience of supervision. Alongside the learning, learning about how to learn is painful and I have valued supervision of my learning experience. Doyle says that reflexivity is a "state of mind and a practice in which to actively engage" and that "theorizing reflexivity raises further questions about what kinds of event, circumstances and characteristics provide optimal conditions" (Doyle 2012, p.251). I would argue that understanding how we all learn is a mutually required characteristic of supervision, and it would be helpful to overtly address this in the context of the

privilege of written text in academic life (Bell and Birch 2007) at the beginning and at strategic points in the PhD journey. It could be helpful to have a supervision contract that alongside such things as frequency of supervision, and expectations and rights of supervisors and supervisees, names that learning is an emotional experience (Salzberger-Wittenberg 1999) so that thought about this aspect of learning is similarly addressed at strategic points in the PhD journey.

### **Pen portraits**

The reader will recall that the 13 HCPs that took part in the critical incident review (Study One) were asked to describe how they made their decisions that the patient was dying, and how they interacted with the patient and family. After the psychosocial analysis of Study One and two data, pen portraits of the six patients discussed by the 13 HCPs in the critical incident review (Study One) were drawn up and these will be presented in Chapter Four. The purpose of these pen portraits is to provide the reader with a brief description of the patient and their family, the context of the patient's clinical care and decision-making by HCPs about their care. The aim is to bring the complexity and uniqueness of each patient care episode to life for the reader and thus foreground the themed results chapter, psychosocial analysis chapters, and discussion. Consistent with the theory of the defended subject - "I have not ironed out inconsistencies, contradictions or puzzles" (Hollway & Jefferson, 2013, p.65). I have labeled the patients by number to preserve their identity.

### **Ethics**

University Department of Psychology ethics approval was sought and gained for this study - (Reference number 13-2014) on the 9<sup>th</sup> Jan 2014. The Medical Research Council (MRC) and NHS Health Research Authority questionnaire (<http://www.hra-decisiontools.org.uk/ethics/>) was completed and it confirmed that NHS REC approval was not required. NHS Trust Research and Development Committee approved the proposal (RD377) on the 30<sup>th</sup> January 2014. There are a number of ethical issues associated with this study. These have been addressed with the support of written guidance (British Psychological Society, 2009) and Trust guidance; and through discussion with experienced researchers (PhD Supervisors) and lay members of the Trust research and development committee.

The ethical issues were:

*Confidentiality* related to: a) confidentiality for patients and families. This was addressed by asking participants not to mention patient identifiable information in the interview or PAR groups. This was screened for this pre-transcription, and b) confidentiality for participants who work in the same setting as each other. This was addressed by having a clear discussion about this topic within the working agreement for the group. This agreement was written up and displayed clearly at every PAR group. All transcripts were anonymised. c) confidentiality for participants on publication. The consent for the study highlighted that direct quotes would be used, and that I would anonymize them. There is always the possibility the HCPs will identify themselves.

*Recording and Storage of data.* The Research Data Policy of the University of Bath was followed.

*Sensitive professional issues.* There was potential for issues of excellent and poor practice to be raised within the discussions. This was addressed ahead of any disclosure by clear discussion within the working agreement of the group. If there was specific evidence of professional misconduct then the need to breach confidentiality was mentioned in the participant information.

*Potential for participant distress.* All participants of Study One and Two were given information on where to gain support outside of the Trust if taking part in the research distressed them. I was available after the PAR workshops to de-brief participants had it been needed.

*The role of myself as researcher-practitioner.* There is extensive literature both on the researcher – practitioner role (Rolfe, 1998), and the situated ethics of this role (Bell and Nutt 2002). Like others (Lee-Treweek 2000) this study has required extensive use of myself to design the study, manage the conduct of the study, manage my own emotions in the PAR workshops, and in the analysis and write up. For the purpose of this research, my role was made clear within the explanation of the study. I have kept a diary and ensured the anonymised data and themes, the psychosocial analysis and write up were exposed to regular supervision by the



PhD supervisors and also my clinical supervisor (Seale, 1999). The importance of this supervision communication with others is highlighted by Lucey where, in analysing the interview data in the qualitative longitudinal data of girls growing up, she with her co-researchers “reflected as a team on their individual responses in order to shed light on “unconscious to unconscious communication” (Parker (1995) cited in Lucey, Melody, & Walkerdine, 2003) as considered in the discussion of the psychologically defended researcher above.

### Summary

In this chapter, the research question, methodology and method has been covered. In Study One thirteen senior HCPS undertook a critical incident review. These involved the ward based senior HCP who identified dying, and the Hospital Palliative Care Team (HPCT) HCP(s) subsequently involved in the patient’s care. Interviews were recorded, transcribed and themed. In Study Two senior HCPs across the hospital were invited to four consecutive PAR workshops to critically reflect on the themed data from Study One. Ten HCPs took part (three HPCT HCPs were involved in both studies). The interviews were similarly recorded, transcribed and themed.

The themed analysis yielded a model for decision-making but did not explain why dying was identified so late. A psychoanalytically informed psychosocial approach was taken to examine anomalies and contradictions in the data that pointed to less conscious undercurrents in the personal, professional, educational and institutional dynamics involved in the care of patients who are dying. The next two chapters cover the pen portraits of the patients who were the subject of the interviews with the HCPs in Study One and themed analysis of Study One and Two data.

## Chapter Four – Pen Portraits Of The Patient And Health Care Professionals From Study One (Critical Incident Review)

### Introduction

The reader will recall that in the Critical Incident Review (study one) the 13 HCPs were asked to describe how they made their decisions that the patient was dying, and how they interacted with the patient and family. After the psychosocial analysis of study one and two data, pen portraits of the six patients discussed by the 13 HCPs in the critical incident review (study one) were drawn up and these are presented here. The purpose of these pen portraits is to provide the reader with a brief description of the patient and their family, the context of the patient's clinical care and decision-making by HCPs about their care. The aim is to bring the complexity and uniqueness of each patient care episode to life for the reader and thus foreground the themed results chapter, psychosocial analysis chapters, and discussion. Consistent with the theory of the defended subject - "I have not ironed out inconsistencies, contradictions or puzzles" (Hollway & Jefferson, 2013, p.65). I have labeled the patients by number to preserve their identity.

### Pen Portraits of patients and HCPs in Study One

#### Patient One

##### *The Patient's story*

This independent elderly lady<sup>10</sup> had previously survived a breast cancer diagnosis. She was admitted to Intensive Care for management of breathlessness and drainage of pleural effusions. She was conscious despite being intubated and had written for the doctors that she wanted the ventilatory tube removed. They explained it meant she would die, and she agreed. Whilst the team sought second opinions, and communicated with her family, her condition deteriorated, she required more sedation, and she attempted twice to pull the tube out herself. She died in Intensive Care; her family had the opportunity to be present.

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<sup>10</sup> The level of detail about a patient e.g. their actual age is variable and dependent on the narrative of the HCPs.

### *The HCP's story (HCP 1 and 4)*

The ITU team suspected an underlying malignancy when escalating management of the breathlessness did not improve the patient's condition. The laboratory report of a metastatic cancer allowed them to plan the patient's dying. Once the recognition of dying occurred, there was still the process of taking things by the "proper channels" which meant a second opinion from the respiratory team, and to involve palliative care. These processes meant that the patient remained intubated despite her request for the tube to be removed. The ITU HCP was not involved with the family meeting as the ITU Consultant took over.

### **Patient Two**

#### *The patient's story*

This patient had paranoid schizophrenia, previously lived in a care home, and was admitted to a ward with heart failure and sepsis. He was married, although he and his wife did not live together. The patient initially requested the chaplain to provide a bible and prayer for him and his wife, and was expressing concerns that the hospital was holding him against his wishes. However, three days later, as the patient's condition deteriorated, the chaplain was again called. The patient was transferred to Cardiac Care Unit for the management of a pericardial effusion. He died in hospital.

#### *The HCP's story (HCP 2 and 3)*

At the first visit the chaplain recognised the patient's mental health issues. He offered prayer and reassurance to the patient and promised to visit again. The second request for a visit came because the patient was distressed and his wife was asking for "some sort of attention". On that assessment, the chaplain noticed a physical deterioration and raised that the patient might be dying. He also noted he had a look of someone who had died in the manner his jaw line was set.

Palliative Care then reviewed the patient twice. Initially the patient appeared physically and psychologically improved. However, on the second assessment the patient had deteriorated and was transferred to coronary care for the management

of a pericardial effusion. He required oxygen, intravenous therapies and was bedbound and needed all nursing care. The palliative care HCP did not challenge the plan of care, and felt the dying was not missed as retrospectively other HCPs had expressed surprise that the patient had died. He described the patient's condition as "AMBER"<sup>11</sup> – "will he or won't he" [survive]. The HCP understood the medic's treatment plan, and would only consider a "more urgent need to question the medics" if the patient was unresponsive. He felt he has a tendency to "oversee dying".

Neither the patient's wife nor the mental health care worker was present when the palliative care HCP visited. He did reflect that it might have been useful to contact the patient's wife.

### Patient Three

#### *The patient's story*

This 70-year-old gentleman had lymphoma, and was being treated with chemotherapy with curative intent. However, he was admitted to hospital with fatigue, and to biopsy a lump that had grown in his groin. There was a ten-day wait for the results. He, and his wife wanted to know the news "good or bad" and his only wish was to get home "to do the patio". His wife had a degree of dementia, and the patient wanted his younger brother, rather than his son, to take control of things financially to look after his wife. The patient was discharged home from hospital for end of life care, with his brother as key contact.

#### *The HCP's story (HCP 5 and 6)*

There was doubt, four months earlier, at the beginning of curative chemotherapy, whether the patient could tolerate chemotherapy. Since the patient wanted treatment, the lead HCP felt "in her own heart" it was right to try, but this was the limit of treatment. So when the patient presented with a lump whilst having chemotherapy, and the biopsy of the lump was confirmed as lymphoma, the lead

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<sup>11</sup> AMBER is the name of a care bundle, developed by Guys and St Thomas's Hospital, to be used to prompt decision-making and conversations when a patient's recovery is uncertain and death within six weeks is likely.

HCP was clear that the plan of care was “palliative”. She organized a family meeting at a weekend when she was on call when she knew she would have time.

The ward HCP whilst knowing “things weren’t right”, needed “solid evidence/proof” in order to speak with the patient and family. She did not want to deny any patient something meaningful and expressed wariness of “getting the decision (about dying) wrong”. However, she did acknowledge that ward nurses had recognized that the chemotherapy was becoming futile earlier than she did.

The palliative care HCP knew the patient from a previous admission, and found it helpful to have a ward HCP who gave clear information, and who was prepared to make a decision and not maintain “false hope”. The HCP described it as the “hardest thing” when lead HCPs deny the dying when she can “see it”. The HCP led the discharge planning meeting and negotiated that the brother would be the key contact (she knew the patient’s wishes) and the son accepted this.

#### **Patient Four**

##### *The patient’s story*

The patient was a young man admitted under the gastro-intestinal team with vomiting; investigations were indicative of an upper gastrointestinal malignancy. He then had a stroke and went to the stroke ward for care. He did not have capacity to be involved in decision-making, was unable to communicate, was vomiting (as the cancer was blocking the outlet of his stomach), and he was being fed intra-venously. A stent (a tube with an opening) had been placed in his gastric outlet to try and relieve the obstruction and reduce the vomiting. The patient was jaundiced, had no control over his hygiene or any bodily motions, was restless, and had swollen legs.

His brother was almost constantly present on the ward. He was suspicious of the medic’s treatment decisions, questioning whether he was being offered treatment that would have been offered to a UK national as initially the patient’s residency status had been questioned<sup>12</sup>. Additionally, the brother wanted the patient kept

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<sup>12</sup> If he had not been a UK resident he would have been required to pay for his medical treatment.

alive for long enough for his wife and children to visit from abroad. Neither the patient nor the brother's first language was English. The patient died on the ward within two days of the medical recognition of dying.

*The HCP's story (HCP 7,8 and 9)*

The ward HCP for the patient's care empathised with the patient, as he was young, but described it as a "professional relationship with a large degree of detachment". The gastro-team, whose ward the patient was admitted to, were responsible for discussing the cancer diagnosis in the Multi-Disciplinary-Team meeting and securing a treatment plan. The ward HCP was happy to take a "palliative approach", when the patient transferred to his ward, but wanted a "cast-iron" decision that all treatment options were not in his best interests. The ward HCP described how his first instinct that the patient was dying was the weight loss - "the first big alarm bell was just the quantity weight loss after a three week time period".

It was on a routine ward round, seeing that the patient was deteriorating and hoping for a plan in the medical notes from the Gastro team, that the ward HCP saw an entry which said "re x-ray to see if the stent is in place". The HCP who had wanted to know whether the patient was a candidate for surgery or palliative measures, and understood this entry to mean, "I can't do anything here". The HCP seized the moment to speak to the brother who was "hovering" to leave him in "no doubt" that this was an "aggressive malignancy without hope of cure". He introduced the options of hospice and palliative care management for the nausea and vomiting.

The first palliative care HCP to review the patient immediately had a gut instinct that he was "very very sick and not far off starting to die". She felt out of her depth and called for back up. On reflection, she felt it is a nursing culture, to trust your gut instinct and to think and plan.

The second palliative care HCP never saw the patient but looked at the scans and test results, and then rang every consultant involved in the care to secure that there was nothing more they could do. Without an oral route for feeding, this

patient was facing his end of life. The first palliative care team HCP could then, with this knowledge, continue to care for the patient and hold on-going conversations with the brother.

## **Patient Five**

### *Patient's Story*

This elderly gentleman (with dementia and Type 2 diabetes) was admitted from a care home with a gangrenous foot, and sepsis. His admission to the care home was very recent (his wife had previously cared for him at home), and on hospital admission he was bedbound with a reduced dietary intake, and did not have capacity to take part in decision-making. He was described as having a large, odorous and painful leg wound, for which antibiotics were not helping, and for which an amputation was the only option. Movement caused him great discomfort. He had a wife, who wanted him cared for on the ward, a daughter and a son who lived abroad, who returned for his father's dying. The patient died on the ward within a week of medical recognition of dying.

### *HCP's story (HCP 10 and 11)*

The HCP reviewing the patient was not the ward HCP (surgical) but a HCP on a multi-disciplinary foot round (consisting of a vascular surgeon, endocrinologist, and foot specialist) as the ward HCP was not the person with expertise to make a decision about amputation. The HCP reviewing the patient described how being part of a MDT foot team made for a much more robust discussion than making this decision as a lone worker (if she had been alone she would have asked an anaesthetist if the patient was likely to survive the anaesthetic, rather than make the decision alone).

The lead HCP reviewed the patient with the surgical ward junior doctor; it was identified that the patient was too frail to survive surgery and the approach was going to be palliative and comfort focused. What had informed her decision to take a palliative approach was witnessing the nurse taking the dressing down. She described how "you could smell the amount of pus in the legs, and if he had any awareness, you can imagine, no one wants to be in such pain or smell with a

wound and be in so much pain". She did not engage with the family, and assumed that once palliative care were involved the ward team would speak to the family.

She described feeling sad when an end of life decision is made and a moral duty to make sure she has done everything possible. She described how she teaches junior doctors that if they are worrying, they have made the wrong decision, because if they had made the right one they would have argued the justification in their head. She recognises that some decisions are more difficult than others, but in that case you treat and go back and check.

The palliative care HCP was involved subsequent to this decision with the meeting with the family having already been set up by the junior ward doctor. She met with the junior medical team beforehand to agree an approach and the only decision to be made was whether antibiotics were to continue. The palliative care HCP encouraged the family to talk to the son abroad. When she made a bereavement call the son said how much he valued her input.

## **Patient Six**

### *Patient's Story*

This 92 year old gentleman had a past medical history of dementia. He had a laparotomy the previous week for a tumour in the right side of his colon, which had been surgically bypassed to prevent obstruction. The cancer multidisciplinary meeting could not offer other cancer treatment options and a prognosis was expected of months at best. He was described as being very happy reading his books about aeroplanes, talking about the past. He had a very poor short-term memory and he didn't understand that he had cancer.

The patient had a supportive wife. Having nursed her first husband until his death from a progressive neurological condition, she wanted this husband to have a "good death" at home. From her first marriage, there were two daughters and from his first marriage there were two sons. The sons and their families were not speaking to the daughters, and they felt that their father's wife was hastening his death, and felt that more should be done to prolong his life.



On the Friday, he was discharged home for end of life care, he was described as sitting up in the chair, drinking a cup of tea, and eating cake. The patient was readmitted on the Monday with symptoms of either intra-abdominal collection or obstruction. He was barely conscious in the bed, his wound was leaking profusely; he had not been eating and drinking well, he had vomited and had diarrhoea and had fallen at home. On re-admission he looked pale, grey, agitated in the bed and very unwell. His wound was swabbed, intravenous fluids were commenced, but antibiotics were not started until the infection was proven as there was no pyrexia. He was cared for in hospital for a week, whilst the discharge package of care was worked up, and family concerns were addressed. He was discharged home again for end of life care, and died within a day.

*HCP's Story (HCP 12 and 13)*

On the second admission, the ward HCP was immediately clear that this patient was "terminal" - the reasons given for futility were age, extent of the tumour (known from examination of the laparotomy the previous week) and septic shock. He has a personal philosophy of believing that we all die and since this patient was elderly he could accommodate this without too much distress.

The ward HCP could not remember the family at all, but felt they were "probably expecting it and understanding". He spoke about what he usually does in such circumstances. If the patient is terminal then he would involve the family beforehand, take the patient and/or the family into a side room with nurses and other staff and explain the plan of giving fluids, painkillers and whatever other conservative treatment (other than surgery) is possible. He couldn't remember if he had reviewed the patient again, but he described how dying patients would be in a side room, he would prescribe fluid and analgesia, and how he tries to avoid to take a group of doctors to do a formal ward round when their input is very minimal. The intention would be to let the patient have a peaceful death.

The palliative care HCP went straight to the ward, as soon as the referral was received the day after admission. She found a son, his wife and a granddaughter waiting to speak to the doctors. The son wanted all active treatment continued for as long as possible. The meeting involved addressing his concerns and explaining

the rationale for decision-making. She thought the son understood by the end of it. The HCP tried to address with the son how information would be shared with all family members and he explained it would be difficult for all the family to be together.

The palliative care HCP asked palliative care team member to review the patient the next day, to ensure that she hadn't missed anything. Due to the complexity of the family she felt a complaint was on its way.

## Summary

These composite pen portraits are summaries of the critical incident reviews that were used in interviews with HCPs in Study One. They set the context for the reader for the themed analysis which was presented to the Study Two workshop participants for their consideration and discussion, and which is described in the next chapter.

The themed analysis of the Study Two transcripts is also contained in Chapter 5, ahead of progressing to the psychosocial analysis of Study One (Chapter 6 – The Task of the NHS) and Study Two (Chapter 7 – Families and Chapter 8 – How senior HCPs learn to care for the dying patient and family).

## Chapter Five - Themed Results of Critical Incident Reviews (Study One), and Participatory Action Research Workshops (Study Two).

### Introduction

This chapter will document the themed analysis of the thirteen Critical Incident Reviews (Study One), as was presented to the Participatory Action Research (PAR) workshop participants. This thematic analysis identified a four-stage model of decision-making, albeit in rudimentary form, subsequent to HCPs' responses to the Critical Incident Reviews. The stages consisted of: 1) a "gut instinct" that the patient was dying; 2) evidencing this through four techniques; 3) engagement with the patient and family; 4) and managing the fall out of decision-making. I asked HCPs about their personal response to recognising dying and this is included.

The analysis of the four PAR workshops (Study Two) gave depth to the themed analysis of the Critical Incident Review (Study One), and added detail to the model of decision-making. By reflecting specifically on the themed data, HCPs were able to point out what the analysis of study one had not captured, when compared to their experience of clinical practice. They highlighted that all patients in Study One had died, and they described the very significant experience of a patient surviving the prognosis of dying, and the impact that had on the HCP, patient and family relationships. Analysis of the PAR workshops (Study Two) allowed evaluation of PAR as a route to develop this aspect of clinical practice. It also facilitated the addition of a fifth-stage to the decision making model. I have called this "clinical supervision" because the HCPs highly valued the opportunity to reflect and discuss clinical practice, through skilled facilitation of the PAR workshops.

Part of the rationale for this research, argued in Chapter 2, is that identifying dying earlier than the last few days of life is resistant to change. This clinical work takes place in a complex organisation where there are high numbers of patients treated every week, and where the organisation is focused on "no needless deaths" and a political context of much media controversy about end of life care. The Critical Incident Review (Study One), and the PAR workshops (Study Two) gave a voice to

individual HCPs, and what really stood out from the PAR workshops, was the depth of responsibility HCPs felt to make the right decision that the patient was dying, and not to deny the patient any meaningful quality of life, the very strong emotions HCPs felt, the impact of the family on the HCP and patient relationship, and the lack of formal educational preparation for this aspect of clinical care. The level of anger at other HCPs who were perceived as avoiding this work also stood out strongly. The chapter concludes by re-iterating why a psychosocial approach was needed to help illuminate whether there were unconscious, less than rational processes, in decision-making about recognising dying and engaging with patients and families, that might explain why the model of decision-making might or might not be used. The psychosocial analysis is presented in the following chapters; Chapter 6 – The Task of the NHS; Chapter 7 – Families; Chapter 8 – How senior HCPs learn to care for dying patients and families. I recognise this iterative and pragmatic methodology can require understanding by the reader and a flowchart to guide you to the process is located in Appendix 9.

### **Themed Analysis of Critical Incident Reviews (Study One)**

I thematically analysed the data from study One, ahead of the presentation to the workshops of Study Two for the participants' consideration and discussion. An example of one of the PowerPoint presentations used in the four PAR workshops is located in Appendix 7.

### **Decision-making about dying and negotiating decision -making**

From the data, at this stage, I described four stages of decision-making 1) a “gut instinct” that the patient was dying; 2) evidencing this through four techniques; 3) engagement with the patient and family; 4) and managing the fall out of decision-making. I asked HCPs about their personal response to recognising dying and this is included.

#### *Gut instinct*

When the HCPs from Study One were asked about how they recognised “the dying” for the patient they were discussing, most HCPs recognised a “gut instinct” that the patient was dying. This was described as a “*deterioration in his look*” (Patient Two,

HCP 3) or the “*look of the patient*” (Patient 5, HCP 10 and 11) or an “*alarm bell*” about weight loss (Patient Four, HCP 7) or a “*gut instinct*” based on the level of patient distress (Patient Four, HCP 9). One HCP had developed vigilance for a particular cue “*you start to identify signs...one of my favourite signs now is looking out for temporalis wasting*” (Patient Four, HCP 7). One HCP identified that the patient looked as others looked after death.

*I have seen patients who have just died or are just a couple of hours from death & something about their facial experience sometimes; their jawline, you know, the fixed nature of that jaw & when I looked at him I kinda almost got one of those images & gosh I can almost imagine how you are going to look when you die, which I hadn't even thought on the Friday (HCP 3, L71-77 Study One).*

Not all HCPs described a gut instinct but had a general recognition that the patient was not improving despite treatment escalation (Patient One, Patient Three), or the recognition that there were no further treatment options (Patient Three and Patient Six).

#### *Evidencing the gut instinct*

HCPs then denied or evidenced this gut instinct through four techniques, which involved combinations of “treatment escalation” and “staging” (See below for explanation).

I identified treatment escalation and staging as:

- “Justifying treatment escalation and not introducing the concept of dying” as evidenced by Patient Two.
- “Treatment escalation and patient recognises that they are dying” as evidenced by Patient One.
- “Staging dying” as evidenced by Patient Three, Five and Six.
- “Treatment escalation until dying cannot be ignored and then a rapid staging” as evidenced by Patient Four.

“Treatment escalation” is expected medical practice, such that when there is deterioration in the patient’s clinical condition, another treatment is added in a “can I cure this symptom approach?” in an attempt to prolong life. It assumes that death is not imminent, and that all side effects of treatments are worthwhile to attain a cure. This approach is so routine, and expected by patients and families, that neither patients or families are consulted when this approach is taken (Kryworuchko et al., 2012).

“Staging” is an attempt to prognosticate how long a patient could be expected to live in an attempt to work out what treatments are in the patient’s best interests, and does not assume that all medical treatments are tolerable to the patient, or that they will live long enough to appreciate the benefit. Oncologists and haematologists have long had to assess whether a cancer patient will survive to see the benefit of chemotherapy or radiotherapy, and make a decision to stop curative treatment (not care) in a patient’s best interests. This is seen in the care of Patient Three, where the HCP, knew “*in her heart*” that it was the right thing to do to give first line chemotherapy, but that the patient would never be fit for “*salvage chemotherapy*” if the disease progressed through the treatment. Indeed thirty day mortality is now a clinical indicator of avoidable harm, as the patient is likely to have died despite treatment and with the burdens of treatment (Wallington, Saxon, Bomb, & Smittenaar, 2016). There is also evidence that early palliative care prolongs survival in patients with lung cancer (Irwin, Greer, Khatib, Temel, & Pirl, 2013; Temel et al., 2010). In situations where the dying is due to a non-malignant condition, the situation is different as the treatments offered may be fluids, and antibiotics, and have a different risk/benefit profile to chemotherapy or radiotherapy.

#### *Engagement with the patient and family*

What ‘recognising the dying’ allowed was the potential to introduce the concept of dying to the patient and their family. In the data I could see a mixture of engagement and non-engagement with the patient and family. I identified three routes to engagement as:

- “Patient initiated” (Patient Two).

- “Seize the moment” (Patient Four).
- “Planned approach” (Patient Three, Five).

I identified four approaches to non-engagement as:

- “Informed decision not to engage” (Patient Three).
- “Blocked from engagement” (Patient Two).
- “Routine decision not to engage” (Patient Five).
- “Prioritising hope of recovery allows non-engagement” (Patient Two).

#### *Coping with the fall out of the engagement with the patient and family*

Once the HCP had engaged with the patient and family, I could describe two outcomes after breaking the news about the recognition of dying that I described as “managing the fall-out”. Where the dying was accepted (Patient Three and Five) then onward care planning could occur. Where there was no psychological acceptance of dying (on the part of the family), then the meeting was taken up with helping the family accommodate the news and negotiating ceilings of treatment that could be tolerated by both HCP and family (Patients Four and Six). These meetings were fraught and made the HCP feel anxious and frustrated.

I generated a model of conversation (Appendix 10) where the conversation with the patient and family was viewed, not as a route to advance care plan, but a space in which there was assessment of the patient and family’s psychological readiness to accept dying, to understand what psychological work was needed, and to mutually understand what treatments were in the patient’s best interests.

#### *Personal responses to identifying dying*

At the point of recognising the dying, HCPs described a variable personal response to this. For the workshops I did not analyse this further, than describing this.

- Some denied the personal impact of recognising dying, but said that recognising dying promoted a desire to act to address the patient’s care (HCPs associated with Patient One, Two and Five)
- Some felt the personal impact was part of their role and they didn’t battle with it or could rationalise it (HCPs associated with Patient Three and Four)

- One felt sad (HCP associated with Patient Five)
- Some felt recognising dying had an impact on them personally, particularly if the patient was younger (HCPs associated with Patient One, Four and Six)

### **Educational preparation for clinical practice**

I then presented the analysis of education preparation for this work in Workshop Four. This was not possible to theme as the responses were so variable. The importance of this is that I either did not sample enough HCPs to reach saturation point (bearing in mind that thirteen interviews was determined as the point to reach saturation (Guest et al., 2006)) or there has been a very individual experience of learning to care for the dying via clinical practice. It can be seen from the literature that this is a very likely explanation (Dickinson, Clark, & Sque, 2008; Walker et al., 2016), and especially because the HCPs had trained between 3 and 31 years ago and there have been many changes in medical (Greenaway & Greenaway, 2013) and nursing education (Willis Commission, 2012). I divided the results into medical education and nursing and chaplaincy education.

*Learning about dying: Doctor's medical education.*

HCP's educational preparation was in part dependent on the age of the clinician and their specialty. Older doctors could not remember specific teaching but could remember being taught to set up a room for a consultation. They felt that medical tests, drug treatments, and technical interventions (medical treatments) were taught, but how and when to give the treatment was learnt in clinical practice.

*I think the treatments are taught...the softer bits about what you can actually achieve in the real world, with a real patient in front of you...are more learned through experience (HCP 6, L57-62, Study One).*

Younger doctors identified that topics such as assessment of mental capacity and breaking bad news were taught at medical school now, and could take transferable learning skills into the clinical situation. Identifying dying was not taught. They recognised they had more opportunities for rehearsing conversations in the undergraduate curriculum, but this stopped post registration. Palliative medicine specialists identified that the care of the dying was part of the specialty training



curriculum to become a consultant, and breaking bad news was specifically observed and assessed. However, they were self-taught to recognise dying. The palliative medicine specialist used teaching as a time to reflect and process learning for others.

*When I teach, that is when I sort it out as a model in my head; so the teaching is a really good way of using that on-going reflection ...to put it in to something workable and usable (HCP 8, L282-285, Study One).*

The care of the dying patient was an integral part of the elderly care specialty curriculum, and one deanery<sup>13</sup> had a specific module where the training grade doctor had time with the palliative care team.

The surgeon interviewed could not really describe how he had learnt to recognise dying. He attributed it to reading the literature and NICE guidance. He had learnt from the experience of taking patients to surgery, without there being a survivable outcome, and learning from the clinical situation and from colleagues.

*I have seen similar patients before...when I was like quite junior registrar ...I jump on like we need to do something, then obviously then as a junior surgeon you are more like a sort of, your approach is slightly aggressive and I don't know, I guess it is the proper word or not but more prompt to do something...Whether it is helpful or not; and then I realise from my seniors and my colleagues who are more experienced that we need to do what is best for the patient in the long term (HCP 13, L53-58, Study One).*

Many reported asking nurses for feedback after family meetings.

*Obviously I try to get some feedback, also sometimes like I ask the nurses who are next to me am I missing anything or am I giving extra information or anything extra I should have done (HCP 13, L159-162, Study One).*

One HCP reported valuing ad hoc study days provided by palliative care.

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<sup>13</sup> A deanery is a regional organisation responsible for postgraduate medical training, within the structure of the National Health Service (NHS)

*I do think every time that someone does the Monday meeting, the palliative care team or academic half day all those kind of things do make a difference. Keeps people smart (HCP 11, L275-278, Study One).*

*Learning about dying: Nursing and chaplaincy education.*

No nurse could describe specific pre-registration training to identify dying, and associated care. One nurse had found the psychiatry placement helpful for learning about therapeutic relationships. Two could describe inspirational role models in their training.

*When I trained...it was considered ...legitimate at that time that a family might say please don't tell the patient and the patient wasn't told ...and was moved to the side room; interestingly one of my first very positive experiences of how this might be managed differently was the Macmillan nurse when I was training as a nurse came in ...and she was very much promoting open communication talking to the patient, involving them in decision-making which instantly impressed me" (HCP 2, L108-120, Study One).*

Younger nurses could describe how pre-registration nurse training included the care of the family, but not specifically about dying or communication regarding ceilings of treatment. Some HCPs described preparing to teach others, and found this to be helpful for their own learning.

*I have also taught at X University on end of life modules and done further looking at the papers myself to know the evidence (HCP 1, L121-122, Study One).*

Experienced palliative care nurses identified that experience and post basic study in communication skills and bereavement allowed transferrable skills for clinical practice in recognising dying.

*I have attended the Advanced Communication Skills Training, the psychological skills training; it's a lot about experience. There's a confidence in yourself and your role and your ability as a senior nurse to hold those kind*

*of its all of the things...that go into feeling confident to sit in the room and have that conversation with the family (HCP 10, L291-302 Study One).*

Most, senior palliative care nurses, had undertaken post registration training, although even a palliative care degree had not covered recognition of dying. Palliative care nurses had worked hard to gain the skills required.

*I did the diploma in counselling which I think is helpful but I didn't do group therapy or anything like that so again it is – I have done the advance communication skills – that type of training so I think ...there is a foundation of training of theory which experience probably magnifies hugely (Interview 5, L223-227, Study One).*

Most had learnt from role models, although it was identified as harder as they became more senior, and practiced skills in supervision.

*I don't get much opportunity now to watch others you know who can role model to me because of the position I have now; so, but we always pick up things from colleagues so there may be a phrase I like or I think that's a good way of doing that; also supervision. So in supervision sometimes I will have a little practice, role play (HCP 5, L232-237, Study One).*

Chaplaincy colleagues had minimal training.

*I think it has been acquired through practice and through on-going pastoral care training and in communication...throughout my parish based ministry over 25 years and two churches...I haven't had any specific training in the last year since I have been here about that particular thing...but I have some good tutors on the palliative care team and I notice what they do and how they communicate (HCP 3, L208-213, Study One).*

### **Analysis of Four PAR Workshops (Study Two)**

I am going to summarise the main contributions from analysing the workshop transcripts below in relation to the themed analysis presented to the participants.

### *Gut Instinct*

When considering the themes that arose from the Critical Incident Reviews (Study One) HCPs in the PAR workshops (Study Two) identified clinical experiences that had not been captured before. For example when the data about “gut instinct” was presented, two HCPs identified that they could smell when someone was dying.

*INT JW Gut instinct slide...is that something you recognise?*

*Group yeah*

*PART 9 Sometimes the observations are fine, but you just have a look*

*Group (laughter)*

*PART 9 He's dying. It's a look. Maybe with experience you see the other stuff.*

*Another thing I can smell when a patient is dying*

*PART 5 yeah we had a conversation in the office the other day about the smell*

*PART 9 yes I can smell.*

*Group (laughter)*

*PART 9 I am very sensitive. Everyone was afraid in my previous job*

*Group (laughter) (L244-254, Workshop One, Study Two).*

### *Evidencing the gut instinct*

HCPs found looking at how dying was staged interesting and it provoked discussion amongst the PAR workshop participants. They had not considered staging dying previously.

*I have not previously considered the different pathways as we did today. However, I found it useful to do so I as I require several of these. Identifying dying remains a challenge and an individually responsible task! A useful session (HCP 7, Workshop One, Study Two).*

### *Engagement with the patient and family*

When considering the data from Study One about whether HCPs engaged or didn't engage with the patient and family, they recognised the themed data from the critical incident analysis (Study One) and could describe which strategy for engagement they usually used.

*HCP 8 Most of ours is a planned meeting.*

*PART 7 definitely*

*PART 8 A little bit of seize the moment and a little bit of patient initiated I guess*

*INT JW How does it get to be mostly planned for you?*

*PART 8 Because we can see it coming. Most of our patients aren't well one day and dying the next (L478-486, Workshop Two, Study Two).*

HCPs also identified a clinical scenario that was missed in Study One and described how the patient or the family could test whether it was safe to engage. They would do this by not mentioning the topic of dying until the end of the conversation when there was not time to discuss their concerns fully, and it would need to be returned to.

