

The experience of emotional distress and  
help-seeking for distress in families living  
with advanced cancer and receiving  
palliative care: a multi-perspective case  
study approach

Submitted for Fulfilment of the Degree of PhD by Publication

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## **Declaration**

I hereby declare that this thesis embodies the results of my own research and that I am the full author of this thesis, except where otherwise stated.

Signature: \_\_\_\_\_

## **Acknowledgements**

First and foremost, I would like to thank my supervisors Liz Forbat and Annetta Smith for their invaluable support and guidance throughout my PhD.

Thank you to the families who gave so generously of their time to share their experiences with me and to all the staff who supported this project.

Thank you to my parents who always instilled in me the value of learning and working hard, and along with my sister and brothers the joy of growing up in a happy and loving family.

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## Abstract

The emotional impact of serious illness in families is recognised. To enhance well-being in families living we must understand how distress is experienced within families; from this, evidenced-based systemic distress interventions can be derived. However, the success of systemic intervention programmes is reliant on whether families will seek help (or not) for distress. This PhD by publication explores emotional distress and help-seeking in families living with advanced cancer.

Papers one and two used systematic review techniques. Paper one evidenced distress as a systemic construct and proposes the *tiered model of distress* to convey current understandings. Paper two offers the *attaining normality model* to convey why some people seek help for distress to achieve a new normality whereas some choose not to seek help to maintain normality. Together, these papers evidence gaps in systemic understandings of distress and help-seeking; from this an exploratory cross-sectional multiple case study of families was proposed.

Papers three and four provided methodological underpinning to this research through the development of the *DESCARTE model: The Design of Case Study Research in Healthcare* (paper three) used in the case study design; paper four reflects on multi-perspective interviewing methods used.

Distress and help-seeking are conceived as systemic relational phenomena, occurring within the family system and arising from relational interaction with healthcare. Distress is conveyed through four themes: interdependent distress, living in uncertainty, unnecessary distress and oscillatory distress; from this, possible systemic intervention designs are offered (paper five). Non-help-seeking for distress was the predominant response in families. The *mutuality model of help-seeking* is proposed to synthesise current understandings (paper six). Families describe how healthcare interactions cause unnecessary distress and shapes families' help-seeking behaviours. Findings indicate significant gaps between the rhetoric of palliative care policy and families' experience. To improve families' wellbeing, relational care must be embedded in policy and practice.

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## Preface

The care of patients and families living with advanced illness has been at the core of my clinical practice as a doctor for over 25 years. First, as a junior doctor in respiratory medicine, haematology and oncology; second, as a clinical assistant in a hospice; and finally, in my role as a General Practitioner.

The origin of this thesis began at an intersect of two events around 10 years ago. I completed a MSc in Advanced Practice in Palliative Care at Edinburgh Napier University between 2008-2011 which sparked my academic interest in emotional distress in cancer and palliative care. Around the same time in 2009, my sister-in-law was diagnosed with metastatic breast cancer and died two years later. This synthesis of academic knowledge and personal experience identified what I perceived to be significant gaps in our current understanding of emotional distress in families, and with this my PhD journey began.

In this thesis I will explore the experience of emotional distress in families living with advanced cancer and their help-seeking for distress. In doing so this research adheres to a systematic and rigorous process of academic inquiry to derive such knowledge. However, I am mindful that at heart I am, and remain, a practising clinician. I readily acknowledge that my drive to undertake this PhD research is fuelled by my desire to produce '*phronesis*' or practical wisdom to inform care.

Flyvberg (2001) argues that research within the social sciences should aspire to the production of phronesis rather than universal truths; this strengthened my belief that production of phronesis is core to this thesis. My hope is that dissemination of the findings can achieve this aim and in doing so can enhance the future care of patients and families living with advanced illness.

# Chapter 1

## 1. Setting the scene

In this thesis I present an investigation of the experience of emotional distress in families living with advanced cancer who are receiving palliative care and examine their help-seeking for distress. The thesis presents a series of four interrelated phases of investigation and is presented in publication format. In this introductory chapter I introduce some key terms and theoretical concepts and locate this area of study. Next, I present a problem statement and outline the aims and objectives of this thesis. Finally, I describe the structure of the thesis.

### 1.1 Emotional Distress

Distress was defined in National Comprehensive Cancer Network's (NCCN) first set of guidelines on psychosocial care in cancer in 1999 (Holland 1999). Following this Bultz and Holland (2006) conceived detection of distress as the sixth vital sign in cancer. Distress is defined as

*'A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and /or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatments. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis' (NCCN 2010, p. DIS2).*

The term distress was thought to be less stigmatising and more acceptable to patients than conventional psychiatric diagnoses (Bultz and Holland 2006) yet its adoption has provoked debate. White (2018) argues that its wide definitional range of emotional responses to cancer guards *'against the tendency to consider everything through a biomedical lens'* (p.159). On the other hand, the appeal of its inclusiveness means distress remains poorly operationalised placing limits on its usefulness (Mitchell 2013).