*Sometimes patients you will have half an hour consultation in clinic and its not until after twenty minutes and you think that things are OK and you don't have any immediate concerns and they will say to you "I am really concerned about dying" it just comes out and you are not expecting it at all...that's tricky (L629-636, Workshop Two, Study Two).*

HCPs did discuss planned non-engagement with the patient and family due to clinical reasons. They expressed discomfort at the other reasons found in the Critical Incident Review (Study One) for non-engagement.

*PART 5 I find it quite hard to associate with any of them [non-engagement].*

*INT JW OK*

*PART 5 Personally I find it easier to relate to the time thing because time might stop you from getting engaged but I, I don't*

*INT JW recognise those human factors*

*PART 5 No (L912-917 Workshop Two, Study Two).*

*Coping with the fall out of the engagement with the patient and family*

In Workshop Three, I presented the model of conversation I had generated where the conversation with the patient and family was viewed as a space in which there was assessment of the patient and family's psychological readiness to accept dying,

to understand what psychological work needed to go on, and to mutually understand what treatments were in the patient's best interests. It was well received.

*Interesting to see that the psychological assessment of patients and families is a stage / important as although I may have subconsciously realised this I hadn't thought about it and it makes sense. To look at this & think more when talking to pts & families about where they are in the acceptance journey (Feedback from HCP 5, Workshop Three).*

In this PAR workshop participants discussed their experiences of patient's families. It became clear that caring for patients and their families is really difficult clinical work. Just how challenging HCPs find the pleading of families for anything to extend the patients life is detailed in the quote below. HCP 1 had had 32 years of clinical practice and described themselves as "at ease with dying".

*Because everyone, is difficult. When it is difficult it really is difficult. You try and keep consistent, say the same thing but when they are demanding things...and sometimes we had somebody the other day – she was young, she was dying, knew she was dying, she was actively dying and the daughter was saying and the family are saying, young family, why can't you just give antibiotics, why don't you just give it go, what have you got to lose? And I am thinking well maybe for you, if we give it a go, maybe psychologically after the death you will cope better because you will feel we did do something, is that we should be doing for you? But luckily I had a consultant who I called and she held the ground and she was firm and she said to them giving antibiotics could have detrimental effects, and side effects of antibiotics can be great, and they can get diarrhoea and afterwards the daughter said I understand now you are right; but if it had been left to me I was wavering (L424-435, Workshop Three, Study Two).*

They discussed how easy care of the patient was when the family accepted the dying, and the accusatory impact of families of patients who survive a prognosis of dying.

*But we have had problems with this this week as we have had two patients who have got better, and the family are saying you told us they were dying and we are ready for them to die, we wanted them to die, and now they are getting better we have to change our plans (L329-333 Workshop Three, Study Two).*

They discussed the appearance of previously unknown relatives, families who are angry and force doctors to overturn decisions, and families they see as guilty and demanding. All of this is considered in detail in Chapter 7.

#### *Personal responses to identifying dying*

HCPs in the workshops expressed the tremendous responsibility they felt for clinical care of dying patients. One poignantly identified a feeling of constant vulnerability.

*You can always drop the ball at any point and that is where a lot of the stress comes in (L 55-56, Workshop One, Study Two).*

They discussed the emotional impact of caring for dying patients and their families, and again highlighted experiences not captured in Study One.

*I recognise the old and the young difference. One thing that is not described there which I recognise is survivor's guilt remains with you especially if they are younger, and I sometimes feel guilty that they are dying and I am not (L60-62, Workshop One, Study Two).*

HCPs highlighted that all the patients that had informed the Clinical Incident Review (Study One) had died. They discussed how patients who outlived the prognosis of dying had a profound impact on HCPs, causing them to both doubt themselves and their decision-making. It also then had the potential to affect subsequent HCP, patient and family relationship. They discussed how the emotional consequences of this clinical work impacted beyond the physical work boundary into their personal lives, especially if the patient started to recover.

*Because they [family] told me Ok I was trusting you saying to us he was going to die and now he move his eyes, move his limbs so what's the programme now so you have to change things. I have done a night awake just going through things (L241-244, Workshop Two Study One).*

HCPs expressed anger and frustration at colleagues who avoided dealing with the care of the dying patient and their family – HCPs described colleagues who wrote in the clinical notes “consider Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)” to avoid conversations with patients and families and leave the work with others. They described colleagues, who denigrated their clinical work with older adults as easy.

*The same colleague once told me - your job must be very easy because they are all old, who cares if they die (L485-486, Workshop Four, Study Two).*

They described other colleagues who used written referral processes for second opinions, and so avoided honest conversations with the patient and family, and as importantly left the second opinion HCP to deal with the patient and family anger.

*You know if you are on old school consultant then you're used to waiting. Put in the yellow form, doesn't matter if you wait five days...It means they don't have to face those relatives because they can blame it on the haematologists or whoever they are waiting for, when they could have made those decisions (L522-533, Workshop One, Study Two).*

HCPs questioned whether changes in clinical practice over the last thirty years of their careers were all helpful. They discussed how early on in their careers, whilst a DNACPR decision might have been recorded in the medical notes, it was not discussed routinely with patients and their families. Neither was there any form of “care of the dying pathway” (whilst the Liverpool Care Pathway has been withdrawn, care planning for the dying patient hasn't and HCPs still use the older language). HCPs felt that since these topics are now enshrined in national guidance they have to be introduced to the patient and family, which both conveys a false certainty around prognostication, which then means relatives want certainty about when patients will die.



## Educational preparation for clinical practice

HCPs recognised the themed data from the Critical Incident Review (Study One), about how HCPs learn.

*Yeah that very much strikes chords with how I recognise; your taught very factual stuff on how to do this and processes; the softer aspects – and I think that is quite a nice term – are learnt from seeing people do it poorly, badly but also recognising people who are skilled (L177-180, Workshop Four, Study Two).*

They discussed changes in medical and nursing education over their careers. They recognised an isolation and loneliness in clinical practice with regard to families. Whilst they are “expert” in their clinical field, receive on-going training for this, and train others, they rarely have opportunity to watch others who are more skilled with patient and family conversations.

*As you are more senior you lose the chance to be with others...sometimes it happens for some reason that you are with someone, maybe they have a similar role or experience ...is totally precious, and it's not formalised, it happens now and then by chance, or sometimes you can share a conversation – for me this is really really valuable to see things I can see in others (L457-464, Workshop Three, Study Two).*

Apart from Palliative Care professionals, HCPs described a lack of clinical supervision, an increased awareness of general “aloneness” in clinical practice with regard to recognising dying, and that they utilised peer support to manage emotional distress. There was discussion of how HCPs learn and how junior clinicians could be encouraged to be involved in the care of the dying. This is discussed in detail in Chapter Eight.

## Evaluation of the PAR Workshops as a Means to Develop Clinical Practice

A clear aim of this PhD was to evaluate what HCPs thought of PAR and the workshops as a means to develop clinical practice. HCPs who took part in the workshops valued the content and form of the workshop highly and evaluated

workshops positively as a route to learning about how to care for the dying patient and their family. It was also notable that HCPs recognised that this method of learning would not replace other forms of learning, or work for all clinicians, and that it required good facilitation for the emotional safety of the participants.

*I like this method I think it is very good but I think I am not sure it can completely substitute the other forms, and I think this is a compliment. I think it has to have a very good facilitator because I think in the room we are not on the same patient because we all do different things but sort of answering, in my sort of case, that sometimes you may find a group where someone is completely off the page and very well meaning...I think so I think it's down to the facilitator (L95-100 Workshop Four, Study Two).*

There was debate about how often HCPs would value meetings, with some HCPs preferring more frequently than once a month, whilst others felt they could neither commit to this nor do they experience enough dying to make this level of attendance a good use of their time. In Table 8 I have included HCPs feedback after the last session. It should be noted that whilst only eight of the ten PAR workshops participants attended the fourth workshop, all ten gave feedback. I have included each of the HCP's feedback. The reason for this is that whilst some HCPs only gave feedback on Workshop Four e.g. HCP7, many were reflecting on all four workshops. It is clear that they each gained something different from the discussion of Study One data, and from learning together as a group. It is notable that they had enjoyed the experience and the ability to share their experience and emotions and learn from others. This is in line with others' findings (Kraemer 2015). Kraemer (a Consultant Emergency and Liaison Child and Adolescent Psychiatrist at the Whittington Hospital, London, and an honorary consultant at the Tavistock Clinic) ran support groups for front line NHS staff. He describes how that once front line NHS staff were freed from the immediate demands of clinical practice and, in a non-threatening manner, facilitated to think about clinical practice that staff were "capable of emotional courage, and generosity in exploring and sharing their clinical, training, and personal experiences" (Kraemer 2015, p.157).

**Table 8.** HCPs feedback after the final PAR workshop (Study Two)

HCP	Their Personal Reflection after the Fourth Workshop
1	<i>"That End of Life care is not black and white, many shades of grey. That negotiation considering patient / family needs do need consideration BUT WOULD BE GOOD TO HAVE A CLEAR PLAN for care in mind to focus care".</i>
2	<i>"Learning from others specialties and experiences. Avoidance of dying in various forms. Whether empathy and good communication at end of life is enough".</i>
3	<i>"Really enjoyed all workshops. All sessions gave deep insight into this topic. Workshop 1 (identifying dying) helped to learn from emotional impact of recognising dying and how to recognise dying itself. Workshop 2 taught regarding processes for engagement with patient and families. Third workshop taught the importance of knowledge of the patient and family to make planning for conversation and decision. Thank you once again for all". [Was not able to attend 4th workshop but fed back via email]</i>
4	<i>"Yes! Thank you, it was a very good space to share thoughts and experiences".</i>
5	<i>"I enjoyed the workshops very much and thought that they were useful in taking time to reflect on how we deal with dying/ delivering bad news/planning etc. I suppose that like most people I never really take time to think about these things specifically and although we may chat as a team about whether we could have helped plan with a patient better it was good to hear how others manage / or not in different circumstances whilst hearing that there is a common theme to us all. How to deliver bad news/ handle difficult conversations, situations/ family dynamics etc is hard to be taught and develops over time and with experience. The workshops are a nice way to pass on experiences and allow others to mull it over and develop their own practice. Phrases people use are also useful to hear. I have thought more on identifying dying and think the workshop has prompted me to identify a deteriorating patient earlier and consider having the conversation earlier. I hope this is what you needed, apologies again I couldn't make the last one". [Was not able to attend 4th workshop but fed back via email]</i>
6	<i>"Taking part in this workshop has been invaluable. Each workshop allowed for sharing of practice good/bad and looked at relevant and key areas of care of the</i>

	<i>dying in clinical practice that I may not have considered. Meeting monthly, allowed reflection on the learning (through discussion) within the group and to try and take this into my own clinical practice. The group felt safe and was well balanced in experience. The emotional impact this can have on a HCP and how we deal with this became very evident. Reminded me of the need to continue to seek out supervision with peer groups especially when working autonomously. Thankyou”.</i>
7	<i>“Really useful opportunity to reflect upon why we do things and why some people don’t. I liked the reflection that "ownership of end of life care" (everyone’s business) may not be as readily achievable as initially believed. Really useful session”.</i>
8	<i>“I enjoyed realising how far education on this topic has come “since my day” and am pleased that more focus is given to this and other communication skills. I think you can guide and advise someone who wants to improve their skills but remain to be convinced that it can be truly taught especially if the learner is lacking in insight”.</i>
9	<i>“Thank you for the chance to follow this PhD. Great possibility of sharing experiences across different specialities. Importance of experience / role modelling and contribution of personality to be considered. Importance of sharing experiences and feelings”.</i>
10	<i>“Continuous learning. Keep role modelling and challenging practice”.</i>

The purpose of co-operative inquiry is the “mutual creation of owned and usable knowledge” (Baldwin, 2006). Unlike the knowledge from the Critical Incident Review interviews which was shared only between the individual HCP in Study One and myself, the knowledge from the PAR groups held meaning for all the participants including myself, which we are able to own / adopt in clinical practice.

One could ask whether these PAR workshops will result in sustainable change, and this will be critically reflected on in Chapter Eight – “How HCPs learn to care for the dying patient and their family”. Individuals stated that they valued being able to reflect, and did identify that they would seek out peers to reflect with in the future. There were two significant aspects that I noticed across the four workshops that indicated learning had taken place. There was a move from anger at others,

most notably towards surgeons in the early workshops, to a move to tolerance of others in the last workshop, and recognition of their specific skills.

*I know I have been a bit mean to surgeons, but for them dying is failure...Playing devil's advocate though, I couldn't do a hip replacement, either physically or mentally, and therefore are we almost asking too much to expect that everyone can have the same level of [skills to identify dying and communicate this] skills. I am not saying that people should avoid it completely...but then I suppose everyone dies (L495-499, Workshop Four, Study Two).*

The second significant aspect was that during the course of the workshops one of the HCPs had moved from psychological action to a change in clinical practice. She had started a reflective group on the ward to consider any patient death.

*It has just started on our ward to do...it's a way of reflection formally to analyse every death; we ...fill a form and they say what went well, what could have done better that kind of process of speaking between all of us nurses, doctors and saying was it preventable and any teaching points, and usually also my juniors (L656-660 Workshop Three, Study Two).*

In this manner – and similarly to Baldwin's work with social workers (Baldwin, 2006) – one can see that PAR can produce an outcome consistent with the policy intention to deliver good end of life care .

### **Summary of the thematic analysis of Study One and Study Two**

The themed analysis of the Critical Incident Review (Study One) facilitated articulation of a four-stage model for recognising dying and negotiating decision making with patients and families. It also allowed description of the emotional impact of this work, and how HCPs have learnt to deliver this aspect of care. Presenting this themed analysis to HCPs in the four PAR workshops (Study Two) kept them focused on these specific aspects of clinical care, and allowed surprising insights – namely the impact of the patient who survives the prognosis of dying, the significant impact of the family on the HCP and patient relationship, and the

emotional intensity of the clinical work. There was positive evaluation of PAR workshops as a means to facilitate practice development. Thus, a fifth stage of “clinical supervision” was added to the model for recognising dying and negotiating decision making with patients and families.

What the themed analysis did not facilitate was to explain why the five-stage model was not always used, why “recognising dying” could be avoided, or why there was “blending” between stages or unawareness of stages. Through the analysis of Study One and Study Two data I have become more acutely aware of the anxiety – my own and others – engendered by caring for dying patients and their families. I have been introduced to psychosocial studies (Frost & McClean 2014), and psychoanalytically psychosocially informed ways of thinking about research and research data (Clarke & Hoggett, 2009; Frost, 2015; Hollway & Jefferson, 2013; Walkerdine et al., 2001). Through this I have become more attuned to the individual HCP functioning as part of their professional and social group, and as part of an institution, and have been able to observe the “psychic in the social” (Redman, 2016) e.g. PAR participants described how policy, however well intentioned, has not always been helpful for their own clinical practice as they perceive it strengthens an unrealistic desire on the part of families for certainty.

With this in mind a psychosocial analysis was undertaken of the workshop transcripts, and two aspects of this – families, and education – are considered in Chapters Seven and Eight. I then considered study one transcripts and this is presented in Chapter Six – The task of the NHS.

## Chapter Six – The Primary Task Of The NHS, And Social Defences

### Introduction

This chapter is the re-evaluation of the thirteen critical incidents (Study One) data. The psychosocial analysis is based on the concepts previously detailed in Chapter Three - the methodology and method chapter - but as a reminder here:

- Caring for the dying is extremely anxiety provoking both consciously or unconsciously.
- We possess a dynamic unconscious that we can never access or know completely (that protects us from what is harmful and leads us towards what is exciting to us and away from what is harmful).
- Our unconscious affects us and others around us; and similarly we are affected by others – we are relational beings
- Unconscious defence mechanisms are constructed and operate at the level of the individual, the group, the institutional and the societal – we are psychosocial beings
- As psychosocial beings we co-make and co-use socially constructed defence mechanisms. As a reminder a socially constructed defence mechanism is a way by which we emotionally (usually unconsciously) place part of our emotional life into the context of the group in a collaboration to reduce anxieties. However social defence mechanisms can be “bittersweet” if they are counter to how the individual manages their anxiety, and are forced to “swallow” the culture in order to work there (Auestad, 2011).

The reader is also reminded that Chapter 4 – pen portraits – were written to offer a “whole” against which this analysis can be set (Hollway & Jefferson, 2013, p.65). The aim of the psychosocial analysis is to see if there are explanations from the data that may illuminate why the differing stages of the model for identifying dying and negotiating decision-making may or may not be used, and to illuminate why aspects of clinical practice may be resistant to change.

This chapter draws on Menzies-Lyth's study of social defences in a teaching hospital (Menzies, 1970) and extends her work in a contemporary setting and with reference to contemporary psychosocial work. This chapter demonstrates how emotionally impactful, and anxiety provoking, caring for the dying is, and proceeds to discuss the social defences seen in today's NHS about the identification of dying. These are represented in 1) the need for a cast iron decision 2) second opinions and checking 3) making sure the family are on board 4) avoiding the work. Avoidance of the clinical work is seen in the social defences of 5) not seeing the dying 6) dressing up dying as a treatment 7) leaving the emotional work to someone else 8) redistribution of the emotional work. Those HCPs who undertake the clinical work can evidence 9) detachment and denial of feelings 10) break bad news in a ritualistic way. This chapter considers that the Hospital Palliative Care Team (HPCT) are the new social defence of the modern NHS hospital, that alleviates others conscious and unconscious anxieties about the care of the dying. Whilst exhibiting a greater tolerance to recognising and caring for the dying, HPCT HCPs are not immune to conscious and unconscious anxiety. In this chapter parallels are drawn with social work and child protection. Specifically Rustin's "moment of respectful uncertainty" (Rustin, 2005) is used to understand what might unsettle the recognition of dying, and enable social defences to be seen within social defences.

It is necessary at this stage to explain that some of the socially constructed defence mechanisms that can be seen in the critical incident reviews (Study One) are only illuminated by the psychosocial analysis of the PAR workshops (Study Two). A little of relevant Study Two data is included where it specifically assists in this role.

### **The impact on the HCP of caring for the dying**

Let us consider what HCPs in Study One said about death and dying. I was struck in the interviews, that when I asked HCPs what the impact was for them there was always a pause, and they really had to think. Cited below is feedback from a palliative care HCP, and the sentence contains a stutter, two pauses, a filler, and a repeat of words. This HCP really had to think about the questions, yet concludes



that patients rarely affect them. I wonder if this reflects how rarely HCPs are asked about how things are for them.

*I guess I'm (stutters & pause) – it's just my job, it's just what I do – pause - I don't battle with it & I think you know very occasionally it's shocking, very occasionally you get it wrong, on some occasions you get it wrong & you judge it badly, um but you know I very rarely am personally affected by the patients actually (HCP 8, L160-166, Study One)*

In this study, there were examples of individual defences being used. HCPs described how they become desensitised due to the volume of dying they are exposed to.

*I'd say probably in ITU you become desensitised to these type of things...(HCP 4, L96-97, Study One).*

The “it's part of the job” was repeated by others, and their tolerance of this work was also reported.

*I think because this is something we are doing most days of the week, you cope with it (HCP 1, L73-74, Study One).*

Others rationalised the current dying of a patient as they could think of times when the death of a patient had a more significant emotional impact.

*Sigh to be honest (pause) obviously if someone is younger is dying that really hits you...we see people dying in our job so sometimes we do take it as part of the job; and if it is a child or a young patient that is having some terminal disease that is really serious and really sad and it makes me sad; but if a 90 plus obviously (pause) I believe we all have to go one day...So 90 plus probably is not a, but you can't say these things to the patient nor the family yes (HCP 13, L73-83, study one).*

Others though were shocked and saddened by recognising dying. Caring for a dying person of the same age was particularly noticeable:

*Personally it is a bit sad as he is only young this chap...not much older than me in fact & the older I get the more that it shocks me when I see patients of a similar age dying because it brings your own mortality into perspective doesn't it?" (HCP7, L73-76, Study One).*

Other HCPs described, "forgetting" aspects of clinical care. This may be physically due to the volume of clinical care, or the distance in time from the event. Yet one HCP, who could remember the detail of the operation and the patient, could not remember the family.

*I can't remember, but it's something normally I take ...the relative to a side room and then gradually talk to them in the presence of a nurses and other staff...I can't remember I think maybe it's one of the side room of the X ward and the family was quite understanding I would say (HCP 13, L103-107, Study One).*

One wonders if forgetting is purposeful to "enjoy a place to breathe" (Trustram, 2016), or as Bion says in trying to remember there is an "anxious shameful rush" cited in (Trustram, 2016), where maybe avoidance lies? Just one HCP found there was satisfaction to be gained from this aspect of clinical care going well.

*It was nice because I also met the son, and then telephoned after the patient had died and he was very grateful for that support (HCP 10, L282-283 Study One).*

So in this section we have evidence of individuals unused to being asked about the impact of care on themselves; of rationalising the care of the dying patient as something that is expected of them as part of their job; of becoming desensitized due to the volume of dying that they witness; and forgetting. Yet HCPs also identify twice that the care of the dying patient is impactful when the person is the same age or younger than them. Psychosocially one can postulate that the younger patient strikes resonances with the HCP undermining their psychological defences. The phantasy of delaying death through medical and nursing care is rudely shattered in such circumstances, causing HCPs to consider their own mortality, or reflect on their own belief systems. As we proceed through this chapter I will

highlight the wider psychosocial influences – policy, education, culturally embedded expectations of professional practice - on these seemingly individual responses.

## Social defences

### The “cast iron” decision

Senior HCPs, notably consultants as in Patient Three pen portrait, expressed a wariness of getting the “diagnosis of dying” wrong. Making the diagnosis of dying, and changing the orientation of care is a risk. Firstly, HCPs described how they did not want to deny a patient meaningful quality of life.

*I think doctors are very very wary about getting that decision wrong and about potentially denying something that is meaningful and – pause - missing something that is reversible; and in a way that conflict is I don't know whether you can get over that because it is the doctors duty to identify whether something is reversible or not (HCP6, L282-288 Study One).*

So identifying dying runs alongside a constant vigilance for potentially reversible causes. One consultant described a strategy of listening to the “tone” of the handover from nurses about the patient (HCP Seven, Study One) to prompt them to search for evidence for reversible causes rather than asking where they are going with the direction of care (staging). It is therefore not hard to see how treatments are continued so late into the patient's dying trajectory.

*Specific to this chap [Patient Four]...there would have been comments on the morning handover like he had a really bad night and he is not doing well...and the tone of the handover is one of pay attention doctor this is getting worse not better...I often rely on those morning MDTs [multidisciplinary team meetings] to get the signals from the nurses about which patients I really need to focus on in case there is something reversible because they are doing poorly (HCP 7, L337-346, Study One).*

Secondly, HCPs want to be right. The HCP and patient relationship is founded on the premise of beneficence and “doing good” (General Medical Council, 2013).

Thus the risk of getting the prognosis of dying “wrong” and the patient surviving the prognosis of dying, rattles HCP psychological defences and their strong protective phantasy of “being right”, it reminds them of their humanness. Risk is anxiety provoking and causes HCPs to abandon more mature methods to deal with anxiety and regress to more primitive methods (Fraher, 2013), and this is reflected in the “cast iron” decision.

*My first role was to make sure that that decision [that the patient was dying] was cast iron so I wanted to make sure we had all the people involved who would have had an opinion as to whether there was anything that could do - that being oncologists and GI [gastro-intestinal] specialists basically; and once I got the nod from those who said there is nothing we can do here then at that stage my focus was very much on symptom relief and keeping him comfortable (HCP P7 about Patient 4, L79-85, Study One).*

These second opinions are a “must do” as part of the route for good decision-making at end of life (General Medical Council, 2010) but second opinions and tests take time, and HCPs in these interviews were prepared to endure a period of uncertainty whilst the evidence was found. In the case of Patient One and Three the evidence sought was a malignancy. Getting a malignant diagnosis is helpful to decision making regarding dying as it is so defining. The patient has to be well enough to sustain treatment, and policy frowns on patients dying within thirty days of chemotherapy (Wallington, Saxon, Bomb & Smittenaar, 2016). There is thus support for recognising dying, not offering chemotherapy treatment, but offering care.

HCP 7 in Patient Four’s care, described in the quote above, did not though directly undertake the work to gain the second opinions from the oncologists and GI specialists: the second HPCT HCP was involved and reduced the period of uncertainty by directly phoning the oncologist and GI specialists. The palliative care HCP identified that they thought the patient was dying, and were checking there was nothing more the specialists could do. When phrased in this way, the specialists admitted they had no more treatments to offer and expressed regret. Thus there was not a pressure, except from palliative care, at this time for the GI

specialists, to recognise they were offering futile treatments, and to take a step back from care, in order that end of life care can be managed. Without the resource of the HPCT, HPC 7 would have been left managing a symptomatic and ultimately dying patient with futile and ineffective interventions whilst the second opinions took time. This may start to explain how dying can be identified so near to death.

It is likely that nursing colleagues add to the “anxiety” of the situation, whilst the “cast iron decision” is being worked up, in their desire to do and act. The first HPCT HCP, in Patient Four’s care recognised the culture of nursing is to trust your gut feeling, and immediately start to think and plan. Nurses want a decision, so they can care appropriately. However, giving interventional nursing care, which causes discomfort and may be futile when a patient is dying is distressing.

*What impacts on me much more dramatically emotionally is when I am faced with situations where I am can’t see the justification for the treatment that is being done; often the people are being over treated and subjected to interventions that feel to me to be to be possibly promoting suffering as opposed to alleviating it (HCP 2, L204-208, Study One).*

### **Second opinions and checking**

As discussed above, HCPs do use second opinions as informed diligent practice because it brings appropriate expertise to the patient’s care e.g. in the case of Patient Five the “foot team” brought expertise to the general surgeon’s ability to care for the patient. However, the HCP articulated how, if she had been the sole clinician (rather than part of a team) she would have come to the same decision but referred the patient to an anaesthetist, and if they had been able to say the patient would not survive surgery then she would have found that helpful. In this manner, the seeking of second opinions is routinized and minimises anxiety, and prolongs the period of time before dying is formally recognised.

In the case of Patient One, even though the patient had requested extubation, and she was not improving despite being maximally ventilated, when the diagnosis of lung malignancy arrived, the ITU team agreed to take things through the “proper channels” i.e. a referral to the respiratory team to confirm the “dying decision”, and

made a referral to palliative care. The patient experienced at least another 24 hours on the ventilator, and lost consciousness, whilst second opinions and the family were bought on board. I would suggest that her wishes were not acted on soon enough, and procedural containment of HCP anxieties prevented this. One also has to ask if the referral to the respiratory team and the palliative care team was a good use of resources.

As in Menzies-Lyth observations there is avoidance of a single committing decision by checking and counter-checking. Senior HCPs were able to explain how they taught junior doctors not to worry by making a decision and then to returning to the patient to check. In Patient One's case the palliative care HCP was called after the ITU team recognised dying, the respiratory team were called, and then when the nurse arrived she described how she checked the blood results, talked to the doctors, and checked herself to ensure she wasn't writing the patient off.

*So it is a combination of the blood results, talking to all the other professionals, putting all our heads together...I want to make sure that that information is correct, that we are not writing somebody off...whose condition might be reversible, so I need to check in my own head that we have got the information correct (HCP 1, L58-64, Study One).*

A team approach is helpful in managing families' distress but much work goes on to ensure there is a collective approach, which dissipates individual responsibility and anxiety.

*We had a good discussion beforehand so we had a collective approach as it were (HCP 10, L119-120, Study One).*

It is not that checking, not counter-checking is incorrect, but the patient's voice can be lost in this process.

### **Making sure the family are "on board"**

I have been struck by how HCPT HCPs describe working with some patients and their families. This is not easy clinical work.

*Some conversations I have to brace myself for...I didn't for him 'cos...he is...a very easy man (HCP 5, L52-55, Study One).*

*And the complicated families I take to supervision to try and work out strategies of how to cope with them; with the psychologist" (HCP 5 L252-254, Study One).*

The impact of the family will be covered in detail in Chapter X. At this stage, it is important to highlight that the family are a major source of anxiety in this decision-making process, and teams work very hard to ensure that the family are in agreement with the decision-making. When families are in disagreement amongst themselves this is very challenging to HCPs as in the case of Patient 6. HCP 13 asked for another member of the team to be involved, not because there was unhappiness at the clinical care or decision-making, but because a complaint was anticipated from one portion of the family who wanted the patient to have end of life care and die at home, whilst other members of the family wanted active treatment and life prolongation. After-death complaints have to be dealt with, and these are demoralising to HCPs (Menzies-Lyth, 1999) and use valuable time that can be given to other patients. In addition, on a personal level, they have a significant impact on HCPs professional lives. Sharing the burden of this reduces anxiety.

### **Avoiding the work**

#### *Not "seeing" dying*

Palliative care professionals used the term "seeing" or "not seeing" the dying frequently to explain how some patient's dying was missed. It's important to note that not all "missed deaths" are a result of avoidance or of "not seeing the dying". Patients can die suddenly in hospices, in an "expected death period". Some palliative care HCPs saw "seeing the dying" as a puzzle and a challenge to be worked out.

*I guess...it's just my job, it's just what I do...I don't battle with it...It is what it is – it's pattern recognition and diagnostics isn't it? It's a puzzle isn't it? (HCP 8, L160-169, Study One).*

Where a medical HCP (doctors) saw the dying, and acted on this to communicate honestly to the patient and family, it provoked a feeling of gratefulness from the nurse.

*I was very fortunate that I had clear information from the consultant...[that there were no more oncological treatment options and the patient was dying] when you do not have clear information; when there is uncertainty or lack of commitment to make a decision that's makes it very complicated; so if people do not communicate accurately; so if they; if they we want to maintain hope but it cannot be false hope (HCP 5, L268-275, Study one).*

However, HCPs in this study identified that some HCPs choose not to see dying and continue to offer treatments - a continuation of the "can I cure this problem approach?" - that to others are therefore seen as futile and causing suffering and distress. This might constitute 'denial', that is, an attempt to avoid psychological pain and to refuse to know something because the anticipated knowledge of it is feared to be devastating. Nurses agreed that caring for a patient where the others involved in the care could not "see the dying" was "the hardest thing".

*So it is the hardest thing ...when you do not have somebody who will; you can see somebody in front of you and you say, and you can see they are dying, and you have a senior medical practitioner who is not seeing it.... they will have symptoms – they have lost weight, they are rarely wakeful, they have a poor swallow, they will, they may have erratic breathing, they are bed bound, different pallor, you know the skin tone - you touch them and you look, their feet are cyanosed (HCP 5, L292-307, Study One).*

The reason it is the "hardest thing" is that nurses physically have to administer the treatments the doctors are prescribing, and therefore have to continue to explain to the patient and the family why they are giving them. It puts them in an ethically challenging position. The description of the patient's condition below was the prompt for a palliative care HCP to recognise dying and she found the level of distress intolerable, yet ward nurses and doctors had tolerated this in the hope of a reversible cause.



*His stomach was quite distended, and his colour he was quite jaundiced and so restless, ...he had no control over anything; unfortunately over his personal hygiene...which was quite offensive so as soon as you walked into the bay that was quite offensive...and just him not being able to keep still which was almost really disturbing to see (HCP 9, L7-19 Study One).*

It is possible that sometimes nurses collude with doctors in their hopefulness for life through medical treatment, but doctors recognised that nurse's frequently recognised the futility of treatments more quickly, and as a result identified the need to change the focus of care before they did.

*I suspect some of the nursing staff felt earlier on that this was becoming futile (HCP 6, L90-91, Study One).*

It isn't only ward HCPs who do not see the dying; a HPCT HCP also "didn't see" the dying (Patient Two) and trusted the ward doctor's decisions to continue active treatment. This nurse used the Amber Care Bundle<sup>14</sup> as an explanation for the patient being in a "will he / won't he die" clinical condition; yet did not use the bundle to prompt others to engage with the patient and his wife about their wishes and preferences. This hopeful trusting of recovery, when there is a gut feeling about the potential for dying means suffering is accommodated within the ward nurses', and ward doctors' daily vision of care. Specifically, in the case of Patient Two, he felt he was being held in hospital against his wishes, was expressing spiritual distress, was physically unwell enough to have his care escalated to Coronary Care Unit, and all this was tolerated for a "will he / won't he recover approach", without the uncertainty of recovery being named. Nurses in this period will have been required to wash and assist this patient with care, ensure he was connected to a cardiac monitor, and administer clinical treatments despite his clinical deterioration. As a HCP it is extremely hard to undertake clinical care that causes the patient pain (even if it is transient pain), and it is easier to tolerate this if the patient survives and gets better because of the treatment. I wonder if

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<sup>14</sup> The Amber Care Bundle is a paper-based tool, designed to prompt clinicians to communicate well with patients and families, when they recognize that a patient could die in the next six weeks, and whose current clinical condition has an uncertain recovery. The aim is prioritize patient's wishes for care.

routinely being expected to administer clinical care in the hope of cure, and if in addition nurses' views about suffering and recognition of dying are ignored by doctors, this blunts nurse's sensitivity to suffering. Their ability to recognise "their own gut instinct" and "seeing dying" and to act on it may thus be impaired.

The concept of "respectful uncertainty" (Rustin, 2005) is used in child protection to describe both the ability to work with families with compassion, but to retain an open and questioning mind set about their motivations and narratives. This has parallels with the moment (s) of "gut recognition of dying" and "seeing the dying". I have found it helpful to note that others (Rustin, 2005) explain that at this point of respectful uncertainty, it is the time most vulnerable to professional anxiety (inadequate resources to do the work, blame, challenging other professionals) and anxieties arising from the interactions from the patient and family. That patients and families project their suffering and anxieties (sometimes consciously, sometimes unconsciously), and that to work in this scenario requires careful clinical supervision (Munro, 2011). This is psychologically very skilled work.

If one considers in the case of Patient Two, that the palliative care HCPs gut instinct about dying, equates to the moment of "respectful uncertainty" (Rustin, 2005) then it allows contemplation of what factors might unsettle this moment. The HCP highlighted he had seen others in this position before and they had recovered, and we appreciate that cardiology deaths can appear unpredictable and sudden. This has to be weighed up alongside the unsettling factors mentioned by Rustin. These could be such things as the pressure of the HCP's caseload, the need to challenge a cardiology consultant about their decision-making, the need to engage with a wife with mental health concerns, or their key worker, the need to get home and put the work off. These may all play a part in preferring to live hopefully and not inject a "respectful uncertainty" into the assessment and communication. However, similarly to the wait for the "cast iron" decision, ahead of recognising dying, it is helpful if the uncertainty is named and worked with (Krawczyk & Gallagher, 2016).