Within the scope of this thesis the term distress was chosen to enable families in this research to self-identify as distressed as opposed to a healthcare professional assessed criterion based diagnostic label such as depression. In the literature the term psychological distress and emotional distress are often used interchangeably. It is important to highlight a shift in the use of the term distress in this thesis. In paper one psychological distress is used, thereafter emotional distress. This was purposeful and reflected Patient and Public Involvement (PPI) in

study design; two user groups emphatically rejected the term ‘psychological distress’ and endorsed ‘emotional distress’ instead.

## **1.2 Palliative care**

The World Health Organisation (WHO) currently defines palliative care as:

*‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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.’ (WHO n.p)*

Thus, palliative care can apply to earlier stages of illness and not solely the end of life. Additionally, palliative care can be stratified according to perceived level of need and professional skill level (Gamondi et al. 2013; Milligan 2018). Generalist palliative care is delivered by professionals with good basic competencies, but palliative care is not their main area of expertise e.g. healthcare professionals such as GPs and community nurses in primary care settings. Specialist palliative care is care provided to patients with complex need by professionals who have extensive palliative care expertise e.g. clinicians in hospice settings. Thus, palliative care aims to provide holistic and inclusive care to families living with advanced illness in variable contexts of care.

## **1.3 The family and systems theories**

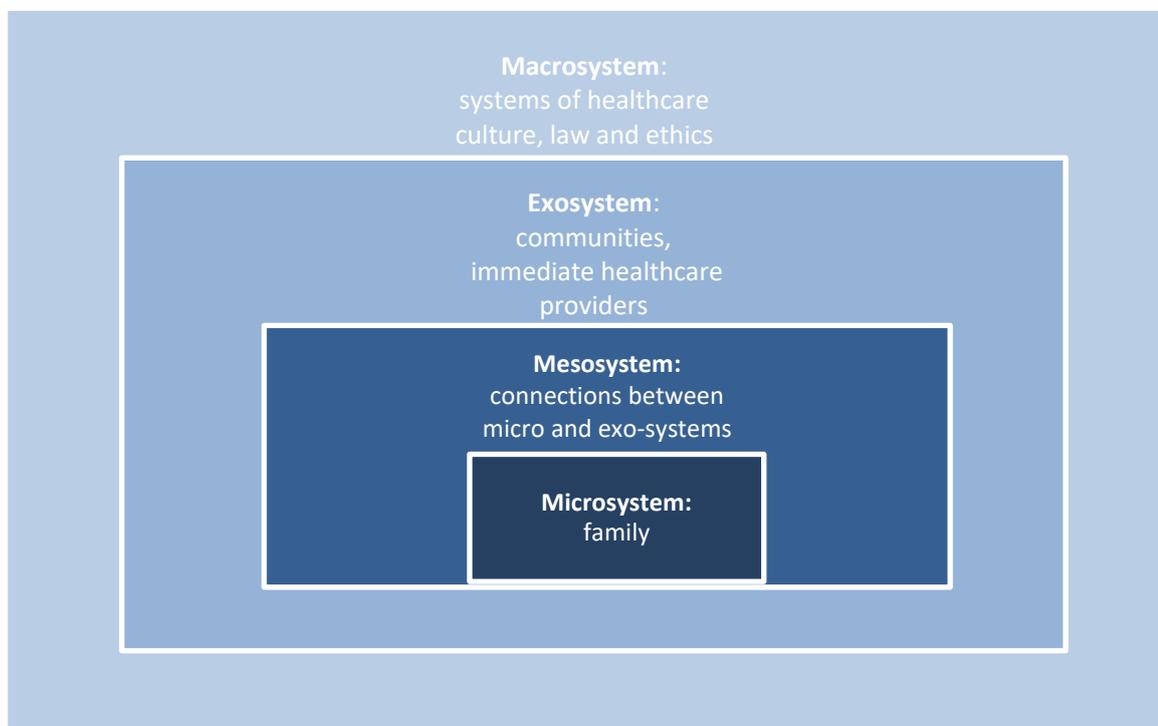
### **1.3.1 The family**

Historically, the family was situated as a bounded system of close kinship as a nuclear conjugal family (Parson and Bales 1955; Parson 1959). Later definitions of family supported the primacy of individuals to self-define themselves and included Whall’s (1986) definition as those who *‘may or may not be related by blood lines or by law but who function in a way that considers themselves to be family’* (p.241) or Bozett’s (1987) concise view of *‘who the patient says it is’* (p.4). Similarly, this thesis supports the primacy of individuals to self-identify their family in a meaningful way rather than imposing a pre-determined definition of family. Whall’s (1986) definition emphasises the family as a functional unit, thus family is more than a collection of individuals but an interactional system (Goldenberg and Goldenberg 2013). Before moving to discuss family systems theories it is useful to contextualise the family system within systems theories more generally.