#### *Dressing up dying as a treatment*

It is apparent that some of the HCPs offering a second opinion e.g. in the case of Patient Five, commit to the decision that the patient is dying, and identify that the

focus of care should be comfort, and document this for the ward team to work with the patient and family. However, some HCPs are avoiding both the decision-making and the patient and family work around breaking the news about dying by dressing the deterioration up as requiring yet another treatment and only writing this in the notes rather than calling the ward team.

In the case of Patient Four this occurred when the stent that had been put in place to open the blockage in his stomach outlet had become blocked again. The ward HCP in charge of his care asked for an opinion from the gastro-intestinal specialists about whether they could assist with this. Instead of saying “no, there was nothing more they could do”, it was dressed up as “re-x-ray to see if the stent is in place”. The gastro-intestinal specialists could only admit that the patient was dying when the palliative care team rang and re-framed the care for them. Dressing up dying as a treatment both links to avoidance of dying and avoidance of a single committing decision.

#### *Leaving the emotional work to someone else*

HCPs in Study Two could highlight ways in which the emotional work around the care of the dying was avoided by HCPs. One example given was for doctors to write, “Consider Do Not Attempt Cardio Pulmonary Resuscitation” in the medical notes, leaving this work for the following doctor to pick up at the next patient review. In Study One, avoidance of emotional work can be seen in the case of Patient Two. When the possibility for dying was not introduced, and dying was missed, then the emotional work of preparing the wife, which should have been undertaken by a senior HCP, was transformed into the responsibility of ward staff at the time of death. Bearing in mind this patient’s wife had a history of mental illness, then the least qualified clinical staff, and at a weekend, will have had to break bad news and cope with her grief at his death. From there on, once the deceased patient transferred to the mortuary no one on the ward would be exposed to her emotion, and hence any emotional work is left with the bereaved and to others in the community who come into contact with her.

### *Re-Distribution of the emotional work*

How the emotional work was re-distributed was not predictable. For example, in the case of Patient One the consultant undertook all of the family work after the decision was made that the patient was dying. HCP 4 until this time had been caring daily for the patient and knew the family, opened the test results on the computer and knew she had a malignancy and was dying, and yet accepted this Consultant take over of the breaking bad news to the family without question. There are consequences for core and specialty training grade doctors not routinely going with consultants to family meetings such as these, as it limits their opportunities for learning (the learning opportunity will specifically be addressed within Chapter Eight – How senior HCPs learn to care for the dying patient and family).

However, in Patient Five's case the surgical consultant in charge of the patient's care avoided the patient and family work. Once the second opinion was sourced from the multi-disciplinary foot team, and the dying was recognised, the junior ward doctor was left to set up and conduct the family meeting. They asked palliative care for assistance with this.

### *Detachment and denial of feelings*

Detachment has two meanings in psychology. It can be a positive behaviour, which allows a person to react calmly to highly emotional circumstances, whilst still being empathetic. In this circumstance it is a decision to avoid engaging in emotional connections. It can also be used to describe, "emotional numbing" i.e. dissociation and depersonalization, when faced with too much anxiety and distress. Mental states are opaque, and thus we have to imagine what lies behind behaviour (Fonagy, 2014) and thus it's challenging to separate what is an individual defence, and what might be part of the culture of the NHS. Some HCPs in Study One did describe feeling sad; some denied that caring for the dying had an impact and took it as part of their job; others though could describe the impact and the detachment.

*Personally it is a bit sad as he is only young this chap... But it was a very professional relationship with a large degree of detachment (HCP 7, L73-77, Study One).*

Looking at Study One data with the lens of Study Two does indicate that there may be a cultural narrative and social defence of HCPs emotions being shut down, and encouragement of dissociation from their feelings. One of the HCPs in Study Two felt the anger of a family very strongly, took it very personally, and thus expressed a feeling that she hadn't cared for the patient and family well. Rather than explore her emotions, or help her reflect, another senior HCP encouraged her to build her defences.

*If you let every single death affect you, particularly in the specialties we work in, you would be a basket case wouldn't you...You have to build that suit of armour (L196-200, Workshop One, Study Two).*

The comment was meant kindly but the HCP was effectively silenced. This is an example of where the social defence is constructed beyond the individual, into professional narratives. No attention is paid to the emotional impact of clinical care in either medical (General Medical Council, 2013) or nursing practice (Nursing and Midwifery Council, 2015), they are completely focused on how the HCP must and should behave. This is embedded into training and then clinical practice, and perpetuated. HCPs in Study Two though, discussed how they relied on informal debriefs with colleagues.

*Yeah we have some informal debriefs, definitely all the time...Its when we are sitting around on a Friday night in the office, its nothing more formal than that is it...but if someone has had a particularly difficult case then just sort of diluting it out (L221-225, Workshop Two, Study Two).*

This study has not looked at humour or informal relationships and resilience and this would be worthy of study in the future (Frost, Höjer, Campanini, Sicora, & Kullburg, 2017).

### *Breaking Bad news as a ritual*

Despite much communication skills training occurring to ensure that HCPs can undertake breaking bad news with kindness and empathy (Moore, Mercado, Artigues, & Lawrie, 2013), there is evidence that breaking bad news is seen as another “task” in the clinical situation. For example HCP 13 could not remember the family but knew what he would do in the circumstance of recognising a patient as “terminal”.

*He was in my opinion at that time terminal, and any patient who is terminal it is advised decision to involve the family beforehand; that this patient is not doing well and this is a possible expected outcome...normally I take the patient, not the patient, the relative to a side room and then gradually talk to them in the presence of a nurse and other staff (HCP 13, L96-105, Study One).*

Doctors who do not undertake this aspect of clinical care regularly have still learnt models of communication from medical school teaching, and are endeavouring to follow this, and have even rote learnt where they should pause.

*It's the similar conversation you have when you are trying to explain that patient's already died...I am trying to remember the term ...you have to find the right you have to prepare the situation, ...you have to find out what the relatives already knows about the situation ...(pause) provide them with any additional information pause explain to them that you know things aren't good, give them a few warning shots before hand and ... but ultimately you have to say, you know, explicitly that this person is dying and use those words not avoiding those words because if you avoid those words then it won't register ...people hear what they want to hear ...pause and just – pause - see what their thoughts are on that (HCP 4, L156-167, Study One).*

Yet, due to the fluctuant condition with patients with long-term conditions, they can regularly present to hospital looking as if they are dying. HCPs who are only meeting the patient for the first time may well “break bad news” because the clinical situation warrants this. However, patients can survive and HCPs in the workshops described families who didn’t want to hear the news again.

*They say we have had this conversation so many times that they might not recover this time; I don't want to talk about it anymore (Workshop Two, L143-145 Study Two).*

I am suggesting that HCPs have linked recognising dying with the need to break bad news and have honest conversations to give good end of life care (National Palliative and End of Life Care Partnership, 2015). However the conscious and unconscious anxieties surrounding this process means it is being undertaken in a ritualistic manner, and possibly without assessment of the capacity of the patient (Kobayashi, Kato, & Takeuchi, 2014) and meaningful engagement about what the perceived “bad news” will mean (Tuffrey-Wijne, 2012). There is nothing in the literature, but relatives now are expressing dis-engagement from hearing bad news when it is repeatedly given, and this would warrant a research study of its own. However, the social defence of breaking bad news in a ritualistic way, despite the good intentions that motivate it, may make the breaking of bad news at the actual time of recognising dying very challenging.

### **Hospital Palliative Care Team – the new social defence**

There were multiple examples of evidence in this Study of HPCTs being used as the route to contain others anxiety about dying. For example they offered a second opinion (Patient One), undertook the family work (Patient Three, Four, Five and Six), broke bad news with a junior doctor and allowed more senior doctors to avoid this emotional work (Patient Five), and co-ordinated all second opinions to minimise the period of uncertainty and enable the “cast iron” decision to be made (Patient Four). The point of social defences is that they are usually unconscious. In Patient Five’s care, the HCP giving the second, and best interests, opinion that the patient was dying, did not engage with the family.

*I am thinking now, did we say anything about family? I think my impression was that once we had made this decision [patient is dying] and we knew that we were going to get palliative care involved that someone from the patient’s team would of then have engaged with the family; but I didn’t follow through with that (HCP 11, L146-152, Study One).*

In this example, it is possible to see how engagement with families may be unconsciously avoided, and palliative care are seen as the route for ward teams to be able to offer care. Palliative Medicine emerged as a medical speciality in 1987 and in the words of sociologist Dr David Clark has “seized hold of the field of caring”, and hospital palliative care (Clark, 2014). Without attending to the politics of the recent dominance of the medical discourse, it can be seen that since Menzies-Lyth undertook the psychoanalytic study of nurses in the 1950’s, the introduction of medically led palliative care services has occurred in hospitals, as has the introduction of standards for the organisation of clinical practice in the specialty (NICE, 2004). My argument is that the HPCT is the social defence of the modern NHS hospital that alleviates others conscious and unconscious anxieties about the care of the dying.

#### **Hospital Palliative Care Teams are not an infallible social defence.**

When I look at the data, despite the confessed acceptance of dying, and recognising the range of social defence mechanisms, I have found it especially challenging to explain how a Palliative Care HCP “missed” the recognition of dying in the case of patient Two.

Menzies-Lyth felt it was best to understand an organisation with the distance of an outsider (Menzies, 1970). I have found it helpful to use the lens of research from social work about the dynamics of social workers and child protection to understand what might be going on as HCPs work with dying patients and families. Death, like sexual abuse, has such a powerful effect on internal boundaries, that it is usually split off and repressed (Harvey, 2010), and I can see how this is “split-off” in the hospital setting in the form of a palliative care team which requires peer review structures, time and psychological supervision to process the work about the care of the dying and their family. The palliative care team is the organisational system (the social defence mechanism of the organisation) that allows others to be protected from their anxiety.

However, individuals in the palliative care team become ever increasingly exposed to a volume of dying, which increases their expertise, but does not make them personally or systematically infallible. Palliative care as a discipline has



endeavoured to anticipate the anxiety of its practitioners and others in caring for the dying and to organise a pathway or plan of care, which others can follow. They have constructed professional and institutional systems e.g. the Liverpool Care Pathway for the imminently dying patient, and the AMBER Care Bundle for the patient likely to die in the next six weeks that others can legitimately use to prompt them to care well for the dying patient and defend against their anxiety. However, these tools were never developed to negate uncertainty but to help other HCPs<sup>15</sup> negotiate it, and prompt standards of clinical care and communication with the patient and family.

If other HCPs find the care of the dying patient and family hard, and use these tools as a recipe i.e. a “social defence” against the anxiety of caring for the dying, then this becomes a very risky procedure. As was seen with the disestablishment of the Liverpool Care Pathway, due to some patients experiencing less than individual care, the defence mechanism was blamed (Regnard, 2013). Palliative care then becomes organisationally vulnerable in promoting these tools. They are also left with a responsibility for recognising dying.

HCPs in Study Two wondered about the abnormality of carrying the weight of looking out for the dying period to prepare patients and families.

*You start to think do I just walk around with a death wish for people (Workshop One, L145, Study Two).*

I wonder if the responsibility for “seeing the dying” i.e. trusting their gut instinct is unfavourably weighted in favour of those HCPs - palliative care professionals - with the skills to manage this aspect of care, as some worried whether they “oversaw” dying especially when they were caring for patients who had disease trajectories other than those they were experienced with.

*I tend to kinda see dying perhaps or maybe I oversee dying (HCP 2, L260-261, Study One).*

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<sup>15</sup> By other I mean those HCPs who have not contributed to the development of the tool, but are mandated to use it as part of an organizational drive to improve care of the dying patient and their family.

Thus it is possible that palliative care professionals, trained and skilled enough to care for the sick and dying all day, (and thus be employed as part of the organisational defence mechanism), using social defence mechanisms their own specialty have developed, to still be vulnerable to professional and personal anxieties at the time of experiencing a “gut instinct about the potential for dying” and their own ‘moment of respectful uncertainty’. This helps give a voice to the complexities of explanation that have paralysed me in this analysis – there are social defences within social defences.

### **Summary and Commentary on the Task of the NHS and Social Defences**

Menzies-Lyth noted that the primary task of the NHS in the 1950s was to care for ill people who could not be cared for in their own homes. She specifically recognised that nurses in the 1950’s cared for the “physically ill, often seriously ill, and when recovery is uncertain or incomplete, and that nurses face the reality of suffering and death as few people do” (Menzies, 1970, p.440). She argued that nurses’ experience of caring for the sick and the vulnerable evoked anxieties (conscious and unconscious) which related to the experience of having been taken care of as a vulnerable infant (Menzies, 1970). Later researchers have considered that Menzies-Lyth’s definition of the “task” was limited. Hoggett highlighted the lack of attention paid to the social construction of the task (how society affects the definition and interpretation of the task), and the gendered nature of nursing and medicine at the time (Hoggett 2015). Others have identified how anxieties about “the task” can be affected by such factors as organisational leadership (Papodopoulos 2015), the volume of patient care (Tutton and Langstaff (2015), against a background of “doing more for less” (Evan 2015), and it is noted that Menzies-Lyth though does not specifically discuss the impact for nurses of caring for the dying.

We know that since the 1970s the rate of people dying at home has decreased, and the rate of dying in hospital has been increasing (Gomes & Higginson, 2008) and has only just started to stabilise (Gomes, Calanzani, & Higginson, 2012). In the Trust where the study took place they experienced 22 deaths / week. Since the time of Menzies-Lyth’s study the provision of care to the dying patient has become

a clinical priority. The care of the dying patient has its own clinical guidelines that differ from those used in the management of the patient who has the potential for recovery (NICE, 2017), expectations of standards of clinical practice (General Medical Council, 2010) (Nursing and Midwifery Council, 2015), and national audits of clinical indicators of care (Marie Care Cancer Care, Royal College of Physicians, 2014). Families are formally being surveyed for their experience of support and care (Department of Health, 2012). The care of the dying patient in hospital has also been subject to external scrutiny (Neuberger 2012); the very public withdrawal of previously agreed NICE guidelines for the care of the dying has caused distress to clinicians who felt it was the equivalent of the “Highway Code being banned because of poor drivers” (Regnard 2013); my own experience was that the withdrawal of the NICE guidelines, and media attention to this, also caused patients and relatives to distrust medical and nursing decisions that the patient was dying.

I argue today that a parallel and primary task of the NHS, alongside caring for the sick, is to identify and care appropriately for the dying. It must also encompass the care of the patient’s family (General Medical Council, 2010) (National Palliative and End of Life Care Partnership, 2015) (Nursing and Midwifery Council, 2015).

In this chapter I argue that caring for dying patients and their families causes individual HCPs as part of their ward team, and within their professional hierarchy and as part of the hospital team, to struggle with and psychologically defend against conscious and unconscious anxieties that are brought up as they try to carry out clinical care, and this is manifested in co-constructed social defence mechanisms specific to the recognition of dying. These social defence mechanisms have the potential to get in the way of and delay the identification of dying to the detriment of the care of the patient. The social defence mechanisms identified in this study specific to dying are represented in 1) the need for a cast iron decision 2) second opinions and checking and 3) making sure the family are on board. All of these, while required for good practice, can take too much time, and can result in the patient’s voice being lost and delay the actual recognition of dying.

Avoidance of the clinical work is seen in the social defences of 5) not seeing the dying 6) dressing up dying as a treatment 7) leaving the emotional work to someone else 8) redistribution of the emotional work. These defences leave patient's potentially at risk of unnecessary and futile interventions (that may increase suffering), and waste clinical resources and cause unnecessary anxiety and distress to teams required to carry to the clinical care certain teams bearing an increased amount of this clinical care.

Those HCPs who undertake the clinical work can evidence 8) detachment and denial of feelings and 9) break bad news in a ritualistic way. It was discussed how the denial of feelings is professionally culturally perpetuated, and is unlikely to help the HCP process their thoughts, learn for future patient care and build strength to continue with this aspect of care (Frost et al., 2017). It is likely that HCPs have informal networks in the Trust that assist with emotional debrief. The question is whether they keep the HCP where they are or help think through different ways of being.

This chapter considers that the Hospital Palliative Care Team (HPCT) are the new social defence of the modern NHS hospital, that alleviates others conscious and unconscious anxieties about the care of the dying. The HPCT though is not immune to their own conscious and unconscious anxieties being overwhelmed and the use of social defences. In this chapter we have not fully considered the impact of families or the educational preparation for this aspect of clinical care. These are taken up in the next two chapters.

## Chapter Seven - Families

### Introduction

The previous chapter discussed the psychosocial analysis of Study One and presented how the “task of the NHS” is not only to care for the sick, but also to care for the dying. Drawing on the work of Menzies-Lyth it postulated that HCPs experienced conscious and unconscious anxieties from providing care to patients who are sick, suffering and dying, and that these anxieties resonated with the HCPs’ earliest experiences of vulnerability or care, and terror of death. There is strong evidence that at the point where dying is recognised, the very sick patient’s care provokes much anxiety for the HCP and for the institution, and so in response to this there is a co-creation of social defence mechanisms specifically about recognising dying. It is asserted that palliative care teams are the new social defence against anxiety about the care of the dying in the NHS.

There was evidence from Study One that the actual death of the patient was less anxiety provoking than recognising that death was likely. Recognising that death was likely brought a responsibility for decision-making about a potential change in the priorities for treatment and care from life prolongation to comfort, and for preparing the family for bereavement. Doctors are responsible for the decision to change the treatment plan, and nurses for delivering the care. The recognition of dying has the potential to become an “emotional and ethical hot potato” being passed between HCPs. If the doctor recognises dying ahead of or with the senior nurse, then the nurse can feel relief. If the senior nurse recognises dying ahead of the doctor, there is a level of ethical distress for the nurse as life-prolonging treatments, which nurses have to administer, usually involve a level of discomfort or pain for the patient. Even having a blood pressure measurement taken is not without discomfort. The patient is not a neutral bystander: they may recognise that they are dying, may want life-prolonging treatment stopped and pass the emotional work to the HCP to prepare their family. The patient could die whilst receiving all life-prolonging treatment and before HCPs could or would recognise dying and prepare the family. In this situation it is possible that the grief of the family is likely to be felt most intensely by the HCPs on the ward at the time. These

may be the most junior doctors and nurses. However, since the deceased body only remains on a ward for four to six hours before transfer to the mortuary, then most of the emotional repercussions are felt outside the hospital.

The family, though, are not disinterested bystanders in the recognition of dying. When HCPs in the four workshops of Study Two discussed the findings of Study One, they returned repeatedly to the topic of families. This chapter presents the psychosocial analysis of discussions about families from the workshops in Study Two. It does not plan to re-describe social defences against anxiety (these continue to be seen in the data). I have drawn on the concepts of liminality and affectivity as helpful concepts to put to work on my data because they open a space to individually consider the dynamics of the HCP and patient and family relationship. This chapter proposes that recognising dying and engaging with the family about this has the potential to jettison the family into an experience of liminality where the reality of death of their family member and possible personal impact becomes a reality. It may also be a liminal experience for the HCP, where their skills to cure or make better have reached an end and they meet the family in a human-being to human-being relationship. It is a time unsupported by ritual or rules for the family, although HCPs have the ritual of the 'breaking bad news' strategy. In this chapter, I argue that it is the lack of ritual and skilled resource for patients and families, or to support HCPs that is neglected in the frequently emotional and affective transition from "likely to live" to "likely to die" or as is recently termed "sick enough to die" (Krawczyk & Gallagher, 2016).

This chapter also proposes that the organisation devolves all its responsibility to the HCP at the time of breaking news and that in order to accommodate the family's distress the patient may be subjected to futile treatments. In addition, relationships with nurses are traded by senior HCPs, as are relationships with colleagues. The presence and involvement of families is extremely anxiety-provoking and likely to contribute to HCPs' defences, including processes of denial about recognising dying.

## Definitions of liminality and affect, and the significance of these concepts for those HCPs who communicate the recognition of dying

Liminality is a concept initially described by anthropologists (Szokolczai 2009). It refers to something universal and simple – “the experience of finding oneself at a boundary or an in-between position, either spatially or temporarily... and is about how human beings in their various social and cultural contexts deal with change” (Thomassen 2015, p. 40). Individual’s personal and community life is made of routines and repetitions, yet life presents us with situations outside our normal. Death is recognised as one of those situations outside of our normal and is described as a liminal situation (Thomassen 2015). In liminal situations we require different tools to navigate that moment(s) and as such human beings tend to ritualise and symbolise such moments. It is this repetition of ritual and symbolisation in memory of the importance of the liminal event that lies at the heart of community formation (Szokolczai 2009). It is important to note that “ritual does not decorate reality; it is about that reality” (Thomassen 2015, p.41). It also brings resource in terms of skilled personnel familiar with the experience of that transition to help people navigate the liminal situation.

Arnold Van Gennep is credited with the identification of the concept of the liminal, in his 1909 book *Rites de Passage* and his observation of ritual passages as they unfold in life from birth to death. The detail of these is described below:

- “First there are rites of separation in which the previous state or social position is, as it were, broken down.
- Then there is a middle phase of passage, which might often involve a trial or test that must be successfully completed.
- The passage then ends with the rites of incorporation during which the new status, position or identity is established and recognized” (Stenner 2012, p. 5)

The use of liminality as a methodological tool to provide explanatory and interpretative accounts in health care has been present since the late 1980s. Anthropologists first used the concept of liminality to consider patients’

experience of disability (Murphy, Scheer, Murphy & Mack 1988). Murphy et al found the deviancy / stigma frameworks (previously used by sociological researchers) limiting, and used liminality to re-frame the experience of the disabled so that it was viewed as historically and culturally malleable, rather than fixed by biology. Using the concept of liminality, Murphy argued that the purpose of rehabilitation units for physically disabled people, was to reconcile the disabled person to their social condition, rather than to help them recognize that their disability was an arrestment in their life history. The authors dramatize this as a rite of passage frozen in its liminal stage. They argued that the disabled should be liberated to fight, rather than accept their outsider status, and in that fight there could be transition to full community membership. In line with current thinkers, such as Horvath et al (2015), liminality was used as a concept to both to understand the situation and to transform it.

Over recent years liminality has been drawn on by palliative care specialists to illuminate such topics as the experience of hospice as compared to home (Broom & Cavenagh 2011). Nicholson and colleagues (Nicholson et al 2012) consider that frail older people live in persistent liminality, caught between living and dying. She argues that frail older adults exhibit agency, through their work to remain secure in their homes via daily routines and social interactions. Her transformation recommendation is that society could alter the experience of the frail older adult by recognizing their agency and social relationships, rather than focusing on their physically frail bodies. In this paper there is nothing about the “middle passage or ritual(s)” that negotiate this transition.

More recent authors have critiqued other’s use of liminality as a “notion of liminality” (MacArtney et al 2015, p2). Utilizing the experience of patients attending palliative care outpatient departments, MacArtney et al (2015) considered that palliative care patients’ abilities to carry on with their lives as normally as possible, whilst considering a future that included death, was more reflective of parallax. Parallax is a positive state that acknowledges participants’ attempt to retain a sense of control and agency and, MacArtney et al argue, useful in thinking about how liminal situations are psychologically and socially managed. I would though argue that patients that are well enough to transport themselves to



a palliative care outpatients department (MacArtney et al 2015), or maintain themselves at home (Nicholson et al 2012), may on some level have a sense that death may be approaching, but may well utilize their own agency to focus on living.

Frommer (2005), a psychoanalyst, describes those moments of living when, rather than unconsciously defending against the knowledge of our own death, the moment contains a sense of knowledge that we will also die. Frommer describes how those moments can be lit with “dark, disturbing hues” (Frommer 2015, p. 482). Yet he argues that the test is to find the “liberating potential of mortality” which enables individuals to “savor life, order priorities and tolerate losses and limitations” (Yalom (1980) cited in Frommer, 2015, p. 482). He concludes that this liberation is “an unstable achievement not easily won” (Frommer 2015, p. 482). He suggests that how the knowledge of death is brought to conscious thought is often through personal loss of someone dear to a person, and the containment of this experience by a psychoanalyst. Again, in this paper there is nothing about the “middle passage or ritual(s)” that negotiate this transition.

I argue that recognizing that dying is imminent brings the liminal period of death much closer both physically and psychologically, than the “living whilst contemplating dying situation” of the MacArtney, Nicholson, and Frommer studies. Whilst these authors use liminality to describe the “betwixt / between” situation, and can make transformation recommendations, none of these recent authors consider the concept of ritual, skilled negotiation of the ritual with those new to the liminal situation, or the building of community.

I have found it helpful to consider Stenner’s paper that links liminality and affectivity as part of a psychosocial process (Stenner 2012), as Stenner includes the importance of ritual to contain the strong emotions experienced in a liminal period. Stenner views affect and liminality as a way for careful, conscious thought to illuminate space and transition between organised structures and in this manner his reflections on affect and liminality help illuminate the HCP and family relationship as the patient transitions from living to dying.

Affect has been understood to refer to the communication of emotions or feelings (Woodward, 2015) such as joy, fear, shame, excitement, hatred and love (Stenner,

2012). “Affects and emotion are liminal phenomena of transition and why liminal experiences are affective and emotional” (Stenner 2012, p.7). Stenner says, “during genuinely formative experiences of transition we are all too aware we are changing and there is no going back”. Stenner draws on the work of Szakolczai – a sociologist – who has used liminality to critique the relationship between society, politics and religion. Szakolczai argues that we ignore liminal situations at our peril. If we deny the importance of liminal situations and ritual then we ignore a way that society, and community is maintained. Ritual also gives a way for imitation and the ability to follow someone as a skilled model to negotiate the way through the affective experience. Szakolczai requests that a liminal situation should only be provoked if “one has a proper form to impose on the soul whose emotions are stimulated by being put on the limit” (Szakolczai 2009, p. 157).

There are many rituals, and thus resources (religious or secular) subsequent to death, and to help people negotiate the transition into bereavement. I do not propose to go into detail about this here and these have been well documented, and critiqued (Kellehear, 2007, Walter 2017). However, far fewer rituals exist to help transition the living to dying. Whilst the Roman Catholic ritual of the “last rites” or “sacrament of the sick” is ministered to the dying, and leaders of faiths may be called to pray for those approaching death, there is little ritual to support those families transitioning to the imminently uncertain future of impending bereavement. The communication of significant news about impending death is likely to be an extremely affective and emotional experience and, apart from referral to the hospital palliative care team, or a request to see the chaplaincy team, few rituals or rites of passage exist in hospitals when the news of impending death is communicated. There is thus, apart from palliative care or chaplaincy, little addition of skilled resource at the time of transition into the liminal period.

Most medical HCPs have a ritual, namely a communication strategy with which to break bad news (Baile, Buckman, Lenzi, & Glober, 2000) and some training to think about where and how this is best to take place. However, from a patient and family perspective there are few rituals and support around hearing bad news and the ramifications of this for their own lives.

## Breaking bad news: the patient's contribution to the HCP and family relationship

Firstly, the patient is not a passive bystander to the HCP and family relationship, but plays a definite (if unconscious) role in this. The patient is entering a period of liminality as they transition from living to imminently dying and then to death, but patients often fail to introduce their families into conversation with HCPs.

*I think I have had three patients who have said "I would really like to talk about this with my family and can we make a date and time and have the whole lot round", and I have had to go and do the whole thing, but two or three at the most (L 460-463 Workshop Two, Study Two).*

They can keep their family away despite the HCP's best attempt to help the patient involve their family.

*I often ask the patients when they come on their own again and again, have you told your children, do they know? And they say yes, but I have the impression that they don't come because they don't really know what's happening (L353-355 Workshop Three, Study Two).*

Patients and families may not have close relationships in life, but as death approaches family still want to understand what is happening to the patient.

*We see that quite a lot actually because a lot of our patients don't have family nearby; you nurse and nurse and nurse and nurse them, you get them prepared and they deteriorate and you make plans with them and you say, you have discussed and they say yes; so then a relative turns up – they are not far away really usually – but they want to know why you are not doing x, y, and z (L365-369, Workshop Three, Study Two).*

It may be that patients are unconsciously defending against considering their own death. It may be that they are protecting their families from being in a period of uncertainty and a liminal period for an extended period of time – this has echoes of the previously described concept of parallax, where patients use their own agency to reframe their current uncertain clinical situation (MacArtney 2015, Nicholson et

al 2014). However, there can be many reasons why patients keep their families at a distance from interaction with the HCP. It was notable in this study that HCPs have experienced that patients and families do not always agree on their attitude towards dying. Whilst HCPs find it helpful if the patient has come to a point where they recognise their own dying, it did not always mean the conversation with the family was easier. For example, in this study HCPs had experienced families who were angry that the patient was ready to recognise they were dying. The family perceived this as “giving up”.

*I have found relatives can be more angry in that sort of situation. Their loved one has just given up and you know “how dare they?” and here they are trying to carry on as normal for them. They are caring for them and doing this all this time and now “that’s it” “they’ve thrown the towel in” (L407-410 Workshop One, Study Two).*

In law, the responsibility of the HCP to the patient with mental capacity is a clearly defined one (Sandman & Munthe, 2009), as is their responsibility to the patient who has lost capacity (British Medical Association, 2008) – the HCP is required to make a “best interests” decision (a best interests decision is where the consultant makes a decision in the best interests of the patient after consulting family or friends who could articulate what the patient’s wishes and preferences would be if they could articulate this). The responsibility of the HCP to the family is much less well defined, and there can be a tension between the responsibility to the patient and their family. The question raised through analysis of the workshop data was “who actually is the family?” to whom HCPs have a duty of care.

## **Family’s contribution to the HCP and family relationship**

### **Who is the family?**

HCPs used the term “family”, “relatives”, “rellies” (Workshop One) or “significant others” (Workshop Two) as the “generic term” for the patient’s key contact. However, listening to HCPs’ descriptions of episodes of care indicates the range of people HCPs relate to at the point of recognising dying. HCPs recalled “patient and carer” (Workshop One), “young adult children” (Workshop One), “daughters”

(Workshop Two), *“son, grandson”* (Workshop two), *“Children”* (Workshop Three), *“young family”* (Workshop Three).

The General Medical Council “End of Life Care” guidance orientates doctors to “ensure that people who are close to the patient (partners, family, carers and others) are involved and supported, while the patient is receiving care and after they have died” (General Medical Council, 2010, p.8). This care is also extended to “legal proxies” (General Medical Council, 2010, p.32). The Nursing Code of Conduct refers little to families except in the broadest terms to say “work with others to protect and promote the health and wellbeing of those in your care, their families and carers and the wider community” (Nursing and Midwifery Council, 2010b). The most recent end of life care guidance broadens both the scope of responsibility to “the patient, family, friends, carers and all those important to the patient” (National Palliative and End of Life Care Partnership, 2015, p.15). This raises the question of where the responsibility ends. It also moves from “involving and supporting” to “providing care we would want for our own families” (National Palliative and End of Life Care Partnership, 2015, p.9).

At the current episode of hospital care, HCPs can have little knowledge of the dynamics within a patient’s family, even if others in the health care system know the family. It is the patient who presents to hospital and it is their clinical record that is available to the HCP. Family is thus whoever presents with the patient, until a more significant relationship or lasting power of attorney becomes known. Additionally, families are also seen as a whole and assumed to be in agreement until demonstrated otherwise.

*We planned palliative care plan and discussed with son who was next of kin, he understood and was with us, everything...and then after one hour many of his relatives came and they were so angry and so annoyed – long long chat - and they forced us to reverse the plan* (L375-379 Workshop Three, Study Two).

The impact on the HCP of the family who is angry is considered shortly. Families also come in differing sizes, and families do not necessarily limit numbers themselves. It would appear that HCPs, without critical reflection, endeavour to

meet the information needs of all who present.

*The more people there are in a room then the longer the meeting will go on for in terms of relatives, and I think that is often because, before you leave that room you want to make sure that everyone is on board...and so therefore you're almost addressing everyone in that, you know, they don't look so happy, they're not, they are not engaging...why're they not. You try and address to them and so the more people there are there you are trying to deal with more expectations and concerns etc. (L786-797, Workshop Two, Study Two).*

Families understandably hear what is conveyed slightly differently. HCPs in this study wanted to talk with others about their experiences of working with families.

*Do you not find that the more people that are there the different messages they hear as well? (L798-799, Workshop Two, Study Two).*

This is not easy clinical work for HCPs. I suggest that HCP's burden of care to communicate with all who are present at the bedside, such that all understand, is extremely unrealistic and anxiety provoking. This is simultaneously compounded by the broad range of people identified in the to national guidance documents about to whom the duty of care extends to. I would also suggest that national documents articulating that HCPs give the care to others that they would give to their own family, without critically under-pinning this in HCP education and offering a space in clinical practice to discuss the impact of decision-making with the patient's family, is likely to agitate and aggravate disagreements in care. In all dimensions of life HCPs, patients and families can have very different values.

### **Families have rights**

HCPs expressed that families, as well as patients, had "rights" to information that the patient was likely dying.

*You know when you make a decision...the patient has a right to know it and if they cannot then the family have a right to know as well (L293-295 Workshop One, Study Two).*

When families recognised that the patient was dying, the HCP found this a much easier conversation than when the family had no recognition of this themselves.

*When the family are there, so when you say to them what do you think is happening and they say to you, they are dying, it makes it much easier. When you say to them what do you think is happening and they start talking about treatments and the future, then it makes it much more difficult because their expectations are very different (L 320-324 Workshop 3, Study Two).*

## **HCPs' contributions to the HCP and family relationship**

### **Echoes of HCP's own family**

HCPs repeatedly discussed how caring for families is never easy. The experience is multifaceted. When they did not know the family, for example, when the patient had only been in hospital for one or two days, then it was easier to break bad news about dying as the HCP was not emotionally involved with the family. The skill was rapidly building the trust with the family in order for them to believe the news. When HCPs knew the family and had worked with the patient and family, they identified that they could tailor the information and pace it more accurately for the family's benefit. Yet this work is enormously emotionally impactful for HCPs, both in the run up to death and at the time of death. There is evidence of identification with likenesses of the patient and their family with the HCP's family, and HCPs being conscious at a level of the additional emotional impact this has.

*I don't think you could prepare anyone for that role [long term condition] because you get so involved professionally with the family and that association with the same age, young adult children, and you work with them all the way through the diagnosis, right through and then maybe they get cognitive decline and you know where it's going. It's very (emphasis) difficult you know (L199-203, Workshop One, Study Two).*

There was evidence that they experienced the death of a patient in a manner they likened to the death a friend or relative.

*We have quite long term relationships with our patients before they die and that's a good thing and a bad thing as it often means you know them and their*

*families that much better and that has an impact more akin to a friend or a relative of your own dying (L66-69 Workshop One, Study Two).*

In this manner one can begin to see how the HCP may consciously and unconsciously project and receive affect, which changes the experience of the liminal space. Recognising dying and introducing this to patients and families rattles the psychological defence of the phantasy that medicine can delay death. The HCP is left facing the family in a human-being to human-being relationship with no more treatment options to offer. It is “hard” as the HCP says in the quote below to have no solutions and physically face the family as they face the future.

*I think when you are dealing with long term conditions there is this expectation that you know you have worked with that patient and their family for many years and you have always been able to tweak things and make things right and they are looking at you “can’t you do anything else” and it’s quite hard to actually have to say we cannot do anything else now (L84-88, Workshop One, Study Two).*

#### **HCP’s own psychological defences**

HCPs regularly described a psychological defence mechanism: a phantasy of “being in control”. Families have the potential to undermine this. In the example below the family had demanded twice-daily updates regarding the patient’s condition and then checked this information out with another specialist. Whilst the HCP at the time did not know this was occurring, she found out later and explained why the action of checking with another HCP made that situation worse.

*It challenges our...sense of control in the communication and that sounds wrong, but these are difficult enough conversation.... conversations to have with families if we do feel in control. If we don’t it makes it even harder. (L769-771 Workshop Two, Study Two).*

In this example, there are also echoes of the HCP’s protective phantasy of “being right”. This is why the situation was worse - because the HCP now knew that the family could have challenged the HCP’s decision-making, informed by the second



specialist they were in contact with. Unsurprisingly then, HCPs said they had colleagues who would avoid family meetings.

*Most of my team ...find that quite threatening to go into a planned family presence...because we know the patients well and don't know the family so well sometimes, so you know, your relationship with the patient is very different to the family. They come and start chipping in (L 84-88 Workshop Two, Study Two).*

Whilst the HCP could have a good relationship with the patient, the introduction of the family and their questions and comments was perceived to be of a different nature. The family appear to unsettle the HCP's sense of control in the relationship they have with the patient.

#### **HCP's own emotions**

HCPs recognised that they picked up the family's emotions about the clinical situation and felt really disappointed when their best care cannot ameliorate the family's deeply felt bleak emotion.

*I sometimes feel frustrated (pause) about it particularly if families are frustrated – particularly what you said about anger...that you think you have done a good job and then it all hits you and actually what you have said is not what they have heard at all ...or is what they have taken forwards or that they can even remember at the time and sometimes the level of that feeling is "I don't think I could have done that any better" but it was still crap for the family (L145-150 Workshop One, Study Two).*

They also have to manage their own emotions and feelings that are not possible to express in a clinical situation.

*I see this in a lot of cases...people stay stuck in the bed for 4,5,6,7,8,9,10 days. Just waiting for that moment there, our patients suffer. I get very frustrated and would really like to be able to kill them (nervous laugh)... I would really like a law, a lot of states like Holland" (L 577-589 Workshop Three, Study Two).*

It is possible that HCPs unconsciously communicate their feelings and they did identify that sometimes they were not alone in finding suffering intolerable and that families had, on occasion, asked if HCPs could kill the patient. HCPs could identify what they did to help themselves. These were such strategies as not being alone when breaking bad news, allowing time for family meetings, giving families warning shots if recovery was uncertain, using supportive clinicians to give second opinions, thinking through ahead of the meeting how far they would be prepared to let the family push their decision-making, accessing palliative care to work with families, debriefing with colleagues and learning communication strategies.

*I always talk to patients, families both in terms of bands of time so days to weeks, weeks to months, months to years and that leaves enough vagueness to...live with your own uncertainty and the uncertainty that inevitably exists but clearly if you tell someone they have got days to weeks they do get the rellies over from abroad or something that they desperately want to do (L407-411, Workshop Two, Study Two).*

In the previous sections we have used the concept of liminality to shine a light on the transition of patient from dying to death, the transition of the family towards bereavement and the transition of the HCP to a relationship with the family independent of the patient. Simultaneously the HCP might deeply feel the loss of that patient and feel a personal challenge to their own psychological defences of control and mastery, both by death and the family. In the next section we consider the situations that the PAR workshop participants found additionally challenging.

## **Challenging situations and the HCP and family relationship**

### **Families can be angry**

HCPs understood that anger was a common response of relatives who had had bad news broken. They did find the anger of families very challenging and did describe a desire to leave situations. HCPs who practiced in a community setting as well as a hospital setting recognised that there was a practical security of being in this situation in a hospital setting, where others could take over the care of the family, rather than on their own in a patient's home, where they felt unable to walk away.

*We have all dealt with angry families in the context of telling them their loved one is dying; it's a very, very common reaction...but you know, you've always, in hospital, have got your colleagues, or team around you and you can walk away from it (L568-574, Workshop Two, Study Two).*

The anger of relatives can go on long after the patient has died and so whilst the patient is removed from the liminal space, the HCP is left alone with the family and cannot easily extract themselves. The importance of this is that whilst the patient may have been happy with their care, their voice is lost at death and the family's anger can become overwhelming.

*Well you get some very angry relatives that are not prepared...for that their nearest and dearest has died even though you might have seen them for a number of years while they have been really sick. You think you have prepared them...you think they are accepting what is happening but actually they are not. Yeah after they have died it's like well I didn't expect that, or I didn't know that was going to happen or why didn't you do something about that (said in a challenging way) and then coming up with things that happened months ago and you think well I've seen you however many times and we haven't discussed this or we have discussed this already and that can be quite difficult (L121-131 Workshop One, Study Two).*

### **Families and doctors may not agree about what is in the patient's best interests**

It is very unusual for patients to remain with full mental capacity to take part in decisions until they die. Thus HCPs are required to consult family, friends and carers as the way of understanding the patient's wishes. The family as described in the Mental Capacity Act 2005 (British Medical Association 2008) is primarily identified as facilitative and equal to the patient. In this manner HCPs are dependent on families, carers and friends to enable clinical decision-making in the patient's best interests.

HCPs in this study reported being asked to collude with relatives regarding not telling a patient their diagnosis.

*I had quite an interesting consultation in the week...it was going to be a*

*planned meeting and I met the relatives because the patient actually was unresponsive and wasn't well and it left with them saying "I don't want you to tell him" as is often the case and I said well let's talk about that again tomorrow I will come back and see him; and I went back to the ward the next day thinking are the relatives here, and just how to address this; the patient was brighter and I walked into the room and the relatives weren't there to be seen and he laid there and he opened his eye and he said so I have got leukaemia have I?..... it was a really useful consultation (L654-663 Workshop Two, Study Two).*

It is notable that the HCP's duty of care is to the patient and when the patient was conscious he both knew what was wrong with him and wanted to talk with the HCP about it. Yet when the patient did not have capacity the family had a different perception of the situation. One could ask if they were protecting themselves by asking for the patient not to be told as they would not have to cope with the patient's grief, or whether they were protecting the patient. Families may (and often do) hold different views to patients about the same topic e.g. place of care (Brazil et al., 2005). In addition they may not always accurately represent patients' views (Winter & Parks, 2012); they may override them as the patient loses capacity or as they find it difficult to cope with the reality of the patient dying (Gomes et al., 2013). The reality of best interests decision-making as the patient loses capacity is that another liminal dimension occurs as the patient transitions out of the HCP and patient and family relationship ahead of death and the HCP is left alone with the family.

Even when these meetings are highly charged, misunderstandings can be resolved through explanations. In the example below, HCPs described how relatives used emotive language and accused them of "killing the patient" or "starving the patient".

*This is what they say to us "you are killing them"; "you are killing them" cos you're not giving them that fluid; the fact is that they are dying, we are not killing but it is very difficult (L570-572 Workshop Three, Study Two).*

The ability to manage the polarity of "letting die rather than killing" is described

(Curtis et al., 2005) (Royal College of Physicians 2010) and it is a skill to be able to reframe such strong language and contain the distress of the family. Some HCPs had learnt this skill and were able to describe this process and how relatives' distress got in the way of them hearing and understanding.

*It is about education and explaining to them what it means you know; terminal dehydration, because they just don't know do they.... and it's...they are so distressed (L573-574 Workshop Three, Study Two).*

The doctor, though, retains the responsibility for the best-interests decision-making and there is a process to follow to resolve any sustained disagreement (British Medical Association, 2008). In the example below, it is clear that the disagreement between the HCP and the family is on interpretation of the word "natural". The family's perspective is that death is natural when it occurs on maximal life- prolonging treatment. The HCP's perspective is that medical treatment cannot be demanded, but is given or withheld in the patient's best interests and they did not think oxygen therapy or intravenous fluids were currently in the patient's interests. The anger expressed by the large family about the disagreement caused the medical team to reverse their previously agreed care plan to allow the patient to end his life comfortably and instead to implement a plan that they did not believe to be in the patient's best interests.

*HCP 5 After one hour many of his relatives came and they were so angry and so annoyed ...and they forced to reverse the plan and they said we only believe in natural death and we can't stop oxygen, we can't stop intravenous fluids;*

*HCP 1 they believe in "natural?"*

*HCP 5 Oxygen's natural; (group laughs)...the situation, the relatives were so angry, they want two hours about the problem, questioning me and Dr X and we reversed the plan and it was just not right for the patient, regarding this...three hours with the relatives. (L577-586 Workshop Three, Study Two).*

It is striking that the medical team gave three hours to the family meeting; there will have been the pressure of the need to attend to other patients (and indeed the patient related to the family) and it is perhaps this that allowed the overturning of

the decision to end the meeting. It may, though, have been that the family had a different faith and culture (Calanzani et al., 2013) and this felt an impossible situation to mediate. The timescales for the management of conflict between the family's opinion and the medics' are affected by the rate of deterioration of the patient and the length of time dying takes. When there is time, then the disagreement can be resolved either locally by understanding the underpinning of the conflict or by a second medical opinion and legal advice. In the case of a dying patient, clinical teams would always seek, if possible, to work with the family as it would lead to improved bereavement outcomes for the family and a better outcome for the HCP, in terms of not dealing with an on-going complaint.

Without the patient's voice the management of the ethics of the dying period are really challenging. Engagement with families is not routine for escalation of care (Kryworuchko et al., 2012) and escalation of care until death can be very helpful for families whose culture is non-western (Calanzani et al., 2013). In this manner, though, families can be avoided. I suggest that complexity surrounding the engagement with families may be a reason that the recognition of dying is delayed until very near death. It reduces that time needed to engage with the family.

#### **HCPs have personal theories about families that may be unhelpful**

HCPs do have personal theories about families – these may or may not be helpful. HCPs do helpfully sense that what is occurring during the conflict may not be about the HCP and healthcare system, but a projection of the family's feelings. In the excerpt below one of the doctors offers a personal theory that the intensity of demand from a relative relates to the lack of times they have routinely been involved in a patient's care. Participant is a doctor and participant 1 and 6 are nurses.

*HCP 9 I think that usually the degree of the relative demanding is an inverse proportion of how many times they see the patient*

*INT JW ok?*

*HCP 9 oh they just tell us I live in Australia and they are so demanding*

*HCP 1 erm*

*HCP 9 all of a sudden*

*HCP 1 Guilt*

*HCP 9 We have got a lot of guilt there, that the patient is just left in the NH, and probably tell you we have never seen the next of kin, and when they are admitted everyone is coming, asking and sometimes it is just that*

*HCP 6 In a short space of time you have got to deal with all those issues the family have and their guilt, their relationship in such an alien environment really in an acute setting, for everybody. And then it's very hard when you don't know the family or the patient and all the dynamics – but you can't move on and reach that acceptance until that is all dealt with can you? But you can do a quick fix and try and get them on board and understanding. So a lot of it is their misunderstanding ...of their whole situation isn't it, if they have not been that close to the family member / patient? It is very difficult isn't it to deal with that in a short space of time? (L388-405, Workshop Three, Study Two).*

In this excerpt, there are large assumptions about families and their motivations, judgment and blame by the doctor (HCP 9) and nurse (HCP 1), with the fault for the situation laid firmly at the door of the family. In this scenario one can see that consequent to the doctor perceiving the relative as demanding, psychological defenses come into play and there is splitting and projection and guilt used to describe as the underpinning motivators for the relatives' demands. There is judgment too about the relative and their previous role in the patient's care. In the workshop the nurse (HCP 6) offers containment and an alternative viewpoint on the situation. HCP6 also discusses how much emotional work there is to do in a hospital when the family has not caught up with the patient's narrative and the clinical situation requires rapid decision-making; HCP6 highlights that time is of the essence. HCP6 alludes to a "quick fix" to gain understanding; whilst this was not explored I would suggest that the ability to therapeutically work in this compressed and pressured space is very skilled. In this circumstance it may be

that the level of work the family requires is not resourced within the hospital and the doctor takes the brunt of this, without either the skill to assist the family or the time or space to undertake this work without compromising other aspects of patient care.

### Families can be mistrusting

HCPs identified very strongly in Study Two that what they found extraordinarily challenging were the consequences of the patient taking longer to die than expected or the patient surviving the prognosis. This caused the family to doubt the HCP. Some HCPs have learnt strategies to manage this.

*So when the dying takes longer than expected, it is difficult... for the family, it's difficult for us going in everyday because they start to question you and I do say to them sometimes and you know they are going to die but they just aren't dying as quickly as you anticipated and I do say to them "I expect you are now doubting what we are saying, that you are thinking that maybe we have got it wrong"...and they say "yes". (L165-171, Workshop Two, Study Two).*

HCPs also identified the consequences for themselves and families when the patient survived the prognosis of dying, especially when the family felt that death is preferable to the patient's suffering.

*But we have had problems with this this week as we have had two patients who have got better, and the family are saying you told us they were dying and we ready for them to die, we wanted them to die, and now they are getting better we have to change our plans (L329-332 Workshop Three, Study Two).*

There are consequences when the family did not want the dying, but accepted it was likely: when the patient survived, the HCP had to work extremely hard to regain the family's trust in order to secure an onward care plan.

*It happens only once to me this situation when one patient put on the end of life care pathway and then woke up after four days ...the problem was with*



*the family because it is true that the patient woke up but from a quality point of view he was not able to understand what was going on, but I must admit with the family I had a really tough period.... I think most of the family in the end trust you and then they see things go exactly in the opposite way and...it takes me a lot of hours of conversation with them to gain confidence again. (L234-243 Workshop Two, Study Two).*

There is little in the medical and nursing literature about relationship repair within the therapeutic relationship following such experiences of a patient having survived a prognosis. When families have had repeated experiences of having bad news broken, it can make them resistant to HCPs trying to communicate with them.

*They say we have had this conversation so many times that they might not recover this time; I don't want to talk about it anymore. (Workshop Two).*

This links with Szakolcaizai's request that a liminal situation should only be provoked if "one has a proper form to impose on the soul of whose emotions are stimulated by being put on the limit" (Szakolcaizai 2009), and MacArtney's paper that indicates how people resist entering a liminal period (MacArtney et al 2015). These families, who have repeatedly been told their loved one is about to die, take their part in resisting engagement in the HCP and family relationship about a situation they have repeatedly had experience of without the transition to bereavement occurring. Breaking bad news about recognising dying has no relevance to them. A patient's family can be in denial that the patient will die and carrying on with life, or so used to living with uncertainty and managing their own lives around this that the predicted death of their family member is not a liminal experience. It has become their daily norm.

### **Families may not understand**

HCPs described situations in which the family's lack of comprehension or inability to hear the news being conveyed resulted in the HCP being physically sought out and followed. This interrupted the HCP's sense of control over the plan for the patient and sense of control over time-management, which caused the HCP to

doubt themselves. It also made them wonder to whom they should give their time – the patient or the family.

*There's a patient whose relative will follow you round the unit and you can sit and think that you have had a consultation and you tried to communicate everything and then ten minutes later he is following you round the door and you're thinking did we not have this conversation a minute ago. That's quite difficult, but they do, they can follow you ...it instils a doubt in your communication skills and it means that you, you sort of can't compartmentalise your time; ok we have done that, I think I've gained / made something there, I have spoken to the nurses and got a plan and then have you not? You are back to square one you know and it's almost like groundhog day and you're not making progress and its, its time consuming, it's you know all the simple stuff as well as the actually addressing the needs for the patient, and this brings to light the needs for the patient often differ from the needs of the relative and family and I am not sure which you are addressing (L690 – 676 Workshop Two, Study Two).*

The doctor in this scenario finds themselves stuck and unable to address patient needs or the needs of the family. There may be many reasons why this has occurred. Whilst some might think the patient has not heard the news, it may be that the news is so awful that when the doctor leaves the relative alone with the sick patient that it is unbearable for the relative to be alone with the patient and their own thoughts. They might not be able to bear to move into that liminal space and consider their future losses and how their life will change. In the next chapter we consider Bion's theory of how thought, thinking and a move to learning can only occur when the emotional needs are addressed and the situation safely contained (Bibby, 2011). The doctor may have given information to the relative, but not allowed for emotional containment or the need for comfort. Additionally, there is no structure and ritual here, as per Szakolczai's request, or additional skilled resource, and thus the family member is left seeking comfort out.

### **Managing care at a “clinical crisis point”**

Earlier in this chapter it was discussed that time could be pressured, even in a

ward situation, to help the extended family understand and psychologically accommodate the clinical decision-making about the recognition of dying. In emergency clinical situations – in the Emergency Department - time may be extremely pressured with the patient requiring treatment if the appropriateness of end of life care was not previously determined. Clinical crisis points can occur any time of the day or night, seven days a week.

#### **Lack of written information about the patient's care and wishes**

HCPs in this study found it both anxiety-producing when patients were admitted to the Emergency Department without any accompanying written information and frustrating when it was their patient who was transferred in from a community setting and treated, when they had been prepared for end of life care.

*What I find very hard from a nursing point of view is sometimes you have spent a lot of time with these patients and then come into hospital, and our patients come into hospital so infrequently now that they are not very well known in hospital and so this whole approach from the medical team is "let's do this, let's do the other" and you're thinking "well we've just spent the last twelve months actually talking about we don't want this and we don't that and we don't the other and we are dying" (L450-456 Workshop One, Study Two).*

Electronic co-ordination systems are being worked on nationally (Millington-Sanders & Nadicksbernd, 2013). The aim of these is that advanced treatment and care plans, and patients' wishes and preferences are available to all – ambulance services, out-of-hours services and Emergency Departments – at a point of clinical deterioration. HCPs in this study did not discuss them. This raises the question about whether electronic care plans are not yet available or not embedded in routine clinical practice. Thus, for this hospital there still remains a lack of information available electronically, from the home setting, at the clinical crisis point in the Emergency Department.

In some situations, the family can accompany the patient into hospital and be a source of advice. When the patient travels alone and does not have capacity, the

Mental Capacity Act advises that an Independent Mental Capacity Advocate (IMCA) must be sought. An IMCA is a safeguard for the patient and the HCP and assesses the patient and their clinical records, and can challenge HCPs about decision-making. Since the IMCA service is only available Monday to Friday 9-5pm, experience dictates that a response is never achieved in time for decision-making around dying in the Emergency Department. This means that HCPs take personal responsibility for all clinical decisions. If a family appears after the decision that the patient is dying they can challenge the decision-making of the HCP. Whilst the Mental Capacity Act offers the HCP protection - "An action or intervention will be lawful – i.e. health professionals will enjoy protection from liability – where the decision-maker has a reasonable belief that individual lacks capacity to consent to what is proposed" (British Medical Association, 2008, p.15), the suggestion that any of this is "enjoyable" highlights the lack of understanding of the level of underpinning anxiety in this clinical situation.

#### **Lack of organisational resources for care**

HCPs identified a lack of time and space for significant conversations with families and were personally creative about how they undertook this aspect of clinical care.

*Can I say something about the environment? I couldn't have that type of conversation in clinic generally; I would bring them up outside of clinic hours and I could bring them to the day unit, where we have got private, quiet space there. Often with Advanced Nurse Practitioner or a Registrar, rather than trying, that pressure of feeling that this might take fifteen minutes, it might take three quarters of an hour and there is a whole clinic backing up behind you...which is not nice for you or the patient (L919-924, Workshop Two, Study Two).*

In this quote it is notable that the outpatient clinic setting is ill equipped, both in terms of private space to break bad news and skilled multi-professional resource with capacity to manage the patient and family distress such that others patients in the clinic are not affected. The poor experience of patients and families in hearing bad news in an outpatient setting has long been noted and whilst this can be consequent to the HCP's skills, it is also due to the lack of private space (McCulloch,

2004). I suggest that the lack of physical space for breaking bad news in a clinic area represents something the NHS organisation cannot bear to consider and, whilst this may be unconscious and wrapped up as a lack of finance or physical space, it does suggest a link to the defended and less rational aspects of HCPs who design hospitals. In this quote the day unit has private and quiet space. Whilst not discussed by the HCPs, Macmillan, a cancer charity that has done much work to improve the patient experience, funded this unit.

Families were also creative and initiated conversations, and took advantage of transitional (liminal) spaces. In the example below the HCP was just returning from leave and met the family in the car park.

*I can remember coming back from a week's holiday and walking in the front of the hospital to be accosted by a patient's partner – I mean he wasn't looking out for me – we just happened to bump into each other um.... How are you, social niceties and he said what do you think is going to happen? And I – the patient was on ITU – I had no idea and you know I pussy footed – I said I am just back from holiday I will find out and come and see you later. (L747-753 Workshop Two, Study Two).*

“Pussy footing” and acting cautiously is likely to have been additionally anxiety-provoking for an HCP whose preference is to be in control. Additionally, at the beginning of a return to work to promise a family a meeting is also a burden when the clinical demands of the day are unknown.

## **What do HCPs trade when the family is emotionally struggling to accept the diagnosis of dying?**

### **The patient's dying trajectory**

HCPs were compassionate to families who were emotionally struggling to accept that the patient was dying and there is repeated evidence of a point in some patient's care where the care to the family is prioritised over the patient. HCPs use medical interventions to “buy” time for families to accommodate the news, even though they know the ultimate outcome of death is unchanged for the patient (Abadir et al., 2011). In this study HCPs (nurses) recognised when they are

transitioning the care from “doing good” for the patient to “not doing harm”, in order for the family to psychologically accommodate the impending death of the patient.

*I've worked in A and E... people...have to have that space and time to accept they are dying and sometimes you do have to go along with OK I will put up fluids, or I will do that, we all know it's pointless; they know it's pointless but they need that time to adjust to that person dying. So they need that space and you are giving them that space in that acute type thing, to be able to say we did everything we could and accept” (L498-503 Workshop Three, Study Two).*

They are clear that if the intervention harms the patient e.g. they become overloaded with fluid from infusions, then the patient’s comfort is not traded for the family, but there is a space, while the patient is comfortable, where the family is willingly prioritised over the preferred treatment plan for the patient.

### **Relationships with their peers**

Some doctors are avoiding making decisions about dying, even though they recognise the dying. Three ways were described - firstly by making a paper based referral for a second opinion (described below as the “yellow form”). This can take up to three days to get a clinical review. The consequence of this is that the referrer can delay a conversation with the patient and family and the HCP giving the second opinion has to negotiate all of the family’s concerns.

*You know if you are an old school consultant then you're used to waiting. Put in the yellow form, doesn't matter if you wait five days, because it gives you an excuse to say to the rellies, oh well, people will just have to believe um we can't make any decision until they have (L491-494 Workshop One, Study Two).*

Secondly, by recognising that a person is dying, but writing in the notes an intervention that is viewed by others as futile. For example, a case was described where an elderly patient was admitted with pulmonary oedema, advanced congestive cardiac failure, sepsis, acute kidney injury and a Glasgow Coma Scale of ten (meaning they have a decreased level of consciousness), a systolic blood

pressure of 70-80mmHG and aneuric. The doctor had written “consider palliative if creatinine over 300”. The group stifled a laugh, but there was personal shock of the HCP at the doctor’s care of the patient and anger at the lack of decision-making and care. Thirdly, by writing an instruction in the clinical notes, but leaving others to undertake the work.

*Got a colleague recently worked in care of the elderly, but on every single elderly patient he writes “please consider DNACPR discussion”, do it (emphasized)....in every single note, every single note, I followed him, I will do an audit, in every single note, please consider DNACPR decision (L466-470 Workshop Four, Study Two).*

Some HCPs feel they bear a bigger burden of the family work because colleagues avoid it. This links to the analogy of recognising dying being passed around like a “hot potato”, as was seen in Study One. It also leads to anger with the colleagues avoiding dying patients and families.

Clinicians who cannot or will not emotionally engage with the patient and family to acknowledge the impending death and help the family navigate the uncertain period to the patient’s death and their impending bereavement, instead offer the promise of certainty through continuing medical treatment. In reality though, this strategy, shortens the period between the recognition of dying and death and can leave the family with few tools to negotiate the liminal period, and the preparations that can be made that may allow a smoother transition to bereavement. .

To complicate this though, at the point where dying is recognised I suggest the organisation devolves its responsibilities to the individual HCP through lack of current information at the time of transfer across care boundaries into the Emergency Department (although HCPs may play a part in not accessing this); through a lack of resources to offer families and a lack of places for conversations; and through the lack of formal emotional support for HCPs. Thus, at the time of a clinical crisis point, in order to communicate with families and give them time to accommodate the news, there is evidence that HCPs are trading the patient’s dying trajectory and lengthening it with treatments that are ultimately futile. Some are

trading relationships with their peers by avoiding making a decision about dying and communicating with the patient and families. Whilst this might protect the individual HCP it leaves other clinicians to pick up the work, leading to anger and resentment.

## Conclusion

Drawing on the concepts of liminality and affectivity has opened a space to consider the dynamics of the HCP and patient and family relationship as dying is recognised and communicated. This chapter proposes that recognising dying and engaging with the family about this has the potential to jettison the family into an experience of liminality where the reality of death of their family member and possible personal impact becomes a reality. It also changes the focus from the HCP – patient relationship to include the family. HCPs do not discuss national guidance and its broad remit of people to whom care is owed, but care for whoever of the family that is present at the bedside (until other relations and / or conflict get introduced). It is suggested that the broad range of people cited in national guidance documents about whom HCPs owe a duty of care to makes the clinical task challenging, and the suggestion that families are cared for as HCPs would like their own families cared for is unhelpful in terms of raising the emotional tone and promoting the chance of conflict.

Dying is a liminal experience for the patient, but the loss of mental capacity to take part in decision-making can and is likely to occur ahead of death and withdraws the patient from the decision making process. The formal introduction of the family, in a best interests decision-making scenario, is additionally challenging. I suggest the HCP continues to seek out the voice of the patient even when they have lost capacity, as the HCP is left in a HCP and family relationship, where there was evidence in this study as with others that families do not accurately represent the views of patients. This situation is ethically challenging for HCPs for whom the duty of care is to the patient. However, the relationship between the HCP and family relationship has the ability to go beyond the death of the patient, which is experienced negatively by HCPs when families are angry and complaining.



The engagement with the family may also be a liminal experience for the HCP as they can recognise similarities with their own families or experience the death of a patient as they would a family or friend. Additionally, HCPs' protective phantasies of being right and in control can be undermined in a situation where their skills to cure or make better have reached an end and they meet the family in a human-being to human-being relationship. HCPs in this study were committed to caring well for families, but experienced families who were angry, disbelieving, demanding and unable to accept the news. These families had the ability through their demands and anger to force HCPs to overturn decisions they had made in the patient's best interests. This study was not focused strongly on cultural issues, but this chapter highlighted how different people perceived a "natural" death.

Anthropological researchers have suggested that liminal events be structured by ritual for the emotional safety and containment of strong emotions and for people to understand the behaviours of the role. I am suggesting there is no ritual or clue for families to know what to expect in the process of receiving bad news of imminent death of a family member. There is no ritual or role to support HCPs as their psychological defences of mastery and cure are stripped away and they meet the family in a human-being to human-being relationship.

This chapter proposes that the organisation devolves all its responsibility to the HCP at the time of breaking news and that, in order to accommodate the family's distress, the patient may be subjected to futile treatments. In addition, relationships with nurses are traded by senior HCPs, as are relationships with colleagues. It is suggested that the presence and involvement of families is extremely anxiety-provoking and likely to contribute to HCPs' defences, including processes of denial about recognising dying. HCPs discussed feeling poorly prepared educationally for the clinical work with families. Educational preparation for clinical practice is covered in the next chapter.

## Chapter Eight – How HCPs Learn To Care For The Dying Patient And Their Family

### Introduction

Over the course of the previous two chapters, the psychosocial analysis of Study One and Study Two data has been developed. In Chapter 6, drawing on Menzies-Lyth's study of social defences in a teaching hospital (Menzies, 1970) I extended her work in a contemporary setting and with reference to contemporary psychosocial work. The chapter demonstrated how emotionally impactful, and anxiety provoking, caring for the dying patient is, and proceeded to discuss the social defences seen in today's NHS about the identification of dying. These are represented in 1) the need for a cast iron decision, 2) second opinions and checking, 3) making sure the family are on board, 4) avoiding the work. Avoidance of the clinical work is seen in the social defences of 5) not seeing the dying, 6) dressing up dying as a treatment, 7) leaving the emotional work to someone else, 8) redistribution of the emotional work. Those HCPs who undertake the clinical work can evidence 9) detachment and denial of feelings and 10) break bad news in a ritualistic way. This chapter considered that the Hospital Palliative Care Team (HPCT) are the new social defence of the modern NHS hospital.

In Chapter 7, drawing on the concepts of liminality and affectivity, I considered the impact of the family in the HCP and patient relationship. Dying is a liminal experience for the patient, but the loss of mental capacity to take part in decision-making can and is likely to occur ahead of death, which means the family are formally introduced to the HCP and patient relationship in a best interests decision-making scenario. I proposed that recognising dying and engaging with the family about the patient dying has the potential to jettison the family into an experience of liminality where the reality of death of their family member, and possible personal impact becomes a reality. HCPs in this study were committed to caring well for families, but experienced families who were angry, disbelieving, demanding, and unable to accept the news that the patient is dying.

I also considered that the recognition of dying and engagement with the family may also be a liminal and affective experience for the HCP, as some HCPs

experienced the death of a long term patient as they would a family or friend. They could also identify with similarities with their own families. At the same time the HCP's protective phantasies of "being right" and "in control" are undermined by death; their skills to cure or make better have reached an end; and they can meet the family in a human-being to human-being relationship. Thus it is suggested that alongside the recognition of dying, that the presence and involvement of families is extremely anxiety provoking and likely to contribute to HCP's defences including processes of denial about recognising dying. The current lack of ritual, and thus resource, alongside the communication of the recognition of dying, is recognised as problematic for the emotional containment of strong emotions.

The focus of this chapter is on how medical and nursing HCPs learn to care for the dying patient and their family. It comes from the psychosocial analysis of the Study Two Workshops, as participants considered the themed results from the Critical Incident Review (Study One). HCPs who took part in the PAR workshops discussed feeling very poorly prepared educationally for identifying dying and working with families, and that they learnt mainly from direct clinical practice. This chapter examines the structure of current medical and nursing education. It examines the education literature that shows that despite the national commitment to providing education about the care of the dying, setting standards for education and educational supervision, and evaluating novel methods of teaching, there is a tension about what is achieved, and it is expressed in several absences, gaps and disjunctions. I have turned to psychoanalytic psychosocial theory to consider the possibility of the irrational, unconsciously defended subject. I have considered Bion's theories of learning to critically examine how the PAR workshop participants discussed the supervised learning event. Outside of the supervised learning event I considered how HCPs manage their anxiety to "see" and to learn, the contributions of the PAR workshops to learning and the organisation's contribution to learning.

### **Current medical and nursing education**

Current medical and nursing education, whilst of differing lengths, is based on an "apprentice" type model of learning. In this approach teaching occurs in a

university and higher education setting for both medical and nursing students, and is underpinned by time spent observing clinical practice, and taking part in clinical care. In the context of the changing age and health demographics, where many patients now are elderly and have multiple co-morbidities, post registration medical training has recently undergone six reviews (Greenaway & Greenaway, 2013), to ensure that patient care is improved. In essence these reviews found that medical education was slow to adapt to patient and service needs. In the past doctors tended to specialise in one clinical area, but now need a much broader range of skills to manage multiple illnesses occurring simultaneously, in the context of the patient's social, financial and family resources. Additionally the training structure has previously prevented doctors changing specialties mid career, or developing knowledge and skills outside of their specialty, or, with the introduction of the doctor's own family commitments and children, to move into and out of training (Greenaway, 2013). Similarly, pre-registration nurses' training has also undergone a review titled "The Willis Commission" (Willis Commission, 2012) to ensure nurses are able to care for patients in hospital, but also in community settings. These locations may be the patient's own home, in residential and care homes, in general practice and out-patient settings. Despite recent reviews of medical training, the notion of 'seeing', in the sense of observing others and role modelling, continue to be seen as critical to the development of competent HCPs at the time of qualification (Kopelman, 2014) (Willis Commission, 2012).

Typically, a medical course comprises a preclinical core science component in years one to three, and a clinical component in years four to six. The care of the dying patient is pre-dominantly covered in the clinical component (Barclay et al., 2015). The nursing curriculum is orientated to a life-course perspective that includes experience of death and the social context of dying (Cavaye & Watts, 2012) and exposure to the care of the dying is more variably experienced depending on the kind of clinical placements undertaken. A few students can receive a direct clinical placement with a palliative care team (Bassah, Seymour, & Cox, 2014). There is evidence from the literature that Institutes of Higher Education – both nursing and medicine - are endeavouring to use and evaluate a range of teaching methods to enhance learning about the care of the dying,

including e-learning (Gibbins, Williams, Cooke, Alder, & Forbes, 2012), simulation (Kopp & Hanson, 2012) (Gillan, Jeong, & van der Riet, 2014) and group work (Poultney, Berridge, & Malkin, 2014).

### **The learning opportunity - part one**

Medical and nursing education curriculums are focused around “learning opportunities” in clinical practice. These are recognised to occur wherever the student practices. Whilst each clinical experience has the potential to be a learning opportunity (Academy of Medical Royal Colleges, 2012) (Nursing and Midwifery Council, 2010a), there are pre-set expected experiences mapped onto assessment procedures so that the student can be evaluated as being able to practice competently. This means that in clinical practice a student needs to be able to seize opportunities to learn, and reflect on them with a more experienced clinician. These learning opportunities have been formalised in the junior doctor curriculum and called “supervised learning events”. These opportunities are also linked to assessment for competence for registered practice.

Standards have been set for medical education throughout a medical ‘career’, from medical student through to consultant, in order to access these learning opportunities. The learning opportunity is to be safe for patients and supportive for learners and educators, occurring within a caring, compassionate culture and providing a good standard of clinical care. The institution offering the place of training must visibly value and support education and training so learners can demonstrate what is expected in “Good Medical Practice” and to achieve the learning outcomes required by their curriculum (General Medical Council, 2016, p.9). A junior doctor’s post-graduate medical education is supported by educational supervisors – recognised by the medical deanery - who are responsible for the overall supervision and management of a specific doctor’s education (or part of their education) (General Medical Council, 2016). In clinical practice all senior clinicians supervise junior doctors’ care, as they do not necessarily work with their educational supervisor.