### 1.3.2 Ecological systems theories

von Bertalanffy (1950) and Parsons (1951) were early proponents of systems theories and considered the interrelatedness and interactions between units within systems and considers how each unit affects the whole, and how the whole affects the part (Braden, 1984). Biological systems are not bounded systems but open responsive systems interacting with the wider environment to maintain equilibrium (von Bertalanffy 1950). Barker (1968) a founding proponent of ecological psychology posits that behaviour is environmentally situated and context dependent. Bronfenbrenner (1979) draws on ecological psychology and systems theory in his ecological systems theory comprising of interacting microsystem, mesosystem, exosystem and macrosystems. How systems levels are applied within ecological systems theories is influenced by the unit of study. A microsystem may be conceived at the level of the individual or at the level of the family. In this thesis the family system is conceived at the level of the microsystem (Figure 1).

**Figure 1: Ecological systems framework in this thesis**



Adapted from Thomas 2011, p.58.

### 1.3.3 Family systems theories

Bateson (1972; 1979) applied systems theories to families arguing that behaviours within families cannot be described in simple linear terms but must acknowledge the interrelatedness of responses and actions within families. There is a plethora of differing family systems theories with an extensive array of differing theoretical standpoints (Goldenberg et al. 2013). A detailed discussion of family systems theories is beyond the scope of this thesis. However, the main tenets of family systems theories can be summarised as:

- **Subsystems, supra-systems and boundaries:** meaning that two or more interrelating family members can form a subsystem e.g. spousal subsystem, parent-child subsystem. Each family member can be part of more than one subsystem and subsystems can be nested within the family system which can be nested within larger supra-systems (e.g. healthcare systems) with permeable boundaries existing between systems (Auger 1976; Boss et al. 1993; Friedman 1998; Whitchurch and Constantine 1993; Wright and Leahey 2005).
- **Holism:** meaning that the whole family is greater than the sum of its individual parts and that families cannot be understood by viewing a single constituent part (Friedman 1998; Whitchurch et al. 1993; Wright et al. 2005).
- **As a site of interaction:** meaning that change in one family member affects another (Bateson 1972; Bateson 1979; Friedman 1998; Wright et al. 2005).
- **Homeostasis:** meaning that families react to change to try to achieve a state of equilibrium (Friedman 1998; Whitchurch et al. 1993; Wright et al. 2005).

Rolland's Family Systems Illness Model shows that impact of serious illness in families. This impact is understood through the interrelationship of the illness, the individual and the family life-cycle (Rolland 1987; Rolland 1994; Rolland 2005). Rolland highlights the importance of temporal understandings: first, the time phases of the current illness experience (described as crisis, chronic and terminal) and second the influence of past family experience (including multigenerational legacies and beliefs).

## **1.4 The family in palliative care**

How the family is conceived in the context of palliative care has been debated for several years. Parkes (2007) argues that the family should be the unit of care while others counter that patient is unit of care (Randall and Downie 2006). In contrast Hudson and Payne (2008) consider that healthcare professionals have a duty of care towards family members but acknowledge the primacy of patients in decision making. Distinguishing between the patient and family as the recipient of care is challenging in general palliative care settings such as primary care. In such contexts primary care professionals can frequently be the provider of healthcare concurrently to several family members. Moreover, this is further problematised by whether family members are construed as both co-workers (jointly providing care to the patient with healthcare professionals) or as co-recipients of care (receiving care alongside patients) (Payne 2010). Currently, the WHO definition of palliative care positions family as co-recipients of care.

## **1.5 What is the problem?**

Serious life-threatening illness such as cancer impacts on the family system (Carlander et al. 2011; Forbat et al. 2009 Rolland 2005). Palliative care patients (Gao et al. 2010; Goetze et al. 2014; Mitchell et al. 2011) and their family members (Gotze et al. 2014; Kissane et al. 1994; Trevino et al. 2016) experience significant emotional distress. Emotional distress has significant adverse impacts for patients including increased symptom burden (Delgado-Guay et al. 2009; Gotze et al. 2014; Teunissen et al. 2007), poorer quality of life (Gotze et al. 2014) and desire for hastened death (Breitbart et al. 2000). Emotional distress in family members is associated with a poorer quality of life (Gotze et al. 2014; Gotze et al. 2016), greater perceived caregiving burden (Govina et al. 2015; Northouse et al. 2012) and higher mortality (Schultz and Beach 1999).

These significant impacts on patients and their family members indicate the need to develop family-focussed interventions to enhance families' emotional well-being (Kissane 2016). However, there is currently limited understanding of how emotional distress is experienced within the family system (McLean and Jones 2007; Zhang and Siminoff 2009; Zaider and Kissane 2009); such understanding is necessary to theorise the development of systemic distress interventions. However, whether systemic distress interventions can enhance the emotional-wellbeing of families is also dependent on whether families choose to seek help (or not) for their distress. To develop systemic distress interventions, it is necessary to understand both the experience of distress in families and why they decide to seek help or not. Developing such

understanding will facilitate the development of evidenced based and acceptable psychosocial interventions to improve families' emotional well-being and quality of life.