Standards are set for the education of student nurses, but they do not exist for the continued professional development post qualification. With regard to the learning

opportunity, the Nursing and Midwifery Council (NMC) says “practice learning opportunities must be safe, effective and integral to the programme outcome” (Nursing and Midwifery Council, 2010a). The mentor and “sign off mentor” is key to student nurse assessment of competence, and as well as “selecting and supporting a range of learning opportunities”, they have to be able to make judgements about competence and proficiency of NMC students on the same part of the register and same field of practice and be accountable for such decisions” (Nursing and Midwifery Council, 2010a, p.24).

Reflection is seen as key to medical and nursing development, and the route to make sense of learning, and is directly linked to a change in practice or behaviour – “doctors must understand their strengths and weakness, their personal style, assumptions and beliefs. This requires doctors to be open to feedback and with reflection and guidance, to be able to modify their behaviour” (The UK Foundation Programme Curriculum, 2016). Reflective based nursing curriculums based on Gibb’s single loop of learning, and Kolb’s double reflective learning cycle were introduced in the early 1990s (Murphy & Atkins, 1994) as a method to stimulate nurses to learn from clinical practice as it was deemed that practitioners who have “learned to learn...may be more effective in meeting client needs” (Murphy & Atkins, 1994, p.17). In these cycles, nurses were asked to reflect on “what happened in clinical practice, how they felt about it, what the evidence base indicates and to formulate a new plan of action for the future” (single loop), and then what they learnt about trialling this process (double loop) to engender “deep learning”.

The learning theories that broadly underpin the current education curriculum presuppose that learning is mainly a rational and cognitive process, and are informed by behaviourism, cognitive constructivism and social constructivism. They also assume that learning can be straightforwardly assessed. Behaviourism presupposes a passive absorption of a body of knowledge, promoted by repetition and positive reinforcement as exemplified by taught lectures, feedback and examinations. Cognitive constructivism assumes that new information is discovered by learners with the teacher’s facilitation and is able to be assimilated and accommodated, as exemplified by watching and being involved in clinical

practice and discussing learning from this with role models and mentors and in the classroom. Social constructivism assumes that new information is collaboratively assimilated and accommodated and integrates students into a community of knowledge and practice through group learning. This would be exemplified by HCPs learning from role models and contributing to care in the clinical area. Reflection as it is currently articulated is a rational and cognitive process.

However, despite the commitment to providing education about the care of the dying, setting standards for education and educational supervision, and evaluating novel methods of teaching, there is a tension about what is achieved, and it is expressed in several absences, gaps and disjunctions. Firstly, there is evidence that the amount of time given to palliative care and care of the dying patient on the UK medical curriculum can vary from as little as 7 to as much as 98 hours, and it is notable that there is still “a trend towards patient contact” (Walker et al., 2016, p.1) rather than actual patient contact. There is evidence that student nurses exposure to education about the care of the dying, was on average forty-five hours in the UK. The attention to the care of the dying varied according to place of study. A quarter of nursing programmes offered a full semester course (76% students took the course, and 62% spent time in a hospice or palliative care team), and over a half of nursing programmes offered a lecture (s) in various courses (Dickinson et al., 2008). This has the potential to leave a gap in the ability to utilise fully the “apprenticeship” model of seeing and learning in relation to care of the dying.

Secondly, senior medical educators have recorded that it is hard to produce sustained positive attitudinal change of medical students to the care of the dying over the course of medical training, and have linked this to the attitude of core clinical science educators. They found negative attitudinal changes occurring during the core science colleagues delivering years one to three, which contrasted with the positive attitude generated by clinical colleagues delivering years four to six (Barclay et al., 2015).

Thirdly, there is also a disjuncture between what skills educators think junior doctors require in order for them to care for the dying patient; what clinical care consultants believe junior doctors can provide; and what junior doctors feel they

can provide. This is exemplified in Bowden's research where surveyed junior doctors found themselves prepared to speak with patients and families, and manage the patient's pain, but ill equipped to manage the psychological, spiritual and social distress of dying patients and families that are expressed consequent to the conversations (Bowden et al., 2013). Over half of junior doctors reported significant emotional distress consequent to this clinical work, yet few felt they had anyone they could seek help from. The majority of consultants felt that junior doctors were equipped for medical practice, felt confident that junior doctors would ask for help, yet few had provided help (Bowden et al., 2013).

Student nurses are experiencing the care of their first dying patient within their training (Costello, 2013) and some feel very unprepared for the level of communication skills required of them when caring for dying patients (Okoye & Arber, 2014). They are learning to emotionally care for and be alongside the patient unsupervised whilst undertaking general nursing care tasks. They value hospice placements as a learning experience (Okoye & Arber, 2014), in part because they felt that they could be themselves whilst caring for the dying patient, and not find the care of the patient at odds with their natural disposition. In the hospice scenario there was humour and the student nurses found this helpful. Students are learning about themselves, as they learn to care for the dying. They also recognise there is a skill in being able to sit with the patient and tolerate a high level of emotional distress, and they want more education on this topic both in the university and in the clinical area. However, whilst some students frame caring for dying patients in a positive light, others find that caring for the dying can have significant negative emotional impact (Kent, Anderson, & Owens, 2012) and actively avoid caring for these patients (Okoye & Arber, 2014).

Fourthly, in both the medical and nursing literature, the role of palliative care teams in supporting learning in clinical practice is recognised as helpful as a support to junior clinicians with limited teaching from senior colleagues (Price & Schofield, 2015) and to debriefing clinicians after the death of a patient (Hockley, 2014). Thus specialist support is required to attain the maximum learning from the clinical situations, rather than this being delivered by generalists. So education



of nurses and doctors about how to care for the dying patient and their family is proving resistant to easy improvement without specialist palliative care support.

### **The possibility of the irrational defended subject...psychoanalytic learning theory**

Psychoanalytic approaches turn cognitive and rational approaches to education on their head - "the thoughts come first, and thinking may follow" (Bibby, 2011, p.98 ). Bibby says a "difficult thought to bear is that thought and thinking are uncontrollable, radical and subversive" (Bibby, 2011, p.114). An equally difficult thought to bear is that reflection subsequent to thinking may not proceed to learning due to our unconscious defences blocking this (Doyle, 2012) – learning is painful (Salzberger-Wittenberg, 1999).

It is helpful to site Wilfred Bion's work as key here as he articulated theories of how we think and learn. He returned to the earliest development of this capacity as it develops between mother and child. As a baby cannot make sense of experiences such as pain and hunger, these are projected into the parent (through crying, physical distress), so the parent can feel something of them – contain and hold them - and understand the baby's experience. The parent can then think about the baby's distress and transform it into something that the baby is more easily able to 'digest'. Through the parent's thinking the baby is able to develop the capacity to think in relation with another and gradually learns to self-soothe independently. "Being able to think has its roots in the meeting of minds between mother and baby" (Doyle, 2012). If the mother cannot contain the baby's distress and "think" about the baby to make the experience safe for him/her, then the baby is left with its own difficult feelings, and also perhaps its mother's overwhelming emotions to endure. Feelings of vulnerability and terror can "re-ignite in relationships in later life" (Frost & McClean, 2014, p.144), including in relationships of learning.

Thought, thinking and emotion then are linked and as Bibby says they are "anchored fast in the unconscious" (Bibby, 2011, p.98). Doyle says the importance of the early parent – child interaction in adulthood is three fold. Firstly, these early experiences shape the individual's sense of self, and help to frame ways of relating to others and the wider social world. A representation of the world is formed that

can be reworked and modified according to subsequent experiences, but that over time is likely to become a kind of template for interpersonal engagement. Secondly, the process of parent-child relationship prepares the individual to retain thoughtfulness, and curiosity even when feelings of discomfort overwhelm. Thirdly in the face of unsettling feelings and experience, individuals can potentially return to earlier patterns of communication. By this I mean they may only be able to tolerate a situation which is comfortable and manageable and may need to avoid a situation that unsettles (Doyle, 2012).

### **What does psychoanalytic learning theory mean for those learning to care for the dying?**

What might this mean for nurses and doctors who are learning to care for the dying and their families? In this context, there are parallels with the educational context, where part of the teacher's role, like the mother's, is to hold the anxiety and frustration of students "not knowing", thereby helping students to approach unknown and potentially devastating knowledge. In the process teachers learn both about the student, the situation and themselves (Salzberger-Wittenberg, 1999). We have already discussed that caring for the dying evokes such powerful feelings that it challenges our internal psychological boundaries. It is likely that educators will need to hold the strong emotions of our novice doctors and nurses, to be thoughtful about the person (s) and situation, to transform the encounter in a helpful way so the novice can learn.

Whilst recognising the "good enough" concept (Winnicott cited in Bibby, 2011, p.145), it is helpful at this point to think about some of the work that may go on in the supervised learning opportunity with a senior HCP about breaking bad news to a patient and family. It would be helpful for the HCP to 1) hold and contain the patient and family's immediate anxieties and distress, in order to facilitate decision-making that is meaningful to the patient and family, and help them to tell a cogent narrative of care (so important to bereavement outcomes). 2) Convey to the family a sense that this potentially devastating experience is survivable, and that this level of distress will pass and help them identify their own emotional support (where this is a gap in support a referral to other agencies can be offered). 3) Convey to the patient a sense of comfort and care until death (knowing that this

is an uncertain journey we will undergo and is fundamentally unknowable by us in advance). 4) Contain the emotional impact for junior doctors witnessing the impact of negotiated ethical decision-making, distress of the patient and family, and anticipating what the expected psychological, physical, financial, social, and spiritual losses might be for the patient and family, in order that the junior doctor can begin to hold a “thinking state of mind” and learn about the patient, family, professional interaction.

However, if the senior doctor is unable to contain, and retain a “moment by moment - thinking state” (Doyle, 2012) about the family’s grief, and it reignites their own, so that the HCPs grief is projected into the families, then the family are left not only with their own grief but the HCPs as well. In circumstances such as this the family may be so distressed that they are unable to understand their role in decision-making, or contribute to any decision. If the senior doctor is unable to tolerate, and contain the grief, such that bad news is given with the clinical plan and the doctor walks away, then again the family are left alone with unmanageable anxiety and grief, and the senior doctor may be left unwise as to the family’s views (so important in best interests decision-making). What is also at stake is the junior HCP in the consultation learning to undertake this work. If the senior HCP is observed as not being able to contain the distress of patients and families and work with this, others in the consultation may find themselves absorbing the emotional impact. If those others are not in a position to transform the consultation (a palliative care specialist would attend to this), then they can be left feeling the weight of the family’s grief and their own. Without the opportunity to express their thoughts and to talk about their feelings and to have them held and contained safely then unconscious defences can block the ability to be reflective (Doyle, 2012) and learn. Psychoanalytic theories would hold that re-engagement with dying patients and families might engender such feelings of anxiety that avoidance (conscious and unconscious) may occur.

### **Discussing the un-discussable**

Psychoanalytic theory may also yield a radical perspective on assessment for competence in the care of the dying. Learning comes from thought, thinking, tolerating difficult feelings, and considering fresh perspectives. What though are

clinicians learning? What is being assessed? Let's examine two examples from the workshops in Study Two, where consultants discussed their experiences of caring for the dying. These same consultants will be responsible for sourcing learning opportunities and assessment of competence for junior clinicians.

In the first extract taken from Workshop Three (Study Two) a consultant discussed their experience of caring for patients whose dying is drawn out over days and weeks.

*HCP 9 I see this in a lot of cases, and honestly I'm not really...(sigh)...distressed and sad to see people stay stuck in the bed for 4,5,6,7,8,9,10 days. Just waiting for that moment there, our patients suffer. I get very frustrated and would really like to be able to kill them (nervous laugh); it would, can't really explain it, its a when you know there is nothing else to do and you see just all the family there just waiting for that moment, sometimes it is very very long, or maybe the patient is so distressed and even if you put on drip, syringe driver or whatever they are still distressed and you are just nothing else we can do and it makes me feel pretty uncomfortable. Sometimes also the family say can you kill them can you stop?*

*Group agree*

*INT JW What's it like it when it's said "you are killing him?" or what's it like to be asked to kill them? What's that like?*

*HCP 9 " I would really like a law, a lot of states like Holland or Switzerland – there is a documentation (inaudible) I always say if I was – I don't know maybe one day my mother will be there in the same condition, it's really really tough; I try to carry on empathically but from the outside you are telling me there is nothing to do and see the person that I love struggling, suffering for just to be stuck there for days and you really feel (sighs) un-useful*

Caring for a dying patient, where there are no more curative treatment options, and "nothing to do", engenders strong feelings of uselessness in the HCP. Feeling "un-useful" is fundamentally challenging for this doctor, and even offering

palliation and symptom management, does not relieve the impact of the emotions felt. This medical HCP describes being “very frustrated” at reaching the limit of their skills, and an inability to contain and personally tolerate the impact of observing the level of patient and family distress. She identifies this as a “pretty uncomfortable” situation. She describes how she puts on an empathetic response to the patient and family, but internally feels something completely different. This is emotional labour (Hochschild, 2012). The relentlessness of this situation when a patient’s dying takes a long time increases the distress of the HCP beyond a level that is tolerable. She experiences phantasies of killing the source of their distress – the patient. She also identifies that families sometimes ask if she can kill the patient. Linking this to educational theory, it can be seen that the wish to kill the patient is evidence of the opposite of being able to stay with a very difficult situation and help others think about what might be going on and what might be done to manage the situation. The thought about killing the patient effectively prevents all other options. In effect, it’s a thought that stops her thinking.

Using Kleinian thinking, it is postulated that it isn’t only the distress of the dying patient and their family that challenges the emotional integrity of the HCP. Her professional defence of being useful and able to distract herself is fundamentally challenged. One wonders if the family pick up the HCP’s projection of uselessness and express the longing for death to occur, or whether the HCP absorbs the family’s projection, as they similarly have to watch the patient die. It appears that staring dying and death in the face can be intolerable and is passed around like a hot potato.

At the same time, killing the patient in this country is illegal and unethical and a total breakdown in the ethical principles under-pinning clinical practice of “do no harm”. Unethical and unprofessional thoughts bubbling up will likely increase the HCP’s level of conscious and unconscious anxiety. The sweetener to this terrible phantasy of wishing the patient was dead is that the killing would be a merciful act to alleviate suffering. The question is whose suffering? It’s not just the patient and family that are suffering. The dying patient connects the HCP to her own vulnerability and her own emotional, physical and social upbringing, and takes her to a place where she contemplates her own mother’s death i.e. her own loss. In a

case such as this, the lead HCP is barely containing her own emotional response, let alone building this into a 'learning opportunity'.

In the second example taken from Workshop Two (Study Two) a doctor described the on-going emotional effect for him, of a patient who survived the prognosis of dying and transfer to a hospice, and presented herself back in his hospital out-patient clinic for further active treatment. He found this situation very challenging, despite the patient's forgiveness, and desire for him to remain her doctor. He described how since then, every time he has to recognise that a patient is dying, he has thoughts about this particular patient's case. He also challenged the fact that reflection is helpful as it had not helped him in this specific case.

*HCP 7 And it is difficult and you do, you say we are supposed to reflect more, that case I reflected more, and still reflect on her and in a way it sort of bubbles up with every end of life, still in the back of your mind, with every end of life conversation that you have its always that moment of doubt, because you think actually I have had it not be right in the past.*

*HCP 8 Isn't that about physician confidence and we like to be right?*

*HCP 7 yes exactly. Its true.*

In this quote there is evidence that the HCP is bouncing between thought and thinking without coming to a resolution and learning. His psychological defence was the phantasy of mastery and of being known as a clinician "to be right" consequent to professional qualification. This was undermined by the unpredictability of death, such that he could not contain his own distress and learn. This links to Bion's thinking that learning is painful. Or as Bibby describes it "reason, thinking and learning are inevitably and constitutively difficult; psychoanalytically thinking and learning are tied to difficult feelings and frustrations. There is no way out of this bind: it is the human condition" (Bibby, 2011, p.106). The group then appeared to do what he was unable to do for himself, and name the psychological defence of "being right", and the consequence of "being wrong".

*HCP 8 We cant always be right, but that sometimes destroys the confidence that patients and families have in you, because you might have been right for five or six years that you have been looking after them, and trying this and trying that and whatever, and so even though now I am not going to be able to solve the problem, they still want to think that you are right and have that confidence*

*HCP 7 erm*

*HCP 8 in you.*

The consequences then of “getting it wrong” are a patient and family loss of confidence. The group’s containment offered the HCP something he could not offer himself internally to contain his distress and learn from his thinking. In this study there was no indication that the HCP had moved to a position of learning, but the “erm” indicated a thoughtfulness that stopped the ricocheting between thought and thinking and in the future might have produced further discussion and learning. However, this HCP’s professional narrative of “needing to be right”, and his own inability to forgive himself could undermine the ability for the HCP to build safe learning opportunities for junior doctors, and facilitate their reflection. The need to be right silences the discussion about learning from getting it wrong.

### **The learning opportunity - part two**

We saw in part one that the clinical learning opportunity and reflecting on this is a key part of learning how to become a clinician. Endeavouring to seize learning opportunities for students and junior staff is a key part of senior HCP work. Yet we can see from the above two examples that creating learning opportunities from caring for the dying is particularly challenging work. Let’s examine what HCPs in this study said about their experience of learning from “supervised learning events”, and how they offer them to others.

### **Medical learning opportunities**

Medical consultants in this study described the move from novice clinician to clinician to teacher as chaotic.

*Chaotic - See one, do one, teach one. You have to have to at least have seen a few interactions before (L226-227, Workshop Four, Study Two).*

At this point in the workshops HCPs were discussing how junior doctors could learn to lead patient and family meetings. Consultants felt it was essential to have watched some family meetings take place before being responsible as a consultant for the meeting. They described the experience of medical education as “didactic, tick box, examination”. Thus, they offered learning opportunities for junior doctors to join them for significant family meetings to increase the chance of the opportunity to have witnessed this.

*We try and take the juniors with you as well, because we expect them to have didactic learning, tick box, do their exam, and all of a sudden they are a consultant having to do that; they haven't done it before and haven't seen it done, because inevitably you do not do this sort of thing on a big ward round and everybody crowding round the end of the bed...or shouldn't...yes so you know sometimes you say to the registrar join me at 2pm we are going to have this difficult conversation, do you want to come? (L219-225, Workshop Four, Study Two).*

In this manner the creation of the “learning opportunity”, means that consultants have used their experience to improve the experience for junior doctors they are responsible for. This is a caring, generous and reparative position to take, and possibly an attempt to repair the “chaos” of their own experience. In psychodynamic thinking, the consultant is taking the role of “helpful, tolerant, understanding parent” to expose the junior doctor to a situation, which they themselves recognise, is under represented in formal medical training. In the workshop HCPs expressed anxieties about the impact of a junior doctor at the meeting, and managing the additional dynamics of this.

*There is always a sense of...this is a learning opportunity and I would be interested to hear how patients felt about that, and whether they; whether I am worrying too much or whether they even see the other person in the room, and they were just; there is always the sense of feeling in the back of my mind*



*that there is someone else lurking. I don't know (L233-237, Workshop Four, Study Two).*

The presence of a junior doctor was described as a feeling in the back of the consultant's minds – and “lurking”. The presence isn't reassuring, and it is recognised as a threat. Whether this has conscious or unconscious resonances of the consultant's own learning experiences of clinical care and perhaps the unspeakable, untellable experiences of clinical practice (as expressed in extract one), or there is a worry that the junior doctor might be upset, or intervene in an unhelpful way, it is impossible to tell. It links with the gratefulness for their clinical education experience so far.

*We are very fortunate with the junior doctors who are very good (L232-233 Workshop four, Study Two).*

What consultants did not discuss at all was debriefing the junior doctor afterwards. There is a power differential between consultants and junior doctors. With the level of anxiety and vulnerability consultants are expressing about family meetings and having a junior doctor present, the impact of discussing “how the meeting went” with a view to each person having capacity to learn seems emotionally risky. Perhaps it is enough to let juniors observe.

### **Nursing learning opportunities**

It was harder to ascertain how nurses had learnt about caring for dying patients, but they described learning from direct clinical experience, and with very limited senior support. In the quote below, the junior nurse had previously spent much time talking with the family preparing them for the imminent death of their relative, and all but one of the family had started to accommodate the news that the patient was dying. On this occasion, the nurse returned to the room with the consultant. The consultant did not support her with the skills for the conversation, but reassured the family that he supported the nurse and left. The nurse perceived this as helpful, as all the family's perspective changed, and they were able to trust the nurse's suggestions for a plan of care based on the recognition that the patient was dying.

*I think also [learning – my words] by experience. I had a case where a family were not accepting that their relative was actively dying and spent a lot of time and a lot of talking and they all started to understand apart from one; and I went in the room to see the patient and the consultant came in and said to all the family, “I will leave you with [nurse’s name] my faith is completely [in] what she says, I say; I trust her and her judgement” and then I think they, they really changed then and they really trusted what I was suggesting and what I was trying to get them to see” (L469-474, Workshop Three, Study Two).*

I asked this HCP how she had learnt to stay in the room and not avoid the family or the topic of dying. In the quote below, there is evidence that she knew she could not avoid it, because if the patient died and the family were still unprepared, the nurses would be left with a worse emotional situation to contain – the situation would be “catastrophic”.

*I could see how ill this person was and I thought I cant leave until they [the family] have at least started to get it, because I felt that the person was very close to dying, and there were so many of them it would be just catastrophic if we didn’t get this sorted now. I didn’t think we had the time. It might have been different if I thought we had the time, I would have gone away and let the dust settle a bit and come back you know maybe in the afternoon, but I really felt we didn’t have the time and that they needed to, not whether they wanted to or not, but I needed them to start understanding and take things on board and I couldn’t go until that was done. But I felt quite happy to do that on my own at that point (L481-489, Workshop Three, Study Two).*

Whilst she did not say, it is likely she has had experience of families being significantly upset at the death of a patient. Nurses have a responsibility for the running of the ward and cannot leave a ward as doctors can. The anticipated terror of a worse situation for the ward, with large numbers of distressed family members, gave this nurse the strength to stay in the emotionally charged clinical situation. Having the doctor’s confidence in her publically expressed, meant there was no disagreement between the nursing and medical team and settled that

anxiety for her to work. It would appear though, that nurses do self-select to either undertake patient and family work, or avoid it.

*Most of my team actually don't actually like planned [family meetings]...so the few planned that have had happened they have given to me to do. They don't do it. They find that quite threatening to go into a planned family presence...I don't mind either way really, I am quite easy going but they quite often say "you do that" (L535-577, Workshop Two, Study Two).*

In this manner, certain nurses gain the experience to reflect on and learn from, patient and family meetings and to develop their expertise, whilst others avoid gaining these skills.

### **Palliative care nurses providing doctors with safe learning opportunities**

A palliative care nurse captured the following situation as a learning situation.

*So, I [senior palliative care nurse] went with a junior doctor recently and I was willing him to shut up, and I did speak to him afterwards about his skills because I thought they were so dreadful...I gave him some advice and he was grateful...I was very gentle in how I did it and I gave advice on how to do it in the future...because his supervisor should be talking to him...he was stood at the end of the bed and he told the patient what was what, without asking her (L295-300 Workshop Four Study Two).*

In this exert the palliative care HCP who accompanied the junior doctor, whilst willing him to "shut up" during the consultation, did not interrupt the consultation. She waited until they were in private to give him feedback, and advise him about what to do in the future. It is possible that in not challenging the doctor in front of the patient that she was also working to contain the chaos surrounding the experience for the HCP. She obviously held a strong view that actually whilst she could fulfil this role, that actually this was his educational supervisor's role.

Thus the experience of learning from the structured clinical encounter appears not as easy or as straight forward as the cognitive, rational, safe, learning objective

driven “supervised learning event” might indicate. I want to consider now how else HCPs are learning in clinical practice?

### How does learning occur outside of the planned and supervised learning opportunity?

#### Seeing at a distance without responsibility

HCPs, and especially doctors are learning from watching what is going on clinically.

*We are fortunate enough to be attached to a palliative care team and you come away and feel that [breaking bad news] was done well; it's quite difficult when you are a junior to put your finger on why but it just felt better than a crappy old surgeon standing at the end of the bed...a lot of it is, the problem is it does rely on the type of person you are to take away and reflect on what you have just seen (L180-190 Workshop Four, Study Two).*

This watching is really “watching without responsibility for the clinical decision-making”. Using psychoanalytic thinking allows a safe exposure to a level of conscious or unconscious anxiety that might make what is to be learned about death and dying easier to approach and even prompt an interest to learn more about it. It does though rely on the HCP being prepared to allow thought and thinking and a willingness to process their own learning about this clinical encounter. We have seen that there are aspects of the care of the dying that are discussable, and understand that our unconscious defences protect us from truly knowing (Doyle, 2012) when the knowledge can be devastating. It is notable that the HCP in the above extract cannot articulate the detail of what made the breaking of bad news better, and without skilled debrief, it is challenging to know how he will change his own modus operandi, or give feedback to others, or teach this topic.

#### Choosing to see and choosing to learn

Some palliative care HCPs are actively choosing to see and learn and are doing this by using their own empathy, imagined anxiety to motivate them to provide care, and utilising skilled support to learn to care for dying patients and their families without being overwhelmed.

*I've come right from the other end – I used to be a surgical ward sister and you [Jo Wilson] have made a palliative care nurse out of me...there was no dying...In surgery...I guess...with the saying about the empathy when a patient went for surgery, I used to think how I would feel going to surgery, and I would be absolutely scared out of my mind really and you've often gone through a trauma to go to surgery, so I think of the fear of going through that and the empathy that I would try and care for people with has translated into palliative care (L634-641 Workshop Four, Study Two).*

What this means is that instead of the care of the dying being seen as entirely negative, that with support to care for the dying, the rewards and pleasures of this aspect of care get experienced.

#### **Doing without senior support**

HCPs are seeing patients and families without support, and are “learning on the job”. Senior HCPs remembered the immediate sense on qualification of the responsibility to care, the internal management of the junior doctors’ fear, and the “putting on of a mask” until the junior doctor learns.

*Because I can imagine that there as a junior doctor your first day on the ward and you might come across a dying patient and there is that sense of I am a doctor now, I am supposed to be able to deal with it, which means that often there are all those questions about fear; and then it's almost like playing a game of putting on a mask and trying to do that until you can learn from someone, or you choose to learn from someone else (L538-543 Workshop Four, Study Two).*

Here we have an example of a consciously employed defence of doctors to hide and conceal from patients and families their own anxieties about not knowing and feeling incompetent. In this manner the aim is that the patient and family are unburdened by doctors’ emotional states. However, the management of the mask is likely to be effortful and consciously and unconsciously anxiety provoking; resulting in the junior doctor either withdrawing without gaining all the knowledge of the patient and family that they could; giving information in a clinical

way without emotion; or over-empathising and the family feeling the burden. This method of learning from direct clinical care can come at a cost to the patient in terms of their experience of compassionate care as the quote below demonstrates.

*I have had patients and some stay in your mind don't they and somebody said to me 'I was in A and E – they leaned over the cot sides and they told me “you are dying”’. Those things I think they can't forgive those. They will forgive you if you say I am not sure how to do this, I can ask a colleague and they are more experienced. They don't expect you to know everything...that then again requires a level of insight to say – whether it's junior F1 or you're some surgeon you have got to admit that you can't do it. You are not the right person (L556-563 Workshop Four, Study Two).*

There was recognition that patients did not expect HCPs to know everything, but to know when to seek further help. However, that requires personal insight into the HCPs own skills. Speaking to the patient in a manner that however well intentioned, causes distress has the potential to further distress the HCP that provided the care, and limit the learning. Without reflection there is evidence that HCPs bounce between thought and thinking, when unable to discuss the un-discussable or when they are not offered an opportunity to reflect. It is unlikely that a clinician will offer this encounter up as an assessed learning opportunity with their assessing educator, and so the experience gets stuck. In this manner it has the potential to consciously and unconsciously affect future decisions and clinical encounters.

#### **Nurses as a route for doctors to learn.**

Many doctors in the study described having a nurse in the consultation. This is not unusual, and from a nursing point of view it is helpful to know what has been said, and how the family have reacted, to continue the need for clarification of information or emotional care.

In the quote below, the patient had improved clinically from the day previously, when he had been unresponsive, and the family had asked that the diagnosis be withheld from the patient. This is an ethically challenging situation and doctors

would usually tell families that if patients asked directly they would honestly inform them. The consultant had returned to the ward, the family were not present and the patient had improved and confronted the doctor with his own diagnosis. It became a “wooo” moment for the doctor as it relieved him of an ethical dilemma, but would have left him with dealing with the family and the difference of opinion as to the clinical information they felt was in the patient’s best interests. He went to look for a nurse. What is noticeable is how long a senior doctor will wait to have a nurse present.

*The patient was brighter and I walked into the room...and he laid there and he opened his eye and he said so I have got leukaemia have I?...And I was like, it was a real, you know, “wooo” moment like this and, it throws you ... so I went out and grabbed a nurse from X ward which you can imagine took me about half an hour and ...then came down and sat and it was a really useful consultation (L660-673, Workshop Two, Study Two).*

Whilst the HCP in this quote did not illuminate the benefit of the nurse, the time it took to find an available one shows how important it was to him. He then describes the consultation as “really useful” – likely meaning that the patient understood his clinical situation and an onward care plan was mutually negotiated. It is likely that the nurse both emotionally contains the clinical scenario, which allows the doctor to remain in the room and break bad news; that the nurse adds to the emotional security of undertaking this clinical work by acting as a witness for the doctor in defending that the patient wanted to know his diagnosis if the family challenged this. Additionally, having a nurse present allows the doctor to leave the consultation if it becomes intolerable for the doctor and the doctor knows the patient will have emotional support and does not have to manage this themselves. Doctors regularly debrief with nurses after significant patient and family interactions. In this manner, we might say that the nurse is the emotional container (Salzberger-Wittenberg, 1999), enabling and allowing the doctor to remain in the clinical situation, providing an escape route if they cannot bear to remain, and providing an emotional debrief on what has happened or what is happening, so that the doctor can think and learn (Doyle, 2012). Additionally, it is likely that this consultant avoided discussing with the family the fact that the

patient now knew his diagnosis, and either the patient or the nurse will have undertaken this work.

The need of doctors to have a nurse present is often the reason nurses have built expertise about managing family distress, and possibly the reason nurses put their learning down to experience (Warnock, Tod, Foster, & Soreny, 2010). Additionally the dual medical and nursing presence can be seen as a social defence as neither doctor nor nurse has to take full responsibility for the clinical encounter.

However, whilst there has been long been exploration of senior nurses being a route for junior doctors to learn about clinical practice and communication skills (Vallis, Hesketh, & Macpherson, 2004), the idea that they emotionally contain the clinical situation for consultants to learn has not been explored. In this study senior HCPs described how they became increasingly isolated in clinical practice as the career structure left them to independently manage patients and families. Whilst they continue to receive professional development with respect to disease management, the professional development of their ability to care for families is not similarly attended to. This leaves them short of learning opportunities to see others' skills and develop their skills with families, and they really valued being able watch skilled colleagues.

*I think it is about experience, and then as you are more senior you lose the chance to be with others, for example we [said to me] did a meeting together which I found very helpful, sometimes it happens for some reason that you are with someone, maybe they have a similar role or experience or even less but always I find that happens less and less as you become more senior, is totally precious, and its not formalised, its happens now and then by chance, or sometimes you can share a conversation – for me this is really really valuable to see things I can see in others (L457-464, Workshop Three, Study Two).*

This skill and strategies to work with families is not formally taught, and working alone prevents learning from others. This consultant realised that she could learn from other professions and possibly those junior to her.



## Organisational contribution to lack of learning

The time to safely allow difficult thought, and thinking about it, so some processing and learning can occur seems critical and an organisational responsibility. HCPs regularly report that the volume of patient care can prevent thinking:

*I think certainly with our job because we are going constantly from one to the other you don't always certainly have time to reflect in between patients (L196-197, Workshop three, Study Two).*

Busyness could be a personal defence mechanism, but with the pressure of the clinical caseload it is personally hard to seek time out to think and reflect. Also the lack of time to think and process patient care in work hours means that HCPs are waking in the early hours of the morning. They describe patients as “in my head” and this is additionally disturbing for them. Whether the HCP is dreaming of patients, or whether they are waking and thinking of patients is difficult to tell.

*At the moment we are very busy and I am waking three o'clock, (group murmurs acknowledgement). They [patients] are in my head. But normally, actually, it's just that we are so busy, they are just there (L183-187, Workshop Two, Study Two).*

HCPs did not describe supported reflection at the time of a “learning opportunity”; they described how they personally reflected, for example in the car on the way home, or used informal networks to debrief after very challenging situations. HPCT HCPs were able to utilise multi-disciplinary meetings for emotional support and clinical supervision. However, there was a difference in funding between cancer and palliative care HCPs and those HCPs caring for patients with non-malignant diseases. HCPs caring for patients with non-malignant diseases have much poorer access to readily available emotional support.

There is evidence that the organisationally mandated reflection demanded as part of nurses' and doctors' appraisals and revalidation processes is likely to involve a superficial and guarded response to reflection and learning. No HCP identified that they had the care of the dying patient or their family raised and discussed at

appraisal unless they themselves raised it. It might not be that HCPs don't want to learn; it might be that they cannot learn in such an environment (Bibby, 2011, p.106).

### **Contribution of workshops to learning.**

We saw in Chapter 5 (Table 8) that HCPs highly valued the workshops that they participated in as part of this research. It is clear that the workshops offered time and space, in the midst of pressured clinical caseloads that usually deny HCPs this space, for people to pause and allow thoughts, and thinking about dying, to feel contained, to allow "not knowing" long enough to move to learning. The fact they are a "nice way of learning" seems to tame the chaos of clinical practice a little.

What was really important about having the themed analysis of Study One to present to participants in the subsequent workshops is that it focused HCPs on the very specific areas of recognising dying, initiating contact with the patient and family, communication with the patient and family; and these areas couldn't be avoided. Please note that not a single HCP had had training for this aspect of care, and even palliative care degrees avoided this topic. By having data to consider, it engaged the HCPs in a way that allowed space for them to engage with the data, have an emotional response and be able to reflect in an emotionally safe environment on their practice with other colleagues. I think if they had had to bring examples from their own caseload, then there may have been an initial psychological defensive hurdle to overcome.

*I have not previously considered the different pathways (to identify dying – my words) as we did today. However, I found it useful to do so I as I require several of these. Identifying dying remains a challenge and an individually responsible task! A useful session (HCP7, Workshop One Feedback).*

There was recognition from HCP 5 that she experienced that breaking bad news and caring for families is hard to teach, and she recognised that HCPs' skills develop over time and with experience. HCPs in the workshops valued learning from others, and particularly words and phrases that they use. You will note that the HCP 5 missed the last workshop. Whilst this may well have been the busyness

of the caseload, it is possible that the “forgetting” is not conscious, but an unconscious reflection of anxiety. In Workshop Three, HCP 5 had reflected about how she had missed the dying of a patient in the intervening weeks. The discussion took a significant proportion of the early part of the workshop and she wondered whether she had done the patient a dis-service. She had also started to wonder whether initiating these conversations could take away hope and had really contributed to discussions throughout the workshop. I did wonder whether really thinking this deeply about existential issues such as hope, was just too challenging to face again, and whether forgetting allows “a space to breathe again” (Trustram, 2016). Had the workshops continued I would have been able to quietly observe attendance and gently challenge, and reflect myself. This is part of the learning process – it is intimate and relevant for the facilitator and facilitated.

The workshops revealed to HCPs the amount of emotional work that they manage independently, and have perhaps lost conscious awareness of. One senior nursing HCP in the study who was caring for patients with a long-term condition said:

*Working as a standalone service I have very little supervision. It's the first place I have been in that I have had no supervision, I've had supervision in all other roles; and its it just brings it home to me the enormity of what I am dealing with every day, I'm just getting on really it brings it back to me that I need to seek out support of others, you know my own peer group (L40-45 Workshop Four, Study Two).*

The workshops also reminded her at what level she is functioning (“getting on”). This has echoes of feelings of low personal achievement which is a component of “burn out” (Ramirez et al., 1995), and we know that poor mental health can lead to poorer standards of patient care (Taylor et al., 2007), in a cycle that is self defeating for HCPs who want to do a good job. Through expressing her thoughts, and thinking on this she is able to move herself to where she can contemplate a different course of action – “learning”.

In Chapter 5 there was evidence of a workshop assisting a physical clinical practice change. I won't discuss this again here, but also notable was a change from the workshop of HCPs viewing orthopaedic surgeons as poor at caring for dying

patients, to beginning to understand that they could not undertake an orthopaedic surgeon's job, and that different skills were required for different clinical areas of care. Returning back to the description of Kleinian thinking (described in Chapter 3), initially splitting and projection, allows the "good person narrative" to stay with the workshop HCPs, and the "bad person narrative" to be lodged with others and in this case orthopaedic surgeons. This is the paranoid-schizoid position, and in this space the workshop HCPs have conjured up "objects" to defend their fragile psychological defences. Through safe containment of these HCP's thoughts over the four workshops the workshop HCPs started to take back and own some of the projected feelings, and realise that they could not do the surgeon's job. This is a move to the depressive position. Thought and thinking has occurred and the move from the paranoid-schizoid position to the depressive position is described as learning (Bibby, 2011). With time one could see how, if this move to learning was continued, that might be different ways for workshop HCPs to jointly work with orthopaedic surgeons about the care of the dying patient.

Thinking about the factors around a dying patient and their care can be very difficult, and HCPs in this study both expressed that this method of learning would not suit everyone, and described how they had observed psychological disengagement when they had been teaching about the care of the dying.

*The trouble is that those people who find it very uncomfortable, you can sit them there and they don't engage; we've all taught things and you can see them, they're just not engaged, it is not there; don't know what you are talking about. It's very difficult (L671-674, Workshop Four, Study Two).*

Again from a psychoanalytic point of view one can postulate that thinking about the care of dying patients, even in a teaching scenario away from clinical practice, is so anxiety provoking that HCPs dis-engage with thought. John Steiner would describe this withdrawal as a psychic retreat – this withdrawal is from both paranoid-schizoid and depressive anxieties, and in such a psychological place individuals are spared from unbearable guilt (Steiner & Schafer, 1993). The learning is just too dangerous. Participants identified that if these workshops were

offered to all that they would need to be carefully crafted around a specific case review, and carefully facilitated to prevent splitting, projection and blame.

For those HCPs, however, who want to take part, these workshops were an affordable and sustainable method of practice development. Considering Rustin's "moments of respectful uncertainty" and the ability to truly create a space to "think the unthinkable" (Harvey, 2010), and "discuss the un-discussable", it was important that the workshops took place at a time and place that was easily convenient for HCPs, that they included nourishment and refreshment and space after the workshop if anyone wanted to speak (Salzberger-Wittenberg, 1999). The evidencing of reflective learning for appraisal was an important part in helping HCPs value their learning and also not adding to the burden of defending their practice (Wittenberg & Klein, 1973).

## Conclusion

In this chapter, the context was set for current medical and nursing education. Both of these careers follow an apprenticeship type learning, with time in a university setting, followed by learning in clinical practice. We considered the "learning opportunity" as espoused in the national guidance documents, that sets the standards for learning experience, reflective debrief and assessment of competence. We considered the current literature that indicated that, despite the intention of policy makers, junior doctors and nurses feel poorly equipped to care well for dying patients and their family.

In order to make sense of this conundrum, I turned to psychoanalytic psychosocial theory to consider the possibility of the irrational, unconsciously defended subject. I considered Bion's theories of learning where thought, and thinking, if safely contained, can lead to learning. The need for safety is because learning is dangerous, and we have to deconstruct what is known in order to learn new ways of thinking. In the care of the dying we do not just learn about others or a task, we constantly learn about ourselves, and the unpredictability of death, and its ability to reduce us completely to our humanness.

From the workshop data, there was evidence that senior doctors, once in a psychologically safe environment “speak the unspeakable”. Instead of the answers from the interviews in Study One, where they expressed the impact of caring for the dying as “part of the job”; they expressed feelings of uselessness and frustration when faced with the reality of a patient whose dying takes time. They thought of their families and imagined their own loss. They expressed phantasies of “killing patients” in a merciful and lawful way, and these unethical thoughts are likely to further increase the level of anxiety of the clinician. They expressed phantasies of “wanting to be right”, such that when death defied this they experience such on-going distress, they ricocheted between thought and thinking without challenging the assumption that they are always right. These senior clinicians are the educators of junior clinicians of the future. It is little wonder that no opportunity was given for reflective debrief of the junior afterwards, when the learning might be of such unspeakable emotions and feelings. Yet it is only by letting these emotions and feelings have their space that both educational supervisor and supervisee will learn together.

Nurses described learning from direct clinical care, and doing the care. The ward environment physically contained the nurse for the shift and so the nurse had learnt from previous experience, that avoiding the work of preparing the family for the impending death had worse consequences later on. The family distress at an unprepared for death was anticipated as “catastrophic” and this was a motivator for the nurse remaining in the room and continuing to work with the family. Nurses also have opportunity to learn and to gain expertise from watching doctors break bad news, such they have opportunity to gain real expertise in such emotional containment in these meetings. Not all nurses though want to undertake this aspect of clinical care and there is evidence they ask others who can tolerate this to undertake this work. Skills for family work can be invested in a selected group of nurses (the palliative care nurses of the future) and by gaining expertise these nurses can help provide emotional containment and safety such that senior doctors can learn. The importance of this is that doctors as they become more senior, practice more in isolation and so have limited opportunities to learn from others.

Outside of the organised learning encounter we considered how HCPs manage their anxiety to “see” and to learn. Strategies were seeing at a distance without responsibility; choosing to “see” and learn; and providing care without senior support. Seeing and doing without senior support can be extremely anxiety provoking for the individual and relies on the HCPs own ability to contain their distress. The ability to reflect such that thoughts, thinking and learning occurs, will be affected by the individuals unconscious defences (Doyle, 2012), and the ability of informal support to help find alternative perspectives. It was suggested that in contrast to the General Medical Council (General Medical Council, 2016) rhetoric that organisations should provide a good learning environment, that the organisation contributed to a lack of learning by lack of time for reflection, lack of resources, and mandating reflection for judgement and assessment through appraisal and revalidation. In this manner, it is easy to see how troubling experiences and thoughts about dying could be repressed or projected elsewhere, and dying patients and families avoided.

## Chapter Nine – Discussion and Conclusion

### Introduction

This research has examined how senior HCPs recognise dying and negotiate decision making with patients and families in one hospital. From clinical practice I had realised that managing sustainable practice change in this key aspect of care was challenging, without constant on-going leadership and support at the time of decision-making from palliative care, but could not explain why. From audit it is clear that HCPs in hospitals are only identifying deaths days before this happens (Marie Care Cancer Care, Royal College of Physicians, 2014). This PhD has sought to ask HCPs how they recognise dying and negotiate decision-making with patients and their families. This chapter discusses the novel contributions to practice this research has made, and each of the sections below considers the detail of this contribution.

### Nine novel contributions to clinical practice

#### Introduction of the psychoanalytic psychosocial gives a language to discuss new insights in the care of the dying and a space to consider novel solutions

It is clear from considering the trends in end of life care research, contemporaneous to this study, that other researchers are interested in the same question (Kennedy et al., 2014), and are using similar methodologies (McConnell et al., 2014). The approach taken by Kennedy, McConnell and initially by myself with the themed analysis took as “taken for granted” that HCPs are conscious of all factors involved in how they make a decision that a patient is dying; and that caring for those who are dying is another dimension of clinical work, without significant emotional impact. It also presupposes that rational clinical actions will solve the conundrum about how to help HCPs recognise dying more regularly and earlier in the disease trajectory than the last few days. This conscious and cognitive approach to the research question keeps HCPs where they currently are, resulting in them undertaking more of the same solutions. These are generating more models about how to care for the dying patient and their family, and then teaching this, requesting more integration of palliative care with generalist care



(with limited palliative care resource), and delineating roles and responsibilities (reductionist approach).

The first novel contribution of my research, is to keep the subject of the HCP at the centre of the research question (Frost, 2015), and to introduce the language of the psychoanalytic psychosocial into the care of the dying. The concept of a psychosocial analysis needed to be formally introduced by an expert – Dr Lucey - (Walkerdine et al., 2001), after we had discussed the transcripts of the Study Two workshops. It should be highlighted that general medical and nursing curriculums consider that they attend to helping students consider psychological and social aspects of patient care (Nursing and Midwifery Council, 2014) (The UK Foundation Programme Curriculum, 2016). They do not though take a psychosocial approach to patient and family care that includes the HCP, their profession, team and institution, in the dynamics of what is achieved in relationship with the patient and family. Over the past two years I have learnt an entirely new language and knowledge base in order to re-examine my data and have developed a systematic framework for analysis based on experts in psychosocial studies (Clarke & Hoggett, 2009) (Hollway & Jefferson, 2013) (Walkerdine et al., 2001). This analysis allows the consideration of an individual and collective psychological tenor, about identification of dying, the care of the dying, and the interaction with their family, framed with anxiety as the currency (Hoggett, 2009). It allows consideration of mutually affective unconscious, psychologically defensive practices at an individual, professional, group, and institutional level in the NHS and in Higher Education Institutes preparing junior doctors and nurses.

Using this language and framework, I propose it is helpful to name that death and caring for the dying is extremely anxiety provoking and that we should stop repeating the national rhetoric that “end of life care is everyone’s business” (NHS England, 2016). I think it is helpful to say that whilst this clinical work can be rewarding, it is also hard work. There are some HCPs who do not like this clinical work, feel unprepared for this work, and may not be even conscious of their dislike for it and their attitude towards it. I think it is helpful to name that thought, thinking and learning are intimately linked and that thoughts are linked to our unconscious, and thus our own personal narrative (Bibby, 2011).

The purpose of this naming would allow us to pause and stop passing the “emotional hot potato” round long enough to think creatively together about how we might progress this clinical aspect of care in a humane and kind way that is respectful of HCP’s personal histories, professional development, the organisational resource and complexity, and the contribution our educators can make. Pausing, thinking and considering all of the relationships involved in end of life care such as, the “patient and HCP relationship”, the “patient and the relationship they have with their family”, the “patient and family and HCP relationship”, and personal, professional, educational and organisational resources will allow thought about inter-professional consequences of decisions made by one profession or institution on another.

My second contribution is that proposed solutions that are respectful of HCPs, patients and families are likely to be creative and socially important, and because they include and respect the HCP’s humanness, they have potential to sustain HCPs in clinical practice (Frost et al., 2017; Wren, 2016). For example, taking a psychosocial approach has already led me to thinking with colleagues of innovative solutions for clinical practice. I am now employed in a new Trust. In clinical practice a weekly Multi-Disciplinary Team meeting has been set up on the renal ward where all HCPs can discuss patients and families they are worried about. The MDT data has been analysed and the data is going to conference (See Appendix 11), but it is important to say that only 65% of patients discussed had palliative care needs and only 24% died that admission. As Menzies-Lyth identified, illness and suffering is anxiety provoking (Menzies, 1970). Frailty, patients’ illnesses, and family dynamics and capabilities underpinned by poverty played an important part of the complexity in the patients who were discussed, and the anxiety of the HCP. As HCPs we are realising together where our clinical challenges are and to think creatively about resources.

### **Recognising dying is complex – a five staged model is proposed**

From the literature review the reader will recall that decision – making about end of life care is complicated, underpinned by the mental capacity act (British Medical Association, 2008) and ethical guidance (General Medical Council, 2010). In

clinical practice the law effectively divides patients into three groups. Firstly, there are those patients who have capacity to take part in decision-making about their end of life care, and the evidence pointed to the fact that patients preferred to focus on living, rather than advance planning the process of dying (Nicholson et al., 2012). There was though evidence that at the point of significant sustained ill health, and with skilled professional and family support, that some patients could make very difficult decisions to plan their dying (Clinch & Le, 2011). Secondly, there are those patients who have lost mental capacity to take part in decisions subsequent to a long-term condition. The evidence pointed to families having a significant role in the decision-making and management of the care for the patients (Livingston et al., 2010). This could be formalised in law under the mental capacity act, as a power of attorney for health and / or finance. Finally, there are those patients who have lost capacity to take part in decisions in an acute condition. The family in these circumstances were consulted as part of a best interests decision. In these circumstances there was evidence that decision-making took time as there was need for psychological adjustment (Kryworuchko et al., 2012) and there is a perceived “turning point” that requires “time, work and energy” (Hiltunen cited in Limerick, 2007, p.129). The fact that doctors and families disagree is acknowledged (Abadir et al., 2011), and that doctors can prioritise family wishes over the patient’s previously expressed wishes, if the patient has lost mental capacity (Abadir et al., 2011).

Recognising that someone is approaching the end of his or her life requires the skill of prognostication. Research identifies that part of prognosticating is a two stage process of “fore-telling” of the dying - the authors describe this as an “inward cognition that the patient is dying”, and a “fore-telling” - the “communicating of this estimate [prognosis] to the patient and family” (Lamont and Christaskis cited in Krawczyk & Gallagher, 2016 - p6). Using the data from the themed analysis of Study One and Study Two I propose a five-staged, rather than two-staged, model to recognising dying, and then communicate this to the patient and family. The stages are a “gut instinct that the patient is dying”, “evidencing the gut instinct”, “engaging with the patient and family”, “coping with the fall out of the meeting”, and “clinical supervision” of this aspect of care. Details of the stages will

be covered below. This is my third novel contribution. HCPs in this study had not previously considered the detail of the process of recognising dying, and found it helpful to consider each stage. Giving the process of recognising dying and negotiating decision making a framework, means HCPs attention in clinical practice and teaching can be focused on the detail of each of the stages in a timely rather than rushed manner, and there can be pacing of each stage, with spaces open for thought, both for the patient, their family and the HCP, dependent on the clinical situation.

The first stage HCPs in this study described, with respect to recognising dying, was an awareness of a “gut instinct” that a patient might be dying. HCPs described how they noticed “a look”, or “a smell”, or had particular signs they looked out for, for example “temporalis wasting” (hollow temples). HCPs in this study then described how they “evidenced their gut instincts” – the second stage. Palliative care HCPs particularly, but other HCPs too, described how they undertook this confirmatory process, such that they could explain, to other HCPs or patients and their families, where the patient was in the disease trajectory and why they believed the patient was dying. This confirmatory process, of the initial “gut instinct”, was underpinned by clinical work to establish where the patient most likely was in their disease trajectory and thus decide what treatments were likely to help the patient. At this stage, there may be a comprehensive review of the detail of the clinical notes and tests, more tests may be sought out, or second opinions sought. This stage is extremely skilled clinical work. When undertaken in a timely manner, then there can be time to set up conversations with patients and their families and achieve some of their goals. Please see Pen Portraits – Patient Three, Five and Six. Patient Three and Six were discharged home for end of life care, and Patient Five had his care provided in hospital (his wife’s preference), but his son was able to fly home to be present for his father’s death. It should be noted that there were two other strategies that HCPs used in this study. The first was continuing to escalate treatment but simultaneously listen out for patient’s cues that they thought they were dying and respond to this. The second was to listen out for other HCP cues that they thought the patient was dying, and then respond to this. These resulted in dying being recognised very near the point of death.

If the patient was recognised as dying, then the third stage was about engagement with the patient and their family to discuss the recognition of dying, clinical management options, and patient's wishes and preferences. This study identified three routes to engaging with the patient and family. These were "patient initiated", "HCPs seizing the moment on ward round", and a "planned meeting". The study identified four routes to non-engagement. These were "an informed clinical decision not to engage at that time", "being blocked from engagement by other HCPs", a "routine decision not to engage" as that would not be clinically expected, and "prioritising hope of recovery which allows non-engagement". HCPs in the workshops had not previously considered how they engage or delay engagement or avoid engaging with patients and families. They had not thought about their response when families proactively seek the HCP out in transitional spaces such as hospital car parks, and their psychological defence of "being in control" was challenged. How patients and families are engaged with, and the setting up of this meeting, is a key area to influence both the experience of care for the patient and family, and to manage the clinical workload and teaching experience for junior HCPs. The fourth stage was how HCPs worked with the "fall out" emotions of the family and consequences for decision-making of these meetings. When families recognised the patient was dying then onward care planning could ensue. When families did not accept the HCP's decision that the patient was dying, the meeting was taken up with explanations, and helping the family accommodate the news. The fifth and final stage of this model is the clinical supervision of this work. This study has identified that medical and surgical senior HCPs value both nursing presence at the meeting with patients and families, both for emotional containment and debrief. Palliative Care HCPs value clinical supervision to rehearse conversations ahead of encounters that might be challenging. Senior nurses, whose clinical work involves the care of dying patients and families are expressing feelings of burnout, and have recognised they would value supervision.

This study articulates a need for organisational support of this clinical work through the funding and provision of skilled psychological support. Despite recent national guidance – "the national framework for identifying, reporting,

investigating and learning from deaths in care” (National Quality Board 2017) - there is only a call for staff to “engage in retrospective case record review to help identify if a death was more likely than not to have been contributed to by problems of care” (National Quality Board 2017, p.11). There is no mention in this report of clinical supervision of the care of the dying whilst the person is alive. This could though be approached in a multi-factorial way. The first would be to include the education of student nurses and medical students in both communication skills, and how to facilitate, and receive debrief. The second would be to introduce regular monthly ward / team based clinical supervision. The third is direct clinical supervision of the patients and families whose care is most psychologically and emotionally complicated. This is partly resourced already in palliative care, but from this research does not exist in other services (this may not reflect psychological resource in other trusts who may have more funded clinical psychology posts). The multi-factorial approach is necessary to counteract the thinking that individual change on its own will change organisations (Papadopoulos (2015), when there is a weight of NHS strategy and culture, which include financial cuts and target setting which means that managers do not have the ability to provide containment and reverie for staff (Evans 2015). However, it does not mean that clinical staff have the resources to contain themselves through reflective debrief. In this study, HCP 9 had set up a weekly ward reflective session. The question was not asked, but this process did not necessarily include a psychologist. This uncertainty is not raised to negate HCP’s skills to facilitate reflection. However, it is known that HCP’s experience of debrief can be very short and focused on the improvement of clinical procedures, rather than the emotional impact on the HCP (Couper et al., 2016). The fact that one HCP in this study had set up multi-disciplinary reflective practices does indicate that the initiative and resource to start this reflective work is possible within ward capacity and capability.

At the start of this PhD I had hoped that I might find something that makes this topic teachable. At one level, like Kennedy, without the psychosocial analysis I would have been left recommending a model, (albeit a more detailed model) as she did of “the potential [of the framework] for discussion in clinical teams around

strategies for improvement in diagnosing dying” (Kennedy et al., 2014, p.269). The detail of the psychosocial analysis is so important because it considers why this model may or may not be used, and why different HCPs might find different parts of the model open to conscious and unconscious anxiety.

### **Individual and social defence mechanisms related to identifying dying**

At a cognitive level, HCPs in this study recognised that providing end of life care was really important and recognising dying as part of that. This study though highlighted the experience of the HCP responsible for decision-making and providing the care. In this study once a patient was recognised as dying, and especially if the dying took many days to occur, witnessing the dying provided a very real emotional challenge for some HCPs. One HCP described how she felt useless, and frustrated, when she watched the process of the patient dying and their suffering, and even offering symptom management and comfort did not help relieve those feelings. She experienced unethical thoughts, for example wishing she could kill the patient, and at the same time thought of her own family relationships to justify this as a merciful act. Yet just having unethical thoughts is likely to be distressing. Recognising dying has the potential to be really unsettling, and challenge HCPs usual defence mechanisms – the protective phantasies of “mastery of impending death” and of “being right”.

Despite the work of Menzies-Lyth (Menzies, 1970) there is still no language in the NHS for the consideration of co-constructed social defence mechanisms. She herself lamented that her work on social defences had not had more effect (Dartington, 2008). This PhD has named social defence mechanisms associated with the care of the dying – this is my fourth novel contribution. The very real impact of the awfulness of this situation for the HCP may lead them to deny the recognition of dying and continue to treat in the hope that they can be useful. However, apart from denial of dying, there was evidence in this study that the gut recognition that a patient is dying was hugely vulnerable to unconscious anxiety and socially embedded clinical practices.

The defence mechanisms are seen in the expressions of the need for a “cast iron decision” that the patient is dying, or of the need to gain a “second opinion and

check". Families present a special challenge, and the need to make sure "the family are on board" with the medical decision is another co-constructed defence mechanism. The avoidance of the work after recognising dying was seen by the strategy of "not seeing the dying", "dressing up dying as a treatment", "leaving the emotional work to someone else" and "re-distributing the emotional work". Those HCPs who undertake the work can evidence detachment and denial of feelings and break bad news in a ritualistic way. Naming these defence mechanisms is likely to be helpful, as they are an external cue that "a clinical practice driven by anxiety" is likely taking place. Naming the practice allows thought and thinking, and with safe containment Bion cited in (Bibby, 2011), possibly learning about that cue.

It is really important clinically that we recognise that patients with long term conditions can present to hospital looking as if they are dying, but can radically improve with acute management, and be discharged home (Seamark et al., 2012). It will be helpful if HCPs really assess mental capacity ahead of ritually breaking bad news about the potential for death (Krawczyk & Gallagher, 2016), and think with the patient and family about what this means for them specifically (Tuffrey-Wijne, 2012) as HCPs in this study identified that families are resistant to engaging in repeated conversations about the likelihood of death – this is their daily life.

### **Palliative Care – the new social defence**

Palliative Care has had a long nursing history; Royal Trinity Hospice opened in 1892 (Royal Trinity Hospice, 2017), and St Josephs Hospice in Hackney opened in 1905 (St Joseph's Hospice, 2017) with nuns providing nursing care for those who were dying. In my current NHS trust the palliative care service has been nurse led for over thirty years. Palliative Medicine emerged as a medical speciality in 1987 and in the words of sociologist Dr David Clark has "seized hold of the field of caring", and hospital palliative care (Clark, 2014). Without attending to the politics of the recent dominance of the medical discourse, it can be seen that since Menzies-Lyth undertook the psychoanalytic study of nurses in the 1950's, hospitals now have palliative care teams, and there are standards for palliative care clinical practice (NICE, 2004) (NICE, 2017).



Menzies-Lyth felt it was best to understand an organisation with the distance of an outsider (Menzies, 1970). I have found it helpful to use the lens of research from social work about the dynamics of social workers and child protection to understand what might be going on as HCPs work with dying patients and families. Death, like sexual abuse, has such a powerful effect on internal boundaries, that it is usually split off and repressed (Harvey, 2010), and I can see how this is “split-off” in the hospital setting in the form of a palliative care team which requires peer review structures, time and psychological supervision to process the work about the care of the dying and their family. My fifth novel contribution is to identify that the palliative care team is the organisational system (the social defence mechanism of the organisation) that allows others in the hospital to be protected from their anxiety. It is not an infallible defence though.

I could not initially explain why palliative care teams “missed” seeing the dying and preparing families for the potential for bereavement. It has been helpful to use the skills of social work and the considered professional psychosocial reflections about why child abuse can be missed despite glaring evidence, to shine a light on why dying might be missed. Child abuse and death, on every level, conscious and unconscious, rattle our internal psychological defence mechanisms. Rustin describes a moment of “respectful uncertainty” (Rustin, 2005) where the social worker sits and truly allows thought, however awful and anxiety provoking, about the child and family such that evidence indicating child abuse can be thought about and named. Rustin says this is the area of professional work most easily interfered with by anxiety. These anxieties can be both personal, related to anxieties arising from close contact with the difficulties of families, and professional, related to inadequate resources and fear of blame.

At the point of recognizing dying though, I argue that this isn’t a moment of respectful uncertainty, as uncertainty is the underpinning dimension to the moments (s) of recognizing potential for dying. Uncertainty is there because the patient’s condition is deteriorating and the potential for medical and nursing intervention remains. It is a moment of exquisite (not pleasurable) pressure. There is the emotional charge of the patient and their family, and the terror of the HCP recognizing dying wrongly for them. There is also the need for on-going

support in the face of uncertainty, if uncertainty is introduced, and this is un-resourced in the current NHS. There is the history, power, culture and discourse of nursing and medicine. Nursing is reliant on medicine for decisions; medicine is reliant on nursing for care. If a nurse, and particularly a senior nurse such as a Clinical Nurse Specialist, recognises dying, then they are professionally committed to discussing the patient's clinical care and possibly challenging the consultant's decision-making. If the nurse, or CNS, can rationalise on-going active treatment, then undertaking this piece of work with the medical team can be left and the family can also be left. Seeing the dying is particularly exposed to anxiety, both conscious and unconscious, and is likely to provoke defences, rational and irrational desires and these are expressed in actions, decisions and relationships. Palliative care is the route to gain second opinions and resource to care for the patient and family, yet they too can "miss the dying". I suggest this is particularly likely when they are overwhelmed with clinical work, or personally stretched. There are social defences within social defences.

**This study has identified that families are a major source of clinical and emotional work, and may be part of the reason recognising dying is avoided**

Subsequent to the recognition of dying, there is the engagement with the patient and family to progress decision-making. There is evidence from this study that families are a major source of conscious and unconscious anxiety to HCPs, independent of the patient, and may be a contributing reason for the conscious and unconscious avoidance of recognising dying. The detail of this is my sixth novel contribution. Ahead of discussing this it should be noted that patients are not neutral in this process. HCPs in this study described how patients can actively keep their family out of their care when they can independently get themselves to clinic appointments and out patient treatments. Also, patients and families can help contain HCP's conscious and unconscious anxieties, and this happens when patients and families accept the fact the patient is dying or independently raise the topic with the healthcare team.

However, when the patient is recognised as dying and in hospital, HCPs in this study (in line with others (Klager et al., 2008)) indicated that the wider family was

immediately introduced into the patients care. Doctors responsibilities are defined as to “anyone who is close to the patient” (General Medical Council, 2010), whilst nurses are to “families and carers” (Nursing and Midwifery Council, 2015). HCPs can be unsure who is important to the patient, for example (carers who may not be legally related to the individual and neighbours can be hugely important), who constitutes “the family”, and what roles family members play in the patient’s life. This all makes the introduction of the family very challenging.

The loss of mental capacity of the patient to take part in decision-making can and is likely to occur ahead of death, and withdraws the patient from the decision making process. The family may have legal rights as the patient’s Lasting Power of Attorney (British Medical Association, 2008), but the formal introduction of the family, in a best interests decision-making scenario, can be challenging. HCPs described how what is heard and understood by different family members in family meetings was different. I suggest the HCP sometimes mourns the loss of the patient and their voice in their care, and is left in a HCP and family relationship, where there was evidence in this study as with others (Klager et al., 2008; Winter & Parks, 2012) that families do not accurately represent the views of patients. This is ethically challenging for HCPs for whom the duty of care is to the patient. However, the relationship between the HCP and family relationship has the ability to go beyond the death of the patient, which is experienced negatively by HCPs when families are angry and complaining.

HCPs described how these family meetings always take time, sometimes hours of time. The importance of this is that this time for families is not resourced by the organisation, nor are facilities provided. HCPs in this study gave their “on call” time, or re-arranged clinical time to pay attention to this aspect of care, and were inventive about where these meetings took place to give the family privacy and to protect them and shield others from distress.

This study identified that families could escalate the HCP anxieties. Whilst the literature mainly describes families who are helpful (Lowson et al., 2013) (Hanratty et al., 2012), this study identified that families who are in conflict amongst them selves, who are mistrusting, disbelieving and angry, are particularly

hard to contain as the level of emotion is challenging to manage. HCPs discussed how an angry family had resulted in the medical team overturning the treatment decisions they had made in the best interests of the patient. In a long meeting, the family's powerful emotional challenge had silenced the medical team – they had not followed the mental capacity act and sought legal assistance, and second opinions. They allowed treatment to happen to a patient they had not felt wise, but would have stopped it if it had caused harm. This is likely to cause extreme ethical distress and professional distress.

Families reminded HCPs of their own families and losses, and HCPs sometimes felt the impending loss of a long-term patient as they would a friend. Their phantasy of mastery and being right was rudely challenged when there were no more clinical solutions to improve or prolong the life of a patient, and they found it really hard to look at the patient and family and admit there was nothing more they could offer the patient. They are taken from a professional to patient and family relationship, to a human-to-human relationship. This PhD argues that this has potential to be a liminal experience without rules, and this is likely to be additionally distressing.

This study described how the recognition that a patient was dying, and the interaction with the family could occur in a very time pressured environment due to the rapidity of the deterioration of the patient. At that point, if the patient had lost capacity, then futile treatments could be offered to prolong the life of the patient, in order to give the family time to accommodate the news. The HCPs own emotional needs were traded as were their relationships with their peers. This was particularly apparent when nurses were requested to give treatments that might increase the suffering of the patient, when they knew they were futile, but for the benefit of the family.

HCPs described themselves as poorly prepared educationally for these family meetings. It is little wonder then that family meetings are resisted and avoided, or that the recognition of dying is delayed. It is surprising that HCPs are so quiet about the lack of resource for this aspect of clinical practice, and undemanding of resource. I am strongly arguing that there should be understanding of psychosocial, not the psychological and social in professional guidance (General

Medical Council, 2010) (National Palliative and End of Life Care Partnership, 2015) but as discussed in this study (Clarke & Hoggett, 2009; Hollway & Jefferson, 2013; Frost & McClean, 2014; Walkerdine et al., 2001; Woodward, 2015), integrated into the professionals practice in order to help them and the organisation manage the anxiety that dying creates. This (one would hope) would then result in a working practice that could recognise and adapt to the needs of families.

### Getting it wrong and relationship repair – a marginalised discourse

Given that there is much evidence that HCPs are inaccurate at prognostication (Christakis & Lamont, 2000; Gwilliam et al., 2013; Zibelman, Xiang, Muchka, Nickoloff, & Marks, 2014), and really interested in getting this right (S. A. Murphy et al., 2010), it should not be surprising that patients who survive their prognosis can hugely impact the HCP. HCPs in this study explained how when they had honestly prognosticated, changed the treatment plans to focus end of life care and on comfort, and the patient either took a long time to die, or the patients survived the prognosis, that it was really personally and professionally challenging. The challenge was to the doctor's sense of wanting to be right, to fear of having potentially denied a patient an opportunity for meaningful life and then how to re-establish therapeutic relationships with patients and / or their family. For nurses it was the constant challenge by families that the decision-making was wrong.

In the literature, apart from personal accounts of the experience of “being accused of getting it wrong” – which likely increase anxiety of HCPs, (Sara, 2014), and reports in the risk management literature which indicate that being responsible for a mistake is a particularly intense experience (Firth-Cozens, Redfern, & Moss, 2004), there is little documented about how HCPs learn from their mistakes – it has been described as a “marginalised professional discourse” (Vetere, 2007). My seventh novel contribution is to write about the discourse of “getting it wrong”, and “relationship repair”. There is very little in the literature about relationship repair for HCPs and patients and families. Doctors are advised to refer a patient to another doctor when the breakdown of trust prevents good medical care (General Medical Council, 2013). Nurses are instructed to respond “compassionately and politely to those who are anxious and distressed” (Nursing and Midwifery Council,

2015). HCPs in Drought's study (Drought & Koenig, 2002) avoided prognosticating and advance care planning as they wanted to keep a good relationship with the patient, and saw the introduction of talking about end of life care as rocking this. In this study HCPs recalled hours of work to get relationships with families back on track and for families to trust them when the patient had survived the treatment change subject to recognition of dying. They also described how this felt such a personal responsibility that, despite reflecting, the case re-occurred in their memories.

In the literature there is evidence that despite doctors recognising dying, active treatment can be continued until the last twenty four hours (Kennedy et al., 2014). This PhD offers a humane explanation as to why this clinical practice might occur: a patient surviving a diagnosis of dying with a change in treatment plan is so impactful for all involved that it can be preferable that the patient dies despite treatment, or with the treatment plan changing only hours prior to death. HCPs in this study had learnt strategies to minimise the occurrence of patients surviving their prognostication. For example they prognosticated in bands of time (days to weeks; weeks to months; months to years) which is known to be more accurate (Higginson & Costantini, 2002), and to introduce the concept of uncertainty when escalating patients care to intensive care so that patients and families were aware that death was a possible outcome. In the literature there is a new recommendation to name uncertainty - "sick enough to die" (Krawczyk & Gallagher, 2016). The point about recognising dying is that it allows thought with the patient about their wishes and preferences and what treatments are in their best interests, and consideration of treatment limits (not the limitation of care) – for example DNACPR, and ward based care (rather than intensive care). The introduction of the term "sick enough to die", if used alongside responsibility for clear clinical decision-making may be helpful to mitigate the anxiety about "getting the prognosis wrong". However, it again has echoes of avoidance in some HCPs hands.

Given the demographics of an aging population with multiple co-morbidities, it is going to be increasingly challenging to accurately predict dying. Also responsibly offering less active treatment, and combining this with palliative care is extending

people's life expectancy (Irwin et al., 2013), negating the current public conception that treatment equates with survival. For the future it would be really helpful to investigate the patient and families experience of surviving repeated prognosis of dying, and what was helpful for them and unhelpful. It would also be helpful to investigate HCPs experience of patient and family relationship repair.

Ahead of this it would be helpful to have patient and family information on the fact that it is challenging to predict dying, and also that dying can take time e.g. it can take three weeks for death to occur subsequent to withdrawal of dialysis. This information could then be used to think with patients and families about how the remaining time can be best used, and what resources are available to help support them during this time.