## **1.6 Aims and objectives of the thesis**

The aim of this thesis is to explore the experience of emotional distress and help-seeking for distress in families living with advanced cancer who are receiving palliative care. This thesis began with three research objectives

- To ascertain how emotional distress in families is conceptualised in the palliative care literature
- To describe and understand the experience of emotional distress in families living with advanced cancer
- To understand why families living with advanced cancer seek help (or not) for their emotional distress and what influences these actions

Case study was chosen as the research approach by which to investigate experience in families. However, my initial readings of case study literature left me uncertain as to how to effectively use case study, particularly how to collect and analyse multi-perspective interview data. Ethically I had significant concerns about proceeding with this research approach until I was fully cognisant of the methodology and methods that I had proposed. Consequently, two subsidiary methodological objectives emerged during the conduct of this PhD research

- To critically review case study as a research approach
- To critically examine the methodological challenges of using multi-perspective interviewing in the context of family research

## 1.7 Overview of the thesis

### 1.7.1 The publications and their interrelationship

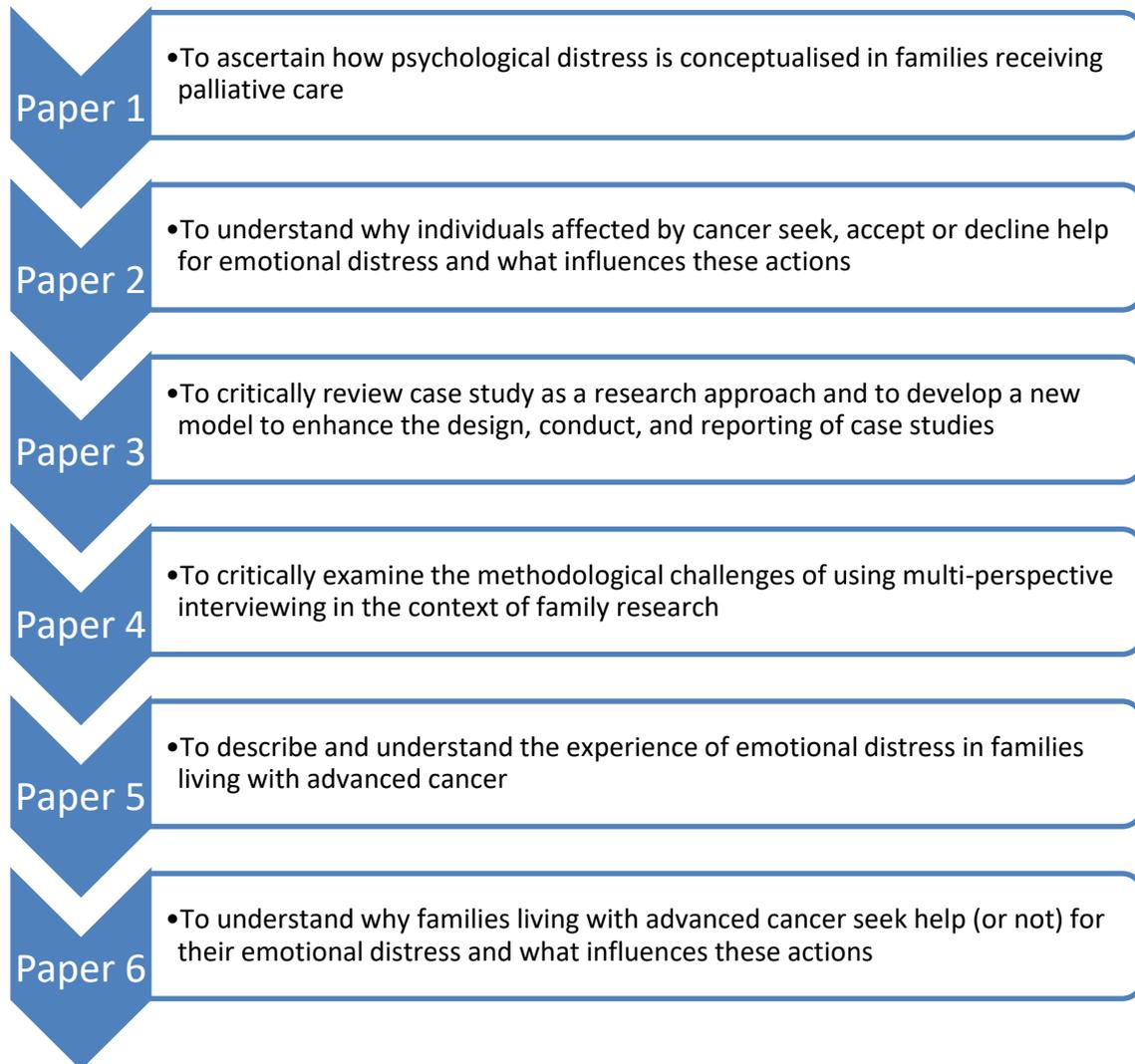
The thesis presents a series of four interrelated phases of investigation presented in publication format in the form of four published papers and two submitted papers (Table 1) accompanied by a linking narrative.

**Table 1: Summary of included papers**

Phases of investigation		Paper	Reference
1	<b>A systematic review and narrative synthesis of psychological distress in families in palliative care</b>	Paper One	Carolan, C.M., Smith, A. and Forbat, L. (2015) Conceptualising psychological distress in families in palliative care: findings from a systematic review. <i>Palliative Medicine</i> , 29(7), pp. 605-632.
2	<b>A systematic review and qualitative synthesis of help-seeking for emotional distress in individuals affected by cancer</b>	Paper Two	Carolan, C.M., Smith, A., Davies, G.R. and Forbat, L. (2018) Seeking, Accepting and Declining Help for Emotional Distress in Cancer: Findings from a Systematic Review and Thematic Synthesis of Qualitative Evidence. <i>European Journal of Cancer Care</i> , 27(2): e12720.
3	<b>A rapid review and critical analysis of case study</b>	Paper Three	Carolan, C.M., Forbat, L. and Smith, A. (2016 (a)) Developing the DESCARTE Model: The Design of Case Study Research in Healthcare. <i>Qualitative Health Research</i> , 26(5), pp. 626-639.
4	<b>A case study of twelve families living with advanced cancer and receiving palliative care</b>	Paper Four	Carolan C.M. (2017) <i>Researching Emotional Distress and Help-Seeking for Distress in Families in Palliative Care Using Multi-Perspective Interviewing</i> . In SAGE Research Methods Cases, SAGE Publications Ltd.
		Paper Five	Carolan, C.M., Smith, A. and Forbat, L. The experience of emotional distress in families living with advanced cancer: a multi-perspective case study approach. (Submission to <i>Psycho-Oncology</i> )
		Paper Six	Carolan, C.M., Forbat, L. and Smith, A. Help-seeking for emotional distress in families living with advanced cancer: a multi-perspective case study approach. (Submission to <i>BMC Palliative Care</i> )

The interrelationship of the papers and linkage to the aims and objectives of the thesis is demonstrated in Figure 2.

**Figure 2: The interrelationship of the papers**



### 1.7.2 Structure of the thesis

In chapter 2 I report the findings of a systematic review and narrative synthesis (paper one). The study evidences the conceptualisation of distress as a systemic construct in families and proposes the Tiered Model of Distress to depict how distress is conceived in families in the palliative care research literature.

In chapter 3 I report the findings of a systematic review and qualitative synthesis examining help-seeking behaviours for emotional distress (paper two). The Attaining Normality Model is

proposed to illustrate current understandings of help-seeking for emotional distress in people affected by cancer. Taken together papers one and two evidence a gap in our understanding of emotional distress and help-seeking in families. I justify the use of case study as a research approach by which to investigate the experience of emotional distress and help-seeking for distress in families living with advanced cancer. I conclude the chapter by identifying concerns about how I will use case study to conduct my research. From this I determine the need to critically review the case study literature.

In chapter 4 I report the findings of a rapid review and critical exploration of the case study and mixed-methods literature and describe the development of the DESCARTE model: The **Design of Case Study Research in Healthcare** (paper three). I conclude the chapter by outlining the proposed case study design and detail how the case study will use a novel method of multi-perspective interviewing.

In chapter 5 I describe how I used individual participant and family group interviewing methods and critically reflect on the methodological and practical challenges of using this approach (paper four). I also detail how patient and public involvement (PPI) informed the design and conduct of this research.

In chapter 6 I present paper five which reports the findings of the case study exploring the experience of emotional distress in families living with advanced cancer. Four themes emerged from data analysis to describe and understand the experience of distress: interdependent distress, living in uncertainty, unnecessary distress and oscillatory distress. Findings cement conceptualisation of distress as a systemic relational phenomenon which is experienced within the family system and as a product of relational interaction between the family microsystem and the healthcare exosystem.

In chapter 7 I present paper six which reports the findings of the case study exploring why families seek help (or not) for their emotional distress and what influences these actions. Five interrelated themes emerged from data analysis describing influences on families' help-seeking: establishing who warrants help; emotional distress as warranting help; identity informing help-seeking; perceived value of help; and contextual influences. Non-help-seeking for emotional distress emerged as the dominant response in families; no families described collective help-seeking for their distress. The Mutuality Model of Help-seeking for Emotional Distress is proposed as a nascent model to help understand help-seeking in families.

In Chapter 8 I use the DESCARTE model as a framework to critically reflect on the methodology and methods used in the case studies reported in papers five and six. Building on the descriptions of the methodological challenges of using multi-perspective interviewing detailed in chapter five, I provide a transparent account of the significant challenges involved in analysing data gathered. I reflect on the ethical implications of conducting sensitive research and my positioning of self during the research process.

In chapter 9, the concluding chapter I demonstrate how these six publication and accompanying narratives address the aims and objectives of this PhD study. I describe the collective contribution of this thesis and consider its implications for clinical practice, policy, research, education and personal professional development.

### **1.7.3 Structure of chapters which contain publications**

Chapters 2-5 are structured as follows: each chapter will present a publication which will be discussed under the following headings: (i) a rationale for the publication; (ii) a critical review of the contribution of the publication to the field; (iii) a critical reflection of the research methodologies and methods used; (iv) a statement of my contribution to the publication; (v) a description of choice of journal and journal standing; (vi) a description of progression of the thesis (vii) a summary of each chapter. Chapters 6 and 7 reporting papers five and six adhere to a similar structure. However, as these papers derive from the same research study a critical reflection of the research methodologies and methods does not appear within each individual chapter but is presented in Chapter 8 to prevent unnecessary duplication.