**The introduction of the psychoanalytic psychosocial allows new insights about the “learning opportunity”.**

The national commitment to clinicians who can care well for dying patients and families is well versed (National Palliative and End of Life Care Partnership, 2015). Yet in the literature there are anomalies, gaps and disjunctions that indicate that the rhetoric is much harder to translate into clinical practice. The literature indicates that there are differences in the amount of time that the pre-registration medical (Walker et al., 2016) and nursing (Dickinson et al., 2008) curriculums devote to the care of the dying; there is a resistance to sustained positive change in attitude towards caring for the dying (Barclay et al., 2015); that there is a mismatch between what skills medical educators think junior doctors need to care for the dying, what senior consultants think junior doctors can do and what junior doctors feel they can do (Bowden et al., 2013); that student nurses are learning to care for the dying without supervision which can cause emotional distress (Kent et al., 2012) and avoidance of such patients in the future (Okoye & Arber, 2014); and that palliative care support at the point of care is seen as helpful (Price & Schofield, 2015), as is skilled reflective debrief (Hockley, 2014). This study's unique contribution is a perspective that offers possible explanations as to why, despite the verbalised and rational commitment to educating HCPs to be able to offer end

of life care, HCPs can feel ill – equipped and resistant to providing this care, and it concentrates on the “learning opportunity in clinical practice”.

The “learning opportunity” that takes place in the clinical environment is seen as one of the key routes to learning and assessment for medical and nursing students. The learning opportunity as described in national documents (Nursing and Midwifery Council, 2010a; The UK Foundation Programme Curriculum, 2016) has standards for the learning experience: it is to be safe for patients, supportive for learners and provide a good standard of clinical care. Reflection is seen as a core skill and the route to make sense of the learning and to underpin a change in practice or behaviour. The learning theories that broadly underpin the current education curriculum pre-suppose that learning is mainly a rational and cognitive process.

In this study senior HCPs, rather than presenting themselves as an unemotional and emotionally unaffected skilled resource, able to assess and meet the needs of dying patients and their families (General Medical Council, 2010) (Nursing and Midwifery Council, 2014), and able to support the learning HCP, did describe the significant emotional impact of caring for the dying patient, and a personal commitment to help junior HCPs learn. What the psychoanalytic psychosocial framework brings is a language and framework to consider the HCP’s voice. As we have already discussed HCPs voiced feelings of frustration and of being un-useful in the face of death, and of experiencing unethical, if merciful, thoughts. HCPs described how, even when they had generously opened a learning opportunity for a junior doctor to watch a conversation with a dying patient’s family, that there was a sense that the junior doctor was “lurking”. Lurking is the language of the psychosocial, not the cognitive and rational, and this study considers that this may relate to the conscious and unconscious experiences of learning of the senior HCP or a worry about whether the junior HCP might be upset, intervene or challenge the senior HCP.

The need for safety is recognised for the patient in the clinical learning opportunity (General Medical Council, 2016), but this study argues that the learning opportunity needs to be safe for the learner. This is my seventh novel



contribution. Caring for the dying patient and their family can provoke uncomfortable emotions, and unethical thoughts which are in contrast to expected professional standards (General Medical Council, 2010) (Nursing and Midwifery Council, 2015). I argue that this silences both the teacher and learner, and has the potential to prevent reflective debrief. Psychosocial theories of learning highlight the importance of safe containment of thoughts to allow thinking and learning (Bion cited in Bibby, 2011)). Learning can be dangerous, as HCPs have to deconstruct what is known in order to learn new ways of knowing. In the care of the dying patient and their family, HCPs do not just learn about others or a task, they constantly learn about themselves, and the unpredictability of death, and its ability to reduce HCPs completely to their humanness. The importance of safe containment is seen in the value placed on having palliative care at the point of the clinical encounter (Price & Schofield, 2015).

I propose that after a clinical learning encounter asking the HCP what their thoughts are in a safe and private environment, and holding that third space (Benjamin, 2012), may enable the HCP to move themselves to a different position and learning, and re-engage with clinical practice. This level of reflection completely contrasts the rational and cognitive demand that they will learn subsequent to reflection (The UK Foundation Programme Curriculum, 2016). It may also engender partnership where the learner HCP can be encouraged to take a lead in a consultation with support rather than the expectation voiced by consultants in this study of “see one, do one, teach one”. It puts the humanness of the learner HCP back at the centre, where they can meet the humanness of the patient and family, with skilled support, and then continue to learn.

#### **The organisation does not resource twenty four hours a day, seven day a week support for learning at the clinical encounter**

In this study nursing HCPs described how some nurses chose to avoid this clinical work and negotiated that others undertake it – thus we can observe both “avoidance” as a protective mechanism, and how others gain increased exposure. The impact of the psychological defence of avoidance appears an exponential one,

when considered looking from the perspective of experienced practice to the start of practice in the undergraduate curriculum.

In clinical practice there is evidence that dying is now mainly segregated in certain specialties, particularly care of the elderly, and palliative care, and so HCPs can choose to practice in areas where there is less dying or more dying and thus minimise or maximise their opportunities for learning both pre and post registration. In this study HCPs discussed how they were able to spot the palliative care nurses of the future by those who did not avoid families and went “the extra mile”, and those nurses who avoided the care of the dying by nursing in areas such as theatres where they “are all asleep”. There is evidence that doctors have made their career choice as early as year one after qualification and certainly by year three (Surman, Lambert, & Goldacre, 2013). It would appear that some HCPs can lean into the care of the dying patient and learn on a level to manage their anxieties, and others can avoid this.

The challenge though currently is that due to the increasing demographics of an aging, co-morbid population, and hospitals under increasing pressure due to increasing activity, dying is occurring in many areas. This has the potential to cause extreme distress to HCPs whose conscious and unconscious defences have led both to avoidance of the care of the dying, professional clinical skill in life prolongation, and lack of “skill honing” in the care of the dying patient and their family. The arrival of a potentially dying patient and distressed family in the emergency department presents as “dirty and polluting” (Bailey & Murphy, 2011), and in areas such as theatres where organ donation occurs nurses describe such extreme distress that they “split their mind up” (Gao, Plummer, & Williams, 2017) in order to cope with the clinical work.

Seeing and doing without senior support can be extremely anxiety provoking for the individual and relies on the HCPs own ability to contain their distress. The ability to reflect such that thoughts, thinking and learning occurs, will be affected by the individuals unconscious defences (Doyle, 2012), and the ability of informal support to help find alternative perspectives. It is suggested that in contrast to the GMC rhetoric (General Medical Council, 2016) that organisations should provide a

good learning environment, that the organisation contributes to a lack of learning by lack of time for reflection, lack of resources, and mandating reflection for judgement and assessment through appraisal and revalidation. In this manner, it is easy to see how troubling experiences and thoughts about dying could be repressed or projected elsewhere, and dying patients and families avoided.

My eighth novel contribution is the articulation of a rationale for the importance of a team of HCPs who have expertise and can cope in such areas as the Emergency Department, and the operating theatre, to support both the clinical care and the ability to safely contain the distress so that there can be learning from these clinical events (Price & Schofield, 2015). Currently palliative care support is only 9-5 Monday-Sunday and this PhD argues that the organisational support required for learning (General Medical Council, 2016) is not met organisationally in the care of the dying patient and their family.

#### **Experienced nurses as the emotional container for doctors learning**

The concept that breaking significant news is a process (Baile et al., 2000), and that there is a recognised role for the nurse has begun to be identified (Warnock et al., 2010). The requirement to have a nurse present at the clinical encounter with the dying patient and their family was an oft-repeated narrative in this study. From a nursing point of view it is helpful to know what has been said and how it has been received in order to continue the care of the patient and family. However, I argue that without formal education, or resourced expectation that this is the role of the nurse (Warnock et al., 2010), there is evidence that some nurses are the emotional container, allowing the doctor to feel safe to undertake the work of delivering significant news, providing a witness for the doctor, and emotional containment if patients and families are angry or distressed. Doctors in this study regularly asked nurses after the meeting for their feedback and saw them as a route for the doctor to continue to learn and improve their skills.

That nurses are a route for junior doctors to learn is not new news (Vallis et al., 2004), but what this study adds is that experienced nurses comfortable with emotional work are the route to reflective debrief, and allowing thought, thinking and thus learning of senior HCPs. This is my ninth novel contribution. Nurse's

formal education is currently leaving them unprepared for this role, and this needs to be included. Detail about models for breaking bad news, self management, legal aspects of decision-making, working with families and how to give and receive feedback need to be covered. This is another dimension of practice that has the potential to be affected by conscious and unconscious anxiety and thus affect the willingness of nurses to be involved in these meetings.

### **Recommendations for clinical practice**

The recommendations for clinical practice are previously considered within each section. They are summarised briefly below:

There is currently a top down call for a system wide response nationally (Leadership Alliance for the care of Dying People, 2014), but this PhD argues for a clinical practice base upwards response that recognises that HCPs are humans, and unconscious avoidance of the dying is on some level inevitable. We need to stop repeating the national rhetoric that “dying is everyone’s business”, and ask what we can do to help individual HCPs in individual cases make the best decisions with and for patients and families. This is at an individual, group, institutional and Higher Education Institute provider level.

It is important that the five - stage model identified in this study is used in teaching and continues to be modified from reflections on clinical practice. Using the model has the potential to open spaces to consider whether the patient is dying, and how to evidence this; it allows thought about how and when to engage, and what to engage about and how to manage the consequences of the meetings. In this manner instead of compressing the recognition of dying into an action plan there is potential to pace the process, and think also about resources that will be helpful at each stage. It is vital that clinical supervision of the care of the dying person is resourced to allow reflection and learning that can affect current patient care, rather than wait to demand that HCPs reflect on deaths caused by a problem in care (National Quality Board 2017)

That the social defence mechanisms related to the care of the dying are named. These give a cue to anxiety driven processes and, if contained safely, will allow

thought and thinking about what is happening in this time to effect practice change.

That palliative care is effectively resourced. Research indicates that palliative care is valued and that joint consultations are a valuable way for others to learn (Price & Schofield, 2015). Palliative care HCPs need time to understand the learning needs and assessment processes of other professions in order to feedback effectively.

That family care is paid attention to and resourced. There are basic skills that could go into early curriculum delivery. For example mapping of family trees, understanding the patient and family relationship, family commitments and strengths and challenges. It would be helpful to define who the HCPs responsibility is to, and for HCPs to receive training on communicating with families, and regular debrief. At the point of recognising dying it can be like turning a shipping tanker around. Family meetings take time and this needs resourcing in order that other clinical care is not missed. There is opportunity for multi-professional work in this domain of care and for involvement of the charitable sector to ensure families have access to information, and places where their needs can be met.

It would be helpful to re-look at the learning opportunity. Whilst mentors and educational supervisors can look out for opportunities, this psychosocial study identifies how opportunities can be unconsciously missed. It would be good to give all students a placement in a hospital palliative care team – the volume of dying that takes place in a hospital means that it is unlikely that the visiting HCP will not see a dying patient and their family. It would be helpful if policy and standards could include a sense of the HCP as a person with emotions, and that working with their emotions can give ways to work in a psychologically helpful way with the family. Students and new HCPs do not have regular, as in daily, opportunities to work consistently with mentors and educational supervisors, both in clinical practice and in reflective supervision, and yet with respect to the care of the dying patient this is so important.

The workshops were well evaluated and whilst they would not suit all, and required skilled facilitation, they did give a space for HCPs to express their thoughts, think, be contained and take both psychological and physical action to improve care.

It is important to equip student nurses in their pre registration curriculum with the tools and experience to cope with current day clinical practice. They are undertaking much emotional work with patients and families, and being part of the breaking bad news process, yet have less communication skills training than medical students. We need to equip them to be able to give feedback to other HCPs and be able to receive it themselves.

### **Critique of the study, and recommendations for future studies**

My first awareness of this study is that it did not start out with a psychosocial framework, or intend to explore the impact of the individual, group, and institutions on decision-making processes around identifying dying. What allowed the psychosocial analysis to take place are the skills I had learnt as a facilitator of communication training to ask open questions and to remain inquisitive about the responses. In the future it would be so helpful to start with a psychosocial ontology and epistemology and to really pick up on cues related to the psychosocial. For example when HCPs described that they woke at night with patients in their head, I did not ask if they were in their dreams, or whether they had forgotten aspects of their care in the day unconsciously or consciously (they may not of course know this) (Trustram, 2016), and then woken and thought about the patient. In the future I would really like to take a psychosocial approach and a consideration of the third space (Benjamin, 2012), rather than affect and liminality (Stenner, 2012) to open this space and really consider how, with someone skilled in psychosocial research, the dynamics of the HCP and patient and family meeting can be explored.

My second critique is the limited attention paid in the analysis to the “social” in the psychosocial with a corresponding over-emphasis on links between individual anxieties relating to HCP’s own psychological make up and their response to dying patients and their families, e.g. the distress caused by the younger person dying

(Chapter Six), or when the patient's family has similarities to the HCPs family (Chapter Seven). At times I have more clearly drawn links with the wider societal realms and processes, for example, where HCPs and a family disagree on what is considered a "natural death" (Chapter Seven) and where HCPs in the workshop discuss whether the move from a paternalistic form of medicine that they practiced earlier in their careers to the current move to involving patients in decision-making is really helpful for them, patients and families with respect to caring for the dying patient (Chapter Five). I have drawn links with the organisational contribution to anxiety e.g. lack of space for conversations (Chapter Seven) and the lack of clinical supervision of this aspect of care (Chapter Eight). I have paid attention to the social in terms of peer relationship affecting how decisions are made (Chapter Seven). The premise of this PhD understood that the volume of patients impacted the ability to recognise dying, which is absolutely related to the demographics of an aging population, and the current structure of the NHS. However, the design set up and analysis of the study data has not considered such specific factors as how gender, ethnicity, power, and class may play a role in either the recognition of dying or the negotiation of decision-making. I have also not paid deep attention to cultural and spiritual issues within this study, which are well known and recognised to affect decision-making for patients and families (Calanzani et al., 2013) and for HCPs (Sprung et al., 2007). I would include these factors up-front in future studies, and explore their potential impact in supervision ahead of designing the study.

My third critique is that I had not anticipated the enormous contribution of the family to the challenges of recognising dying and subsequent work. For the future, it would be helpful to specifically take a psychosocial approach to the experience of HCPs, patients and families who survive a HCP's prognosis of dying. It would be interesting to investigate how HCPs and patients and families have repaired relationships.

My fourth critique is that I have not used the data from the study regarding the use of humour. The workshops were interspersed with humour, which covered shared knowledge of the challenges of this aspect of clinical care (known but hidden truths). This shared humour and camaraderie is part of what makes working in

this clinical area so rewarding, and I suspect sustaining, and it would be helpful to investigate what sustains HCPs working in this clinical field for long periods of time. I would like to write this up as a separate paper.

My final critique is that the data from this study could usefully contribute to the current academic debate on Terror Management Theory. The data evidences that death anxiety, rather than being a simple internal thing to measure, is highly contextual in healthcare. I would like to write this up as a separate paper.

## Conclusion

The research question focused on how senior HCPs identified dying and negotiated decision-making with the patient and family. This study has identified a five-stage model for recognising dying. This is 1) a gut instinct that the patient is likely dying 2) evidencing this gut instinct, 3) engagement with the patient and family to discuss the recognition of dying, clinical management options, and patient's wishes and preferences 4) how HCP's work with the "fall out emotions of the patient and / or family and consequences for decision-making of these meetings, and 5) clinical supervision of this process.

The intention was to develop clinical practice through PAR workshops, and the themed analysis identified that HCPs had valued taking part in the workshops, and there was evidence of learning. Investigations though of the slips, and trips and anomalies expressed in Study One and Two, through the psychosocial analysis has yielded introduction of a new language and knowledge of how HCPs can be more effectively supported to learn.

The psychosocial analysis allows the consideration of an individual and collective psychological tenor, about identification of dying, the care of the dying, and the interaction with their family, framed with anxiety as the currency (Hoggett, 2009). It allows consideration of mutually affective unconscious, psychologically defensive practices at an individual, professional, group, and institutional level in the NHS and in Higher Education Institutes preparing junior doctors and nurses.



There is a professional expectation and desire to not deny any patient meaningful quality of life, and so the recognition of dying is particularly vulnerable to conscious and unconscious anxieties. Co-created social defence mechanisms related to the identification of dying have been identified, and the legitimised use of these through policy and practice, start to explain why dying is identified so near to death.

Families are a major source of conscious and unconscious anxiety, with the potential for the HCP to keenly feel the loss of the patient, and recognise similarities between their own families and patient's families. The position of having nothing more that is "useful" to offer the patient in terms of life prolongation, and the recognition of dying, has the capacity to transform the relationship to one where the full emotional loss of the family can be felt. The formal introduction of the family via best interests decision-making when the patient has lost capacity can be particularly challenging when the doctor and family disagree about what is in the patient's best interests. Educational preparation for family work, and lack of institutional resources for this aspect of clinical care, may also be part of the reason that identification of dying is delayed.

The supervised learning opportunity is the route in clinical practice for both the learning and assessment of junior clinicians. The need for safety is recognised for the patient in the clinical learning opportunity, but this study demonstrates that the learning opportunity needs to be safe for the senior and learning HCP. Caring for the dying patient and their family can provoke uncomfortable emotions, and unethical thoughts, which are in contrast to, expected professional standards. This silences both the teacher and learner, and has the potential to prevent reflective debrief. Psychosocial theories of learning highlight the importance of safe containment of thoughts to allow thinking and learning. The importance of safe containment is seen in the value placed on having palliative care at the point of the clinical encounter (Price & Schofield, 2015). The lack of emotional safety for HCPs if they are unsupervised in the care of the dying patient and their family may well go some way to explaining why recognising dying can be recognised late, or the dying patient avoided. Senior doctors become more isolated in clinical practice as they specialise and have less opportunity to observe others manage family

meetings. This study identified that experienced nurses, comfortable with emotional work, are the route to reflective debrief, and allow thought, thinking and thus learning of senior doctors.

Finally, I have both a model for identifying dying and negotiating decision-making, and informed psychosocial considerations about why it is so challenging to develop sustained clinical practice change to identify dying earlier. Understandably the voice of the patient and family is prioritised in national guidance documents about end of life care, in professional standards, in education and in expectations of hospital care. However, the voice of the HCP needs to be gently re-asserted into priorities for patient, and families, in order that we can find creative solutions that respect social relationships and have potential to sustain HCPs in clinical practice.

I look forward to both publishing the details of this study, and continuing to research HCP, patient and family meetings.

# Appendices

## Appendix 1. Example of the literature review and process

Author and year	Country	What method exposed the knowledge	Type of epistemology	Area of study	Sample	Number who refused to take part	Key findings for pts	Key Findings for families.	Key findings for professionals
Prendergast (1997)	USA	Quantitative/comparative study of patient details rather than patients Detailed analysis of when clinicians did not accede to family requests.	Modern	ITU	224	Does not say	90% Pts. who die in ITU do so after a decision to limit therapy (compared the 1990s to the 1980s) – major change in practice.	Pts. and families accept appropriate recommendation to withhold or withdraw life support.	Physicians will refuse surrogate requests for life support in certain circumstances.
Seymour (2000)	UK	Ethnographic research. Involving observational documentary and interview.	Modern	ITU	14	Does not say			1) Establishment of a 'technical' definition of dying informed by results of investigations and monitoring equipment over and above 'bodily dying informed by clinical experience. 2) The alignment of the trajectories of technical and bodily dying to ensure that the events of non-treatment have no perceived causative link to death. 3) The balancing of medical action with non action, allowing a division of responsibility for death to the patient's body. 4) the incorporation of patient's companions and nursing staff into the decision-making process.

**Appendix 2. The consent forms, participant information, interview schedule for (Study One), and sample of posters as they went to the ethics department**

**Participant Information Sheet  
Study 1**

**How do senior healthcare professionals recognise dying and engage patients and families to negotiate key decisions?**

I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. If there is anything in this letter that is not clear, or you would like more information you can ask me about it. Contact details are at the top of this information sheet.

**What is the purpose of this study?**

The purpose of this study is to understand how senior healthcare professionals recognise dying and engage with patients and families to negotiate decisions at end of life. There are approximately 1500 admissions to XXXHospitals NHS Foundation Trust every week and there are around 22 deaths every week. I want to understand what the triggers are for you to engage in conversations with patients and families about dying, and then how decision making with patients and their families are facilitated.

The second aim of the study (Study 2) is to evaluate Participatory Action Research (PAR) groups (which encourage reflective practice) as a means to practice development. You will be invited separately to take part in Study 2.

**Why am I being invited to take part?**

You are being invited to take part as you are a senior healthcare professional who regularly cares for patients on wards where dying occurs.

**Do I have to take part?**

It is up to you to decide if you wish to take part in the study. This information sheet describes the study. You may keep this information sheet for your records. You are free to withdraw at any time, without giving a reason.

**What would be involved?**

The study involves taking part in an individual interview with a researcher that will last approximately 30 minutes subsequent to a referral to the hospital palliative care team for assistance with end of life care and onward care planning. You will be approached because a) you have identified to the hospital palliative care team a patient requires end of life care planning, or care outside

of the hospital or b) you are a palliative team healthcare professional who facilitated the care of the patient and family subsequent to the referral.

To comply with current regulations governing research, if you are willing to participate in the interview, you will need to give written consent to these arrangements. I will explain the study before starting the interview and you will have the opportunity to ask any questions. You will then be asked to sign a consent form agreeing to participate in the study and for the interview material to be used for research and teaching purposes under the stated conditions. Before the interview begins you will be given a copy of the consent form that you signed to keep.

You will be asked to complete a demographic questionnaire and to address how frequently you care for the dying. “Skills for Care” in combination with the “National End of Life Care Programme” have drawn up three staff groups based on frequency of caring for the dying - Group A (Specialist Palliative Care), Group B (those who deal with dying frequently) and Group C (deal with dying infrequently) – all are vital to the care of the dying patient but their experiences are important to affect how we facilitate learning for all.

The interview will be recorded using an audiotape and will cover topics about your experience of identifying that the patients are dying and how you know to engage with patients and families to facilitate decision-making and then what happens subsequent to that engagement. You will be asked not to use patient names or patient identifiable information.

After the interview, the audiotape will be checked to ensure that there is no patient identifiable information and it will be fully transcribed so that I have a written account of the interview. I will use this information to conduct the analysis that will help me to identify themes that appear to be important to you and to other participants in the study. The original recording will be stored in a protected electronic file on a password-protected computer in a locked office. It will be kept for three years prior to disposal.

In order to maintain confidentiality I will anonymize the transcripts so that no real names are used in any report or subsequent publication of the findings. I may use direct quotes from the interviews in our published findings, or for educational purposes, but again all details relating to any individual will be anonymized so that you cannot be identified.

After the interview I will give you a thank you letter. Finally, if you would like to receive a summary of the final report findings please let me know during the interview and I will send you a copy once the study has been completed.

**What are the possible disadvantages and risks of taking part?**

I do not anticipate that there will be major risks involved in this study. There is always the opportunity of learning from reflection that can make us realise we could have done things differently for previous patients and families. The interviews will be conducted in an appreciative enquiry manner.

In the event that you experience any additional distress due to participation in this study, information about staff counselling services will be provided.

You are not obliged to take part and this will have no impact on your work if you choose not to participate.

**What are the possible benefits of taking part?**

It is hoped that at the same time that we are able to learn and articulate what resources, triggers and knowledge senior healthcare professionals use to identify dying, that the interviews will give you evidence of reflective practice required for portfolios for appraisal and professional re-validation.

**Will my taking part in this study be kept confidential?**

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. All information that is collected about clinical practice during the course of the research will be kept strictly confidential and any information involving you that leaves the Trust will have any personal identification removed so that you cannot be recognised. Data will be kept in locked cabinets and will be access protected when stored on computers. It is not anticipated that clinical malpractice will be disclosed, but in the event of this occurring, confidentiality will be breached and the event will be reported in line with Trust procedures.

**What will happen if I don't want to carry on with the study?**

If you withdraw from the study we would like to use the data collected up to the point at which you withdraw. Any data you have provided will be anonymized so that you cannot be identified from the information in any report or published material.

**What if there is a problem?**

If you have a concern about any aspect of this study, please contact me (contact details can be found at the top). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital.

**What will happen to the results of the research study?**

At the end of the study I will publish the study findings in academic and health professional journals. I will also present the findings at conferences. Information may be used for educational purposes with health and social care professionals. If you would like a copy of the summary findings please let us know and I will send you a copy to you on completion of the study. No individual will be identifiable in any published material or in any educational material, although direct quotes from the interviews may be used as examples of the findings

**Who is organising and funding the research?**

Jo Wilson (PhD student from the University of Bath, Department of Psychology), Macmillan Consultant Nurse Practitioner Palliative Care is conducting this study. Macmillan funded the recording equipment and may fund a volunteer to transcribe the interviews.

**Who has reviewed this study?**

The research has been reviewed and approved by the Psychology ethics group at University of Bath and the research and development team at XXXX

**Are expenses paid?**

Unfortunately we are unable to provide payment for participation in the study.

**Who can I contact for further information?**

If you have any questions, please feel free to contact Jo Wilson, Macmillan Consultant Nurse Practitioner Palliative Care

**Thank you for taking the time to read this information.**





**Chief Investigator**

Jo Wilson

Macmillan Consultant Nurse Practitioner

Palliative Care

**Participant Information Sheet  
Study - 2****How do senior healthcare professionals recognise dying and engage patients and families to negotiate key decisions?**

I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. If there is anything in this letter that is not clear, or you would like more information you can ask me about it. Contact details are at the top of this information sheet.

**What is the purpose of this study?**

The purpose of this study is to understand how senior healthcare professionals recognise dying and engage with patients and families to negotiate decisions at end of life. There are approximately 1500 admissions to XXX Hospitals NHS Foundation Trust every week and there are around 22 deaths every week.

Through a series of Participatory Action Research (PAR) group discussions, I want to understand what the triggers are for you to engage in conversations with patients and families about dying, and then how decision making with patients and their families are facilitated. The second aim of study 2 is to evaluate PAR groups (which encourage reflective practice and action) as a means to practice development.

**Why am I being invited to take part?**

You are being invited to take part as you are a senior healthcare professional who regularly cares for patients on wards where dying occurs.

**Do I have to take part?**

It is up to you to decide if you wish to take part in the study. This information sheet describes the study. You may keep this information sheet for your records. You are free to withdraw at any time, without giving a reason.

**What would be involved?**

Study 2 involves taking part in four one-hour PAR groups (at 1-2pm) involving 10-15 people that will occur at monthly intervals from April to July 2014. Lunch will be provided and you will be given six weeks' notice. In the first PAR group you will be prompted to discuss specific questions about how you know to engage with dying patients and their families and then how patient and family discussions are facilitated in order that decision-making about end of life care issues occurs. It is anticipated that as part of the group you will generate an agreed action to take away and put into action / reflect on in the intervening month. Your learning from this action will inform discussions in the next PAR

group. You will be asked to comment on the process of PAR groups as a method to reflect on and develop clinical practice.

At the first PAR group you will be asked to complete a demographic questionnaire and to address how frequently you care for the dying. "Skills for Care" in combination with the "National End of Life Care Programme" have drawn up three staff groups based on frequency of caring for the dying - Group A (Specialist Palliative Care), Group B (those who deal with dying frequently) and Group C (deal with dying infrequently) – all are vital to the care of the dying patient but their experiences are important to affect how we facilitate learning for all.

To comply with current regulations governing research, if you are willing to participate in the PAR group, I will need you to give written consent to these arrangements. I will explain the study before starting the PAR group and you will have the opportunity to ask any questions. You will then be asked to sign a consent form agreeing to participate in the study and for the interview material to be used for research and teaching purposes under the stated conditions. After the first PAR group you will be given a copy of the consent form that you signed to keep.

The PAR group will be recorded using an audiotape.

At the start of the first PAR group you will be asked, with the group, to agree a working agreement for the four PAR groups, which will clearly identify expectations of group behaviour including the opportunity to challenge each others views as you discuss clinical practice. As part of this - in order to protect patient and family confidentiality - you will be asked not to use patient names or patient identifiable information; you will also be asked to agree that information about colleague's practice also kept confidential to the PAR group.

After the PAR group, the audiotape will be checked to ensure that there is no patient identifiable information and it will be fully transcribed so that I have a written account of the interview. The original recording will be stored in a protected electronic file on a password-protected computer in a locked office. It will be kept for three years prior to disposal. I will use the information given to conduct the analysis that will help me to identify themes that appear to be important to you and to other participants in the study.

In order to maintain your confidentiality I will anonymize the transcripts so that no real names are used in any report or subsequent publication of the findings. I may use direct quotes from the PAR group in our published findings, or for educational purposes, but again all details relating to any individual will be anonymized so that you cannot be identified.

After the interview I will give you a thank you letter. Finally, if you would like to receive a summary of the final report findings please let me know during the interview / PAR group and I will send you a copy once the study has been completed.

### **What are the possible disadvantages and risks of taking part?**

I do not anticipate that there will be major risks involved in this study. There is always the opportunity of learning from colleagues about ways of caring for patients and families that can make us realise we could have tackled things differently for previous patients and families. The PAR groups will be conducted in an appreciative enquiry manner and it is intended that they will attend to good examples of practice as well as areas for learning. In

the event that you experience any additional distress due to participation in this study, information about staff counselling services will be provided

You are not obliged to take part and this will have no impact on your work if you choose not to participate.

### **What are the possible benefits of taking part?**

It is hoped that at the same time that we are able to learn and articulate what resources, triggers and knowledge senior healthcare professionals use to identify dying, that the discussions within the interviews and PAR group will give you evidence of reflective practice required for portfolios for appraisal and professional re-validation. It may well be that there is learning for all from participating in discussions with other senior healthcare professionals.

### **Will my taking part in this study be kept confidential?**

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. All information that is collected about clinical practice during the course of the research will be kept strictly confidential and any information involving you that leaves the university / Trust will have any personal identification removed so that you cannot be recognised. Data will be kept in locked cabinets and will be access protected when stored on computers. It is not anticipated that clinical mal-practice will be disclosed, but in the event of this occurring, confidentiality will be breached and the event will be reported in line with Trust procedures.

### **What will happen if I don't want to carry on with the study?**

If you withdraw from the study I would like to use the data collected up to the point at which you withdraw. Any data you have provided will be anonymized so that you cannot be identified from the information in any report or published material.

### **What if there is a problem?**

If you have a concern about any aspect of this study, please contact me (contact details can be found at the top). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital.

### **What will happen to the results of the research study?**

At the end of the study I will publish the study findings in academic and health professional journals. I will also present the findings at conferences. Information may be used for educational purposes with health and social care professionals. If you would like a copy of the summary findings please let me know and I will send you a copy to you on completion of the study. No individual will be identifiable in any published material or in any educational material, although direct quotes from the interviews may be used as examples of the findings.

### **Who is organising and funding the research?**

Jo Wilson (PhD student from the University of Bath, Department of Psychology) Macmillan Consultant Nurse Practitioner Palliative Care is conducting the study. Macmillan may fund lunch and a volunteer to transcribe the interviews and PAR groups.

### **Who has reviewed this study?**

The research has been reviewed and approved by the Psychology ethics group at University of Bath & the research and development team at XXX Hospitals NHS Foundation Trust.

**Are expenses paid?**

Unfortunately we are unable to provide payment for participation in the study.

**Who can I contact for further information?**

If you have any questions, please feel free to contact Jo Wilson, Macmillan Consultant Nurse Practitioner Palliative Care

**Thank you for taking the time to read this information**

# Consent Form

## Study 2

**Title of project:** How do senior healthcare professionals recognise dying and engage patients and families to negotiate key decisions?  
Evaluation of Participatory Action Research (PAR) as a means to develop clinical practice

**Chief Investigator:** Jo Wilson Macmillan Consultant Nurse Practitioner Palliative Care,

Please initial  
all boxes

1. I confirm that I have read and understand the information sheet, dated .....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 but data up until that point will be used.
3. I understand that the PAR groups will be audio recorded.
4. I understand that parts of the interview may be used verbatim in future publications or presentations but that such quotes will be anonymized.
5. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

# **CARE OF THE DYING PATIENT & FAMILY SENIOR HEALTHCARE PROFESSIONALS WANTED FOR RESEARCH STUDY**

**In clinical practice do you identify patients who may be dying, and facilitate decision-making about end of life care?**

**If so, you may be approached and asked to participate in a participatory action research (PAR) study.**

**The study aims to describe how healthcare professionals identify the dying patient, in the midst of a busy acute trust, in order to facilitate patient and family decision-making at end of life care and to evaluate PAR groups as a means to develop clinical practice.**

**The study will involve taking part in a short interview and / or a series of four one-hour PAR groups (over a four month period). We would be grateful if you could take part, but you have no obligation to do so. You may say no if approached.**

**If you have not yet been approached, but would like to take part in this study please let us know by contacting Jo Wilson (ext XXXX) for further information about the study.  
Thank you for your interest and cooperation**

## Interview Schedule for Study 1

### How do senior healthcare professionals recognise dying and engage patients and families to negotiate key decisions?

First of all I would like to thank you for taking the time to talk to me. As you know I am interested in understanding your experience of identifying patients who are dying and then how you facilitate patients and families to make decisions about end of life care. I have here some topics, which might be useful to discuss, but most important are your experiences.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. Your name will not be mentioned in any reports arising from this study.

I am going to ask you to omit any names of the patient and their family. Could we agree at this stage how you will reference them?

### Section One – Your experience of recognising dying

1. Can you think of a recent specific case<sup>16</sup> and can you talk me through what it was that made you realise the patient was likely to be dying?  
*Prompts: How did you do, this given the large volume of patients you had seen that day? What informed this decision? Where did this knowledge come from – was it formally taught or learnt in the role? What did you do? When did you do that? Why did you do that? What did you have in place to help you do this? What were the barriers?*
2. What was your personal response to recognising the likelihood of dying?  
*Prompts: What effect did this have on you personally with respect to emotional or physical impact? What effect did this have on you professionally? How did you manage this impact?*
3. Were you the first person to recognise dying?  
*Prompts: Did you recognise the dying and initiate the discussion or did others prompt you? Did the patient or family prompt you? Which healthcare professional prompted you?*

### Section two – Engagement with the patient and family

4. How did you know when to engage with the patient and family?  
*Prompts: Did you speak with the patient on their own / at a ward round / other time? Did you set up a patient and family meeting? Did you make a referral to facilitate this meeting?*
5. What did that engagement look like?

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<sup>16</sup> As per the methodology on P.44 – I identified the specific case for the HCP. However, the generalist HCP had identified the patient as likely dying by their referral to the HPCT.