## **1.8 Chapter summary**

In this chapter I have introduced key terms used within this thesis, presented a statement of the problem and outlined the aims and objectives of this thesis. I have detailed the structure of the thesis and provided a summary of the six publications and described their inter-relationships. In subsequent chapters I will sequentially present and critically discuss each publication. In the final chapter I will indicate how the six publications make a significant and original contribution to the field of knowledge.

## Chapter 2

### **2. Paper One: Carolan C.M., Smith, A. and Forbat, L. (2015) Conceptualising psychological distress in families in palliative care: findings from a systematic review. *Palliative Medicine*, 29(7), pp.605-632.**

#### **2.1 Rationale for paper one**

To develop interventions to ameliorate distress in families we must first understand how distress is conceptualised and experienced within the family system. The Medical Research Council guidance (Medical Research Council 2008) and the MORE care statement (Higginson et al. 2013) provide clear guidance on the design of complex interventions. The first step of intervention design involves identifying and theorising the evidence base and constitutes the developmental phase of research (Evans et al. 2013). Systematic reviews are a useful starting point to identify and theorise the evidence base (Evans et al. 2013). Additionally, they can usefully highlight unknown knowledge gaps at the start of a program of research (Medical Research Council 2008; Moller 2008; Scoglio 2014). Therefore, a systematic review was conducted to ascertain how distress is conceptualised in families receiving palliative care.

#### **2.2 Paper one**

This paper was submitted to *Palliative Medicine* in June 2014 and was accepted for publication in February 2015. It was published on-line in March 2015 and published in print in July 2015.

Paper redacted due to publisher restrictions

## **2.3 Critical review of the contribution of paper one to the field**

### **2.3.1 Contribution of paper one to the field**

Paper one is novel because it is the first systematic review to explore how emotional distress in families receiving palliative care is conceptualised in the literature. The paper provides several unique insights which contribute to our understanding of emotional distress in families in palliative care which are now presented.

#### **2.3.1.1 Conceptualisation and measurement of distress**

Paper one evidences that emotional distress is conceptualised as a multi-dimensional construct and aligns with long established understanding of the concept of total pain in palliative care (Clark 1999). Significantly the review evidences the multi-dimensional nature of distress as nebulous concept and supports Ridner's (2004) concept analysis of psychological distress which reports that the concept of psychological distress has not been clearly articulated in the literature and is ill-defined (p. 536). Paper one adds to earlier palliative care literature identifying a lack of clarity in distress assessment. Wasteson et al.'s (2009) systematic review of the assessment of depression in palliative care patients revealed the use of 106 differing assessment methods from 202 included studies in their review, with 65 of these measures being used only once. Likewise, Williams and McCorkle's (2011) systematic review of cancer caregivers in palliative care reported the use of 89 measures across 19 studies. Thekkumpurath et al.'s (2008) systematic review of distress screening tools in palliative care determined that most studies focus on depression rather than distress and to date few studies have examined the validity of screening questionnaires against diagnostic tools such as psychiatric interview. Like Wasteson et al.'s (2009) review, paper one evidences a pronounced diversity of tools used to assess distress and haphazard application of their use. Paper one is therefore of value because it further evidences the pressing needs for collaborative deliberation to determine consensus on measurement of psychological morbidity in palliative care (Rayner et al. 2009; Wasteson et al. 2009).

#### **2.3.1.2 Systemic conceptualisation of distress**

Paper one makes an important contribution to the field because it authenticates distress as a systemic construct and provides a concrete body of evidence to support this assertion. The systematic review demonstrates that distress is influenced by variables within the family system which could potentially be amenable to manipulation through intervention development

including: dyadic coping and adjustment, family support and hardiness, relational functioning, and communication practices. Thus, paper one provides an accessible and credible source of evidence to inform future complex intervention development (Evans et al. 2013; Medical Research Council 2008).

Yet, the review indicates that the body of work supporting distress as a systemic construct is embryonic and contrasts sharply with the plethora of literature which overwhelmingly continues to frame distress as an individualistic construct. Moreover, paper one brings into sharp focus the dearth of papers which investigate distress beyond the spousal dyad and draws attention to the limited theorisation of distress as a systemic construct. The paucity of qualitative papers contained in this review means that emergent current constructions of distress in families are derived from professionals' perspective rather than reflective of families' experience. Unequivocally, paper one signals the clear and present need for research to address this significant gap in the evidence and provides a rationale for the case study of distress in families presented in this thesis.

### **2.3.1.3 Proposing a tiered model of distress**

Paper one makes a useful contribution to current clinical and research practice by proposing a tiered model of distress in palliative care. Application of this model may encourage clinicians to consider distress beyond individual constructions to appreciate the relational context in which distress can occur and the reciprocity of distress. This may provide clinicians with additional means to frame clinical therapeutic interventions in families to ameliorate distress (McLeod et al. 2010; Zaidler et al. 2009). For researchers, the model provides utility by providing a simple yet transparent framework for them to clearly articulate how they are conceptualising distress in their research. Crucially, application of the tiered model of distress enables conceptual differentiation of interventions which are framed systemically from those that are not. Thus, application of the tiered model of distress might help researchers developing interventions to conceptualise the proposed mechanism of action of their intervention and will be especially salient for studies adopting realistic approaches (Pawson and Tilley 1997).

### **2.3.2 Reception of paper one**

Paper one has been cited 18 times in Google Scholar in a variety of peer-reviewed publications, student theses and two books (18<sup>th</sup> July 2018). It has also been referenced in the new edition of Mari Lloyd-William's (2018) book *'Psychosocial Issues in Palliative Care: A community based approach for life limiting illness'*.

## **2.4 Critical reflection of the methodology and methods used in paper one**

### **2.4.1 Why a systematic review?**

Systematic reviews have held a privileged position in the hierarchy of evidenced based research (Greenhalgh et al. 2018; Moher et al. 2009). However, some have questioned whether explicit emphasis on auditability, reproducibility and slavish adherence to the mechanics of process have led to the production of reviews while technically excellent, present restrictive narrow aggregates of results of limited value to the body of knowledge (Greenhalgh et al. 2018; Ioannidis, 2016). Instead, narrative reviews are proffered as an alternative means to review and interpret the literature by using purposeful academic judgement to determine relevance of inclusion of literature for review (Greenhalgh et al. 2018; MacLure 2005). However, several criticisms are levied at narrative reviews and include: risk of researcher bias; intentionally selecting literature to support a certain line of argument; purposively omitting counter-viewpoints or inadvertently omitting salient evidence because of researchers limited grasp of the literature (Grant and Booth, 2009; Greenhalgh et al. 2018). The latter consideration is a risk for novice researchers who might have a limited knowledge of the field of inquiry (Greenhalgh et al. 2018). Given that this review was undertaken by a neophyte researcher it was considered that undertaking a systematic review rather than a narrative review was preferred to minimise the risk inadvertently omitting literature and introducing bias.

### **2.4.2 Conduct of the review**

In addition to limitations of the current evidence and review limitations already described in paper one (p. 626) it is important to consider the potential risk of bias relating to choices made during the conduct of the review. Four choices made relating to the conduct of the review are now deliberated: data sources; searching of grey literature; secondary searching of reference lists; and the use of a single screener.

#### **2.4.2.1 Data sources**

The four databases were chosen because of their ability to capture work across a variety of disciplinary perspectives reflecting multi-disciplinary working within palliative care. Medline and CINAHL capture evidence from medical and nursing peer-reviewed literature whilst Psych INFO and Behavioural Sciences data bases capture evidence from behavioural and mental health disciplines. Moreover, the NHS Knowledge Network enables these four data bases to be

searched simultaneous with removal of duplicates. This meant that the search was easily executed and incurred a positive time benefit and that the risk of manual errors during data management of multiple databases was minimised.

#### **2.4.2.2 Grey literature**

Searching of grey literature was not performed. Searching grey literature is advocated on the basis that studies with negative findings are less likely to be published in peer review journals and thus minimises the risk of publication bias (Hopewell et al. 2007). However, no definitive guidance exists for systematically searching for grey literature. The process is readily acknowledged as difficult with challenges relating to: selection of data repositories; ensuring completeness of search and issues around determination of data saturation; replicability of search; completeness of data and data extraction; time constraints; differentiation of evidence synthesis from primary studies; and confirming ethical compliance of studies (Adams et al. 2016). Moreover, Hartling et al.'s (2017) recent study questions the efficacy of searching grey literature for inclusion. Their recent cross-sectional examination of 129 reviews concluded that while most systematic reviews searched for unpublished studies only 6% of reviews included unpublished studies. Importantly, no significant change in the findings of the reviews occurred following removal of grey literature. The authors conclude that researchers should be reassured that if they chose to limit their searches in the interest of efficiency that this is unlikely to have impacted of the findings of their review. Admittedly, Hartling et al.'s (2017) study focussed on meta-analysis rather than heterogeneous data included in paper one. Despite this, given the time and resource limitations of the conduct of this systematic review within a PhD study the choice not to include grey literature while pragmatic was unlikely to have impacted on the review's findings.

#### **2.4.2.3 Secondary searching of reference lists**

Secondary searching of reference lists was not undertaken. Primarily this was not adopted because the review sought to understand how distress was conceptualised in the literature with papers identified using the search term distress. Inclusion of papers through secondary searching would have shifted the lens of examination potentially compromising the primary aim of the study and thus limiting the value of the synthesis. Additionally, I consider there is a fundamental disconnect in the use of secondary searching within a systematic review for reasons which I will now explain.