*Prompts: Did it take place at bedside, dayroom, clinic room, other place? Were you sitting / standing? Was the patient able to take part in the conversation? Did the patient give you permission to speak to their family separately to them? Did you require a translator?*

6. What were the decisions that were to be agreed in that meeting?

*Prompts: What decisions had to be made? Were any non-negotiable? What of the patients agenda did they raise? What of the family's agenda was raised?*

7. Were any decisions left unspoken or unmade?

8. What therapeutic processes did you notice occurring in the meeting?

*Prompts: How did the decision-making meet the patient's agenda? How did the decision-making meet the family's agenda? Were these in agreement? What did the patient want to happen in their daily lives? What hopes had they still to be realised? What were the family's hopes for their lives? How were relationship issues attended to? What were the relationship issues? How was hope expressed and attended to? How was risk attended to and managed in terms of achieving patient goals? How much time did this meeting take?*

### **Section three – after the meeting**

9. How did you continue to maintain a relationship with the patient and family after the conversation?

*Prompt: How did you agree the on-going plan and next review? How did you ensure there was continuing availability of contact? How did you ensure the patient and family did not feel abandoned at any stage?*

### **Section four – previous training to facilitate patient and family meetings at end of life**

10. How did you learn about patient and family care at end of life and maintaining their relationships?

*Prompt: Was it in your formal training? Was this in post registration training? Was this acquired through practice? Is this aspect of care attended in your appraisal and development plan?*

### **Section five – your current experience of reflection and co-operative enquiry as a means to practice development**

11. What is your experience of reflecting on practice as a means to developing your future practice?

**Thank you for your participation in this study.**



**How do senior healthcare professionals recognise dying and engage patients and families to negotiate key decisions?**

Thank you for taking part in our research study. I really appreciate you taking the time to help me to understand your experiences of recognising dying and engaging patients and families to negotiate key decisions.

If taking part in this study has raised any personal issues that you would like to discuss further, you can make contact with the employee assistance scheme. This is a confidential and free service and is available by phone 365 days of the year. This can be accessed on 0800 282193.

## Demographic Questionnaire

**Initials**

.....

**Role**

.....

**Title**

.....

**Band of**

**role**.....

**Area of clinical practice**

.....

**Length of time since primary qualification**

**(years)**.....

**Frequency of exposure to dying patients:**

Specialist palliative care

Frequently exposed to dying patients

Infrequently exposed to dying patients

Please describe your ease of being with identifying and facilitating patient and family decision-making:

I am at ease with discussions about dying and living with uncertainty

I am moderately at ease with discussions about dying and living with uncertainty

I am ill at ease with discussions about dying and living with uncertainty

**Comments**.....

.....

.....

.....

# Care of the Dying Patient & Their Family

**In clinical practice do you identify patients who maybe dying, and facilitate decision-making about end of life care? Are you a Consultant, senior registrar, or Nurse / Allied Health care Professional above band 6?**

This second study builds on the evidence from Study 1 where senior health care professionals described how they identified dying and negotiated decision-making with patients and families; additionally they described the education so far to equip themselves for this aspect of care.

The aim of study 2 is to discuss the detail of three specific areas of care – identifying dying, negotiating decision-making, and coping with the emotional and physical fall out of decision-making.

At the end of each session the group will identify an area of practice to consider / explore ahead of the next group. We will evaluate these groups as a means to develop clinical practice.

It is anticipated that attendance will be at all four sessions. Please note the groups will be helpful reflective evidence for appraisals / revalidation.

29/04/2015	12.45-14.00		Lunch provided
13/05/2015	12.45-14.00		Lunch provided
03/06/2015	12.45-14.00		Lunch provided
15/072015	12.45-14.00		Lunch provided

We would be grateful if you could take part, but you have no obligation to do so. If you would like to take part in this study please let us know by contacting Jo Wilson (ext 4 [redacted]).

**Thank you for your interest and cooperation**

Appendix 4 – Anonymised Example of Participant Feedback Sheet from PAR workshop

Workshop 1: Identifying Dying  
Wednesday 29<sup>th</sup> April 2015: 13.00-14.00hrs

Time	Topic	Facilitator
13.00-14.00	How we identify dying	Jo Wilson

<b>Development activity:</b> Reflection on evidence from study one about how senior health care professionals identify dying and personal relevance to clinical practice	
<b>Scales (0, 1, 2, 3, 4, 5) 0= not relevant to 5+ highly relevant.</b>	
<b>Relevance:</b>	5
<b>Quality:</b>	5
<b>Effectiveness:</b>	5
<b>Personal Reflection from study day</b>	<p>Very useful to think about process, decision making and listening to others p.o.v.</p> <p>There is <del>more</del> a lot of experience and learning to be shared from others.</p>
<b>Reflection over next two weeks about influences on decision-making</b>	

CPD learning credits' claimed: ..... Signature: .....

(Reference: RCP Continuing Professional Development 2011 & RCGP RCGP Guide to the Credit-Based System for CPD, Version 3, August 2013)

CPD

## Appendix 5 – Example of coding from Critical Incident Review (Study One)

interview / - DS330009  
Transcribed 16<sup>th</sup> June 2014  
2

34 the dying process, **aah**, was probably and probably in retrospect was a  
35 week before he was dying actually. He was complaining of on-going  
36 pain was the other issue, which was **irretractable** despite regular  
37 Diamorphine; so it was the combination of continued cachexia despite  
38 TPN, on-going pain, on-going GI symptoms and just not getting  
39 better.

40 **IntJW** It sounds a bit like a process in a way – trying...is that right?  
41 **So it was over a period of time that you are putting bits together?** Yes.  
42 HCP7 I mean certainly the first big alarm bell was just the quantity  
43 weight loss after a three week time period. That was the time I  
44 thought oh this is a nasty malignancy um and when you get something  
45 like that I knew straight away that even awaiting the histology at that  
46 time I thought; my instinct was that this was not curable and probably  
47 quite aggressive.

48 **IntJW** So tell me where does that knowledge come from? Is that  
49 something that is formally taught so that instinct is that something you  
50 have learnt through years of practice or is that something that is  
51 formally taught?

52 HCP7 There is formal teaching. You are going to ask me to identify  
53 what that was now – um I don't that I ever had classroom teaching on  
54 it um probably bedside teaching in medical school and then when you  
55 are doing bedside teaching as a trainee doctor as well its one of those  
56 things that you pick up as you go along as you do post take ward  
57 rounds and comments by, it may not be formalising of the teaching  
58 but certainly things that we pick up as we go around and then  
59 experience comes into it as well once you have got a consultant role  
60 and you know the buck stops with you and you have to realise you are  
61 going to have to make your own decisions based on your own clinical  
62 acumen. You start to identify signs so for example I will eh one of my  
63 favourite signs now is looking out for temporalis wasting; as soon as  
64 see temporalis going you know I see somebody who is deteriorating.  
65 Now that might be malignancy but that might just be general  
66 malnutrition through whatever, dementia I don't know but that to me

jowilson 22/9/2014 06:56  
**Comment [16]:** Easier to confirm gut instinct in retrospect

jowilson 22/9/2014 06:56  
**Comment [17]:** Symptoms escaping usual pharmacological methods

jowilson 22/9/2014 06:57  
**Comment [18]:** Not improving despite treatment

jowilson 22/9/2014 06:57  
**Comment [19]:** Weight loss was the alarm bell

jowilson 22/9/2014 06:58  
**Comment [20]:** His instinct told him the result ahead of the result

jowilson 22/9/2014 06:58  
**Comment [21]:** Formal teaching

jowilson 22/9/2014 06:58  
**Comment [22]:** Not classroom teaching

jowilson 22/9/2014 06:59  
**Comment [23]:** Bedside teaching at medical school

jowilson 22/9/2014 07:00  
**Comment [24]:** Role modelling on post take ward rounds

jowilson 22/9/2014 07:00  
**Comment [25]:** Experience as a consultant

jowilson 22/9/2014 07:00  
**Comment [26]:** Responsibility for decision-making

jowilson 22/9/2014 07:01  
**Comment [27]:** Start to look for signs

jowilson 22/9/2014 07:02  
**Comment [28]:** Has a favoured sign

jowilson 22/9/2014 07:03  
**Comment [29]:** As soon as sees temporalis wasting knows the pt is deteriorating

jowilson 22/9/2014 07:04  
**Comment [30]:** Differentiates between malignancy and general malnutrition through dementia



# Appendix 7- Example of Powerpoint presentation for the PAR workshop.

## Workshop One.

<p><b>Workshop One</b> Jo Wilson</p>	<p><b>Welcome</b> (Introductions group)</p> <ul style="list-style-type: none"> <li>• Introductions (group)</li> <li>• Recording Equipment.</li> </ul>	<p><b>Workshops</b></p> <table border="1"> <thead> <tr> <th>Workshop</th> <th>Date</th> <th>Location</th> <th>Content</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>20<sup>th</sup> May 2014</td> <td>Research</td> <td>Working with the patient</td> </tr> <tr> <td>2</td> <td>27<sup>th</sup> May 2014</td> <td>Blackburn, Home</td> <td>Working with the patient</td> </tr> <tr> <td>3</td> <td>3<sup>rd</sup> June 2014</td> <td>Research</td> <td>Working with the patient</td> </tr> <tr> <td>4</td> <td>10<sup>th</sup> June 2014</td> <td>Research</td> <td>Working with the patient</td> </tr> </tbody> </table>	Workshop	Date	Location	Content	1	20 <sup>th</sup> May 2014	Research	Working with the patient	2	27 <sup>th</sup> May 2014	Blackburn, Home	Working with the patient	3	3 <sup>rd</sup> June 2014	Research	Working with the patient	4	10 <sup>th</sup> June 2014	Research	Working with the patient	<p><b>Any Questions</b></p> 	<p><b>Working Agreement</b></p> 	<p><b>Context</b></p> 
Workshop	Date	Location	Content																						
1	20 <sup>th</sup> May 2014	Research	Working with the patient																						
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3	3 <sup>rd</sup> June 2014	Research	Working with the patient																						
4	10 <sup>th</sup> June 2014	Research	Working with the patient																						
<p><b>Method</b></p> <ul style="list-style-type: none"> <li>• Randomly selected 6 patients that palliative care were involved with between April and July 2014.</li> <li>• I interviewed both the healthcare professional team member.</li> <li>• Used a structured questionnaire to guide my written transcript.</li> <li>• Engaged with my supervisors about my understanding of the title.</li> </ul>	<p><b>My learning</b></p> <ul style="list-style-type: none"> <li>• As a palliative care researcher I have needed to change to see research as a process rather than a product - 'we are working, we are learning, we are growing'.</li> <li>• Have started to learn about the evidence base - how we make decisions, communication theories, and patient / family therapy.</li> <li>• Have had a lot of support from my supervisors and the research team.</li> <li>• Have had a lot of support from my supervisors and the research team.</li> <li>• Have had a lot of support from my supervisors and the research team.</li> <li>• Have had a lot of support from my supervisors and the research team.</li> </ul>	<p><b>Reflection</b></p> 	<p><b>How do HCP describe the experience of recognizing dying?</b></p> <p>How do you describe the experience of recognizing dying?</p> <p>How do you describe the experience of recognizing dying?</p>	<p><b>What sense do you make of this data when you relate it to your practice</b></p> 	<p><b>How do HCP recognize dying</b></p> <p>How do you describe the experience of recognizing dying?</p> <p>How do you describe the experience of recognizing dying?</p>																				
<p><b>What sense do you make of this data when you relate it to your practice</b></p> 	<p><b>Approaches subsequently taken by senior HCP</b></p> <ol style="list-style-type: none"> <li>1. Verify treatment escalation and do not reduce the amount of dying.</li> <li>2. Treatment escalation &amp; patient recognition dying.</li> <li>3. Treat being given up by backtracking to the patient's wishes.</li> <li>4. Treat being given up by backtracking to the patient's wishes.</li> </ol>	<p><b>Justify on-going escalating treatment &amp; no prediction of dying</b></p> 	<p><b>What are the implications of this approach for patients, families, HCPs</b></p> 	<p><b>Justify on-going escalating treatment, &amp; no prediction of dying. Patient recognizes dying</b></p> 	<p><b>What are the implications of this approach for patients, families, HCPs</b></p> 																				
<p><b>Staging of disease – predicting dying and working backwards</b></p> 	<p><b>What are the implications of this approach for patients, families, HCPs</b></p> 	<p><b>Treatment escalation &amp; rapid staging</b></p> 	<p><b>What are the implications of this approach for patients, families, HCPs</b></p> 	<p><b>Any other thoughts</b></p> 	<p><b>Preparation for next workshop</b></p> <ul style="list-style-type: none"> <li>• Reflective sheet.</li> <li>• Coping mechanisms (handout)</li> </ul>																				

**Appendix 8 – Psychosocial questions raised from two key texts. In normal text this relates to Hollway et al (Hollway & Jefferson, 2013), and in italics this relates to Clarke et al (Clarke & Hoggett, 2009).**

### **Questions to ask of data**

1. “By asking about safety & mentioning fear, the research assumes a relationship between the two that is not spelled out” (P8)...look at my questions...do I link any with emotion? Do I link any with anything?
2. Prefer discourse to language (P13)...discourse can include imagery. Look at discourses about dying; are there any counter-narratives. Also why do some discourses resonate with me? Why are discourses not corrected by reality / clinical practice? HCPs can construct their past and their current life within a particular discourse (P15). Look for this.
3. Klein – we spilt objects into good/bad...paranoid/schizoid position. Can be past /present (look for this)...us /them (look for this)...look for movement of accommodation of good/bad...depressive position (P18).
4. Are HCPs able to make distinctions, which do not amplify a problem e.g. escalation of fear (P20).
5. Is there evidence that HCP find anything threatening to contemplate and this avoid it / thinking about it (P20). Look and see where subjects are changed.
6. “There were constant invitations to explain actions & feelings, motivated by our pursuit of contradictions, inconsistencies and the “irrational explanation” (P25). Look at how I question...am I bothered by irrational explanations...or my agenda / blind spots?
7. Look for HCP owning feelings, and the meaning HCPs are making (P27).
8. Look at my fallibilities e.g. a clumsily worded question & unknowable (at time) sensitivities (P28).
9. Feminist approaches (P28). Who might I have silenced?
10. “According to Polanyi, the difference between a story and a report, is that in the telling a story, the narrator takes responsibility for “making the relevance of the telling clear...this approach emphasizes the meanings created in the research pair”...look at pairs of meaning makers in workshops.
11. “Self identity has been seen as being achieved by narratives of the self” (P30). Look at narratives being told.
12. Schutze (1992) revealed, “elicited accounts such as those of Nazi soldiers will be highly defensive ones, given the painful subject matter” (P32). Consider whether fact that HCP couldn’t recall the family could be a defence. Authors argue that it may not be a defended subject but a “gestalt” where the whole is great than the sum of parts, about order / hidden agenda” (P32). My role is to view the intact data not destroy it with my view.
13. The links in my questions indicate my interests not how HCP make links (P32).
14. Did my questions provoke anxiety?



15. Look at where participants go off the question and set their own agenda / discussion (P38).
16. They saw patterns where unpalatable realities were glossed – gave clues of characteristic defences (P40)...explore role of humour and when humour occurred.
17. Impressions count p41. Need to record my impressions.
18. “Researchers do not usually regard it as important to record their feelings & fantasies in field notes” (P42)...“First impressions contain much that eludes our conscious assessment of another person. Moreover these feelings continue in the relationship” (P43). Need to re-visit my first impressions and reflect on these.
19. Did I impose my meanings ...check this.
20. “Concepts of recognition & containment” (P45)...also a becoming through the process (p49). Look at evidence of becoming.
21. “One reason for in-ordinate haste on behalf of participants is to pre-empt alternative suggestions” (P53). When do participants pre-empt each other? When do I do this?
22. Look at inconsistencies in stories.
23. “The answer is to be found in the theory of the defended subject in which the crucial motivation for investment in particular discourses is the need to defend oneself against feelings of anxiety” (P54)...look at discourses.
24. People split good from bad in order to protect present self (P55)...look out for this e.g. “surgeons never do this” debate.
25. Investigate where I felt rapport (P60).
26. Look at where I felt terrified and shut up. Examine what was going on there for HCP / for me
27. Look at use of subtlety and intuition – “we believe that using these capacities is unavoidable once the researcher has posited a psychosocial approach” (P64)
28. Look at what HCP link together with words and consider if there may be emotional links (P67)
29. Look at what people stop doing / any sickness...maybe a clue to their vulnerability (P69).
30. “Clinicians interpret into the encounter, whereas researchers save their interpretations for later” (P 72). Look at where I interpreted into the interviews or workshops.
31. “The less possible it is to be neutral in fact the more crucial it is to strive towards it” p73.
32. Need to demonstrate reliability...shared meanings (P74). Look at what they recognised from my analysis and where they critiqued it.
33. Re researcher’s responsibility re harm – they suggest “responsibility for a safe context, in which issues of honesty, sympathy and respect are central” (P82). Look for where I did this
34. Individuals who had been coded identically, turned out to be different once biographical factors & personal meanings taken into account (P119). Look at study one and two data.
35. What enables me to feel empathetic despite any differences...Is it HCPs ability to preparedness to consider their actions (P122).

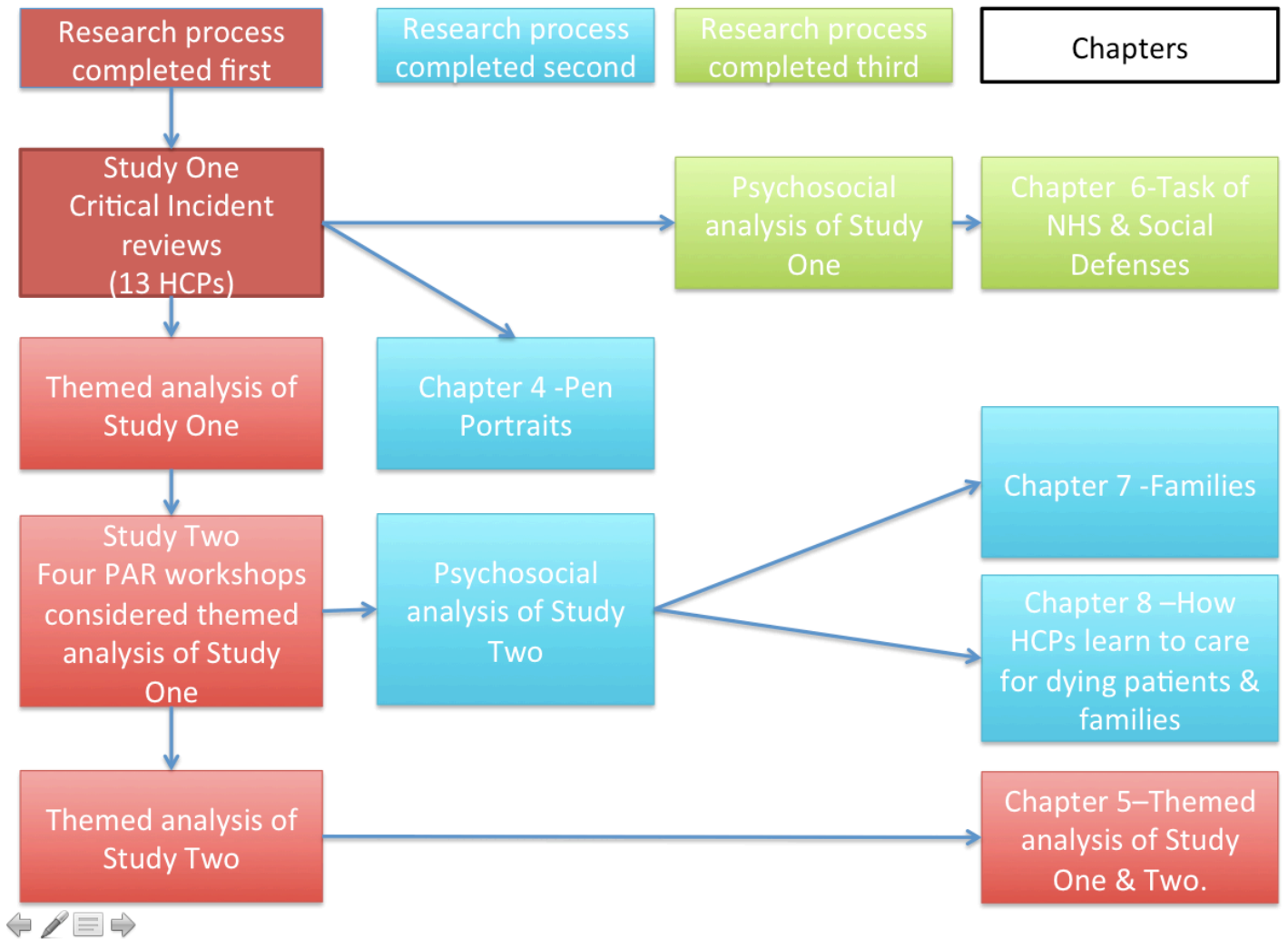
36. "According to Kleinian theory, the fear of personal annihilation is central to the earliest experience and this continues through life whenever anything unfamiliar is encountered" (P127). Think about survivor guilt.
37. Others can contain, and detoxify threats (P128). Look at where this happened and who did this.
38. Are some discourses more available to some than others? Nurses / doctors.
39. The concept of anxiety is employed at individual level (P148), but it also exists at organisational level (Menzies-Lyth) & into groups (Bion). Look for how anxiety is managed within an organisation.
40. A way to engage with my emotional response is what are my hopes and fears for this participant? (P161).
41. They talk of honesty, sympathy and respect (P164). I am not sure about sympathy. I feel very empathetic. They discuss dis-liking participants and how they manage that.
42. Authors argue that people's lives are characterised by provisionality, changeability and unpredictability (P165) and thus should characterise the research processes that attempt to understand them. I can't find a meaning of provisionality but if it means provisional then it means not worked out yet...I would argue that people's lives are characterised by loss. Could look at how many HCPs talk of their own loss. Actually we don't talk about our losses at work...keep it v much to ourselves. Could critique this.
43. *Suggests open-ended questions, eliciting narrative, avoid why, using respondents ordering and phrasing (P10). Need to look at what I did and when I didn't reflect words, content back and why. Allow respondents to freely talk allows expression of unconscious feelings and motivation (P10).*
44. *Look out for identifications including affective attachments to notions of community), nation and belonging (P 10).*
45. *Wengraf and Chamberlayne..."explore the way in which the "unsaid" of the organization may find expression both in the narratives of organizational actors and in the dialogues of the research team" (P11). Look for this.*
46. *"For Bion, containment refers to our capacity to hold onto a feeling without getting rid of it, using the energy of the feeling in order to think about what the feeling communicates" (P12). Look where I do this and where others do this.*
47. *There are forms of knowing that precede discourse (P15). Look at intuition, and gut feeling.*
48. *"Interpretive knowledge is synthetic & integrative, rather than analytic & reductive" (P36)...it's also transformative.*
49. *Relational knowledge ...is inherently communal; it emerges and flourishes in human environments saturated with trust, authenticity and mutuality" (P37). Look at what I did to encourage these aspects.*
50. *"Reflective knowledge up-holds the dignity of human beings as free and autonomous agents who can act effectively and responsibly on their own behalf in context of their inter-dependent relationships" (P37).*
51. *"Human beings are not necessarily rational, especially when involved in exploratory and potentially transformative interactions" (P39). Look for non-rational ways of being*

52. *"One has to ward off...easy answers and the comfort they bring, to bracket the available knowledge for the time being, to remain with uncertainty...long enough to give new knowledge a chance to emerge out of the anxiety of not knowing" (P45). Look at where I did that.*
53. *Julian Manley argues that the attitude of the consultant researcher can be adapted to allow for the emergence of visual imagery as a form of communication from the unconscious which would otherwise not have emerged and been lost (P87). Look at group dynamics and interview dynamics. Look at those who spoke up after silence.*
54. *Look at emotional work I did and emotional relationship.*
55. *Phoebe Beedell mentions "door knob" moments as being significant. Her most defended subject wanted to know about her (P107)...Look what I gave the participants regarding me. Look at where I felt uncomfortable and had to explain more (P108).*
56. *Talks about using intuition / trusting intuition (P111). There is a process of coming to know oneself (P111).*
57. *Talks about our own "empathetic resource"...where we use our own experience to "explore the paths and contours of the reached persons experience, but we can be swept into currents that are dangerous in the pull they exert on the researchers emotions" (P 112).*
58. *Look at my visceral emotions – record them P112). Can demonstrate my emotional labour.*
59. *Am I a courageous undefended researcher or wanting to explore issues for my satisfaction. How do I manage the boundaries (P113).*
60. *Bourdieu sees interviewing as a social relationship affected by distorting factors which the interviewer must try to minimise (P125) e.g. knowing what can and can't be said. I had no idea that consultants in private practice gave their mobile phone numbers to patients. What allowed that to emerge...never knew that happened to look for it in the data.*
61. *Lucey...Reality and experience is co-created...look at discourse...why certain subject positions are taken up and not others (P126)*
62. *When did I feel fear?*
63. *Sue Jervis – "unconscious awareness of another's psyche precedes intellectual understanding"(P149). Look at where I had a gut feeling*
64. *SJ noticed one of her participants had a frequent failure to complete sentences and instead trailed off, and used indicators. She suggests we should be wise to the effect that something important was left being unspoken (P151). Look that the transcripts when participants didn't finish their sentences what I did.*
65. *SJ replaced one of her participants words which with difficult instead of terrible thereby minimising the participants feeling and denying its seriousness. (P152). Look at when I changed participant's words.*
66. *Look how I describe the findings of my research (P154). It may give a clue to the unconscious feelings of the participants and myself.*
67. *SJ felt her participants play down their emotions (P155). Look again at the role of humour and when there was silence*
68. *SJ talks over several pages of identifying with respondents (P156 -P162). I need to explore where this is apparent.*

69. *"In psychoanalysis, analysts can discover much about an analysands as unconscious early relationship by considering how the analysands unconsciously uses the analysis" (P162). Look at how participants used me? What questions did they ask me?*
70. *SJ suggests that by reflecting on my bodily sensations or emotions I might understand a deeper understanding of respondents experiences. (P163)*
71. *She suggests, "although potentially disturbing, if this transient blurring of the boundary between researchers and respondent psyches is sensitively and ethnically explored it may lead to the discovery of elements that will ordinarily remain inaccessible" (P163).*
72. *Lindsey Nichols again talks about the value of being able to check out the researchers hypothesis and describes this as 'a selected fact or an overvalued idea" (P180). The researcher states in their experience" that what was not tolerated by the participant was easily dismissed"(P181). Look at what is my ideas were dismissed.*
73. *LN describes how managerial colleagues without prompting describe the interactive interviews as being therapeutic (P230). Look at the feedback I was given.*
74. *LN describes how closing an interactive interview was a delicate stage and she found herself seeking to express in a few words that she would hold the process, which had been initiated until the next time when she met with the co-researcher. Look at how I closed interviews and workshops.*
75. *LN describes that there was "a sense of something being mindfully held in suspense" (P232). Look for this.*
76. *Leslie Boydell analyses discourse psychosocially. She describes Holloway and Jefferson's argument that "conflict suffering and threats to self operate on the site in ways that affect peoples positioning and investment in certain discourses rather than others" (ibid p19) (P243). I need to look at what stories participants are telling.*
77. *Look at metaphors used by participants (P244).*
78. *LB realises that language use s highly variable and cannot be taken as a realistic or unambiguous account of the phenomenon described and she says, "each partner is using language to perform some function in relation to the partnership or themselves" (P249). Look at transcriptions in light of this perspective*
79. *LB describes interpretive repertoires as a "register of terms and metaphors drawn upon to characterise and evaluate actions and events and she says these are all culturally familiar comprised of recognisable scenes places and tropes" (P250). She says, "conversation is placed with in a historical context and whilst it doesn't rule out something original usually built on common-sense" (P250). Look for discernible clusters of terms, descriptions, figures of speech assembled around metaphors orphanage vivid images (P250-251)*
80. *LB suggests we look at how people positioned themselves in relation to others (P251). Look at how people speak of themselves with in the episodes described*
81. *LB describes how 'on the ground" it was a term commonly used. Look at how practice is described*
82. *LB describes optimism as a defence (P 260). I need to consider is optimism or Hope a defence? Are my models a defence?*

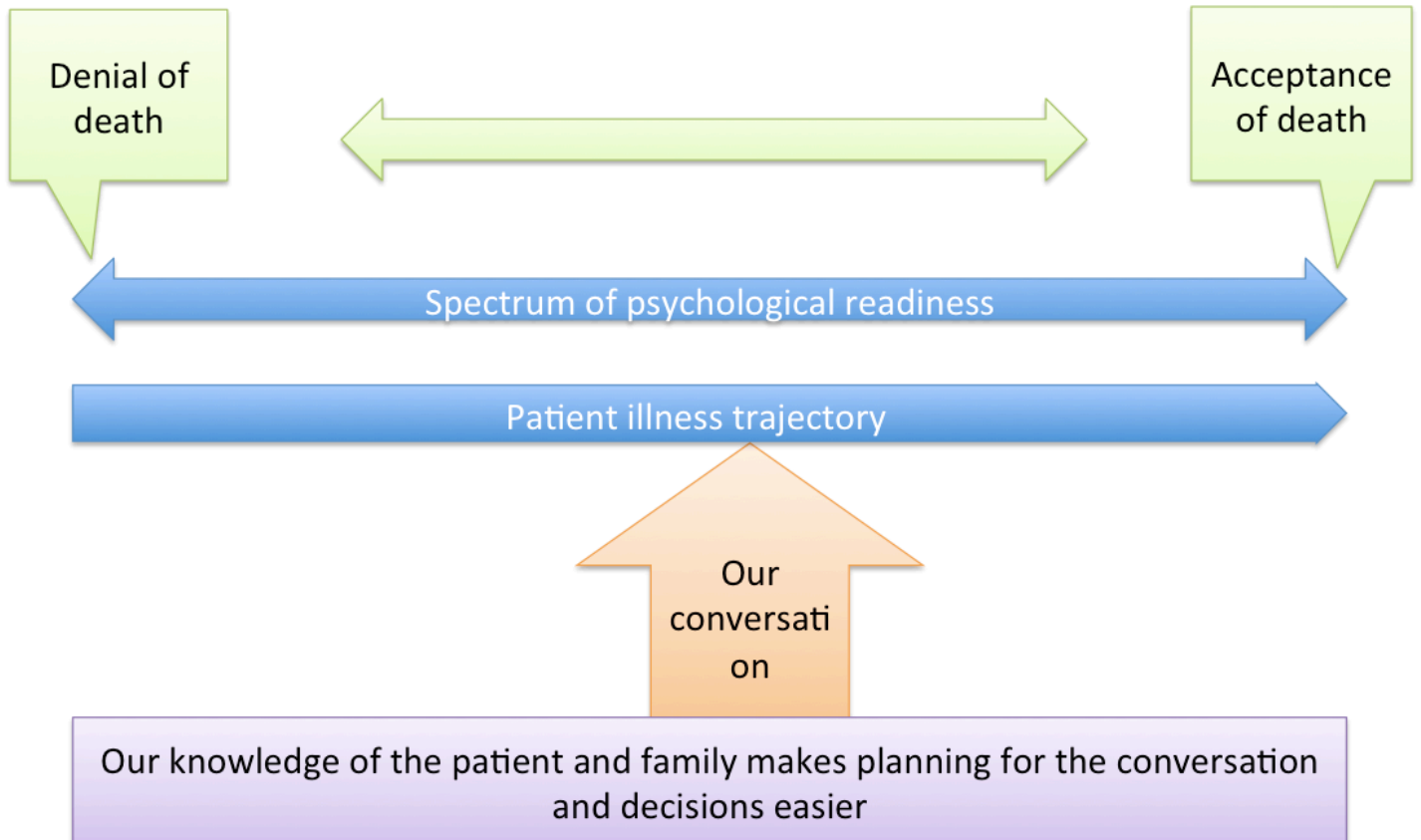
I then split these into questions to ask of me, them and us and placed in an excel spread sheet (see Chapter 3).

## Appendix 9 – Process and visual orientation to study and write up



Appendix 10 – Model generated - psychological readiness to talk about dying

# Model



## Appendix 11 – Abstract of clinical work going to conference subsequent to PhD study insights.

### UK Kidney Week 2017

#### *Conservative/End of Life Care*

17UKKW-201

#### **PRIORITIES MDT: A SINGLE CENTRE EXPERIENCE OF COMPLEX DECISION-MAKING IN RENAL PATIENTS APPROACHING END OF LIFE**

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<sup>1</sup>Renal, <sup>2</sup>Palliative Care, ROYAL FREE HOSPITAL, London, United Kingdom

**Preferred Presentation Method:** Oral or Poster

**Do you wish to apply for a bursary if available?:** Yes

**Introduction:** 5-year survival for elderly patients on RRT remains poor and they face a significant symptom burden<sup>1</sup>. The interwoven challenges of recognising frailty, poor prognostic outcome and advance care planning are often brought to light following repeat or lengthy admissions.

**Objectives:** Working in a tertiary centre we have considered ways to address these concerns in our patient population. We were keen to reduce burdensome yet futile investigations, prevent medicalisation of death, and to identify any inequalities in care.

**Methods:** A weekly 'Priorities' meeting was formed between palliative care and renal teams to discuss patients who meet one of the following criteria: 1) Recurrent admissions; 2) Lack of mental capacity for decision-making; 3) Long in-patient stay; 4) multiple co-morbidities; and 5) imminent end of life. Participants in the Priorities MDT include, the renal consultant, palliative care specialist, ward sister, occupational therapist and dietician. GPs and community care teams are virtually consulted. Discussion topics include consideration of mental capacity and best interest decisions, ascertaining patients' preference for care, ceilings of care and end-of-life care. The MDT is underpinned by administrative support and a clinical database that allows service evaluation.

**Results:** During the first 6 months of the meeting 54 patients were discussed a total of 78 times. 65% patients were deemed to have palliative care needs with 24% patients going on to die during that admission. We found baseline frailty scoring, developed from the Rockwood clinical frailty scale, to be a useful tool in separating intercurrent illness from background function<sup>2</sup>. 22 patients came from the poorest 10% of postcodes, while only 2 came from the richest. During the conference we will present two in-depth case studies illustrating the role the MDT meeting has played.

**Conclusion:** Based on preliminary data, establishing a Priorities MDT is an effective way to prompt professionals to establish the preferred priorities of care for renal patients and their families. The meeting has proved invaluable in complex decision making. At present data is insufficient to conclude whether the meeting reduced rates of readmission. Future work will include considering how to more formally involve patients in the project.

This study would be relevant to any clinicians working with a frail population, both in hospital and in the community, such as is seen in (but not limited to) the UK.

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**Disclosure of Interest:** None Declared

**Keywords:** End of life care, Older people, Symptoms





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