Horsely et al.'s (2011) Cochrane review investigated the effectiveness of secondary searching of reference lists for the identification of additional relevant studies for inclusion in systematic reviews. The review team defined effectiveness as *the proportion of relevant studies identified by review authors solely by checking reference lists* (p.1). Horsely et al.'s review revealed significant disparities in the effectiveness of secondary searching of reference lists and reported varying yields of additional included studies ranging between 2.5% to 42.7%. From studies included in Horsely et al.'s review Greenhalgh and Peacock's (2005) systematic review documented the highest yield of additional included studies. Greenhalgh et al. used a snowballing technique during secondary searching meaning that they obtained additional references from newly included studies in a spiralling iterative manner. Greenhalgh et al.'s method required additional time and resources costs and relied on experiential knowledge and judgement by a leading academic in the field (Horsely et al. 2011). In Greenhalgh et al.'s review given that first, the use of secondary searching was predicated on researcher expertise and second, that a significant number of additional included studies were obtained by secondary searching methods it could be argued that the final review product was actually *narrative* review and that use of the term systematic review was a misnomer. Thus, I assert that my earlier analysis in section 2.4.1 explaining why I excluded the use of narrative review in the conduct of paper one similarly justifies why secondary searching and snowballing of reference lists was not undertaken.

#### **2.4.2.4 Single screener**

In this review only one author screened titles and abstracts. Bias could have been introduced by my pre-conceptions in determining whether a study was eligible for inclusion during screening of titles and abstracts and subsequent full text papers (Centre for Reviews and Dissemination 2009). Using a second researcher could have minimised this risk of bias, additionally it would have provided a further check to minimise inadvertent human error during subsequent data management (Centre for Reviews and Dissemination 2009). However, there are considerable time and resource constraints involved in screening titles and abstracts and subsequent full text papers (Higgins and Green 2008). There was no specific funding available for this PhD to engage someone to do this role. An alternative strategy would have been to enlist the help of a fellow PhD student. However, my position as a part-time PhD student based in a remote and rural setting meant that my interaction with fellow PhD students at this early stage of the research process was somewhat limited. I was also keenly aware that my fellow peers had significant constraints on their time also. I thus elected not to employ an additional screener and accept this as a limitation of the review. While only a third of papers were quality

appraised by my two fellow authors (my PhD supervisors) high levels of agreement had occurred during the quality appraisal process.

## **2.5 My contribution to paper one**

CC conceived and designed the study. CC developed the search strategy and retrieved all papers. CC devised the inclusion criteria and exclusion criteria and applied this to all titles and abstracts. CC quality appraised all identified papers. AS and LF independently appraised one third of the identified papers. CC tabulated the studies and undertook the narrative synthesis. AS and LF assessed the robustness of the analysis in their roles as PhD Supervisors. CC drafted and wrote the manuscript with amendments suggested by LF and AS. Estimated percentage contribution to the paper: CC 90% AS 5%, and LF 5%.

## **2.6 Choice of journal for paper one and journal standing**

*Palliative Medicine* is an international highly respected peer-reviewed journal which has a wide multi-disciplinary readership. The journal is committed to enhancing knowledge and clinical practice in palliative care. I chose to submit my paper to *Palliative Medicine* because it is high impact journal in the field and I believed that the findings of the review would be helpful to readers from both academic and clinical practice backgrounds. *Palliative Medicine* has an impact factor of 3.780 (18th July 2018).

## **2.7 Progressing the thesis**

Paper one identified a gap in our current understanding of emotional distress in families and justified the need for further research to explore the experience of distress in families using a research approach informed by systems theories. Guided by the MRC guidance and the MORECARE statement, a study of distress in families using qualitative methods was determined. I began to contemplate an appropriate study design which would enable me to research family experience. While I had determined that I would like to use family interview methods as a method congruent with systems theories there were other important considerations in study design. One important issue determining the characteristics of the palliative care population that I proposed to sample.

While there is some commonality of symptom burden within the palliative care population (Potter et al. 2003) it is recognised that there are differing illness trajectories within palliative

care with trajectories for cancer, organ failure, physical frailty and dementia described (Murray et al. 2005). Thus, one could speculate that within these differing illness trajectories that differences in the experience of distress within families might exist. For example, the experience of distress in a family of an 87-year-old widow living in a nursing home who has slowly progressing dementia and physical frailty diagnosed over seven years ago might contrast significantly with a 47-year-old married man with adult children living at home who has been diagnosed with advanced lung cancer seven weeks ago. I hazarded that if I chose to sample a heterogeneous population in terms of underlying terminal diagnoses that this could add complexity to data analysis. Moreover, collecting and analysing data from a qualitative group family interview where a member has significant cognitive impairment from dementia would necessitate significant expertise in qualitative interviewing which at the time I did not possess. This would also present significant ethical implications for the conduct of the study. Taking these methodological, practical and ethical issues into account I felt it was necessary to limit my exploration of emotional distresses in families to one recognised illness trajectory in palliative care.

Notwithstanding that the evidence base supporting distress as a systemic construct is nascent, progressing development of systemic approaches to distress interventions in families living with advanced cancer still possessed pragmatic appeal. First, given the recognised impact of cancer in the family system (Forbat et al. 2009) and second, given the high prevalence of documented distress in patients and their family members (Bambauer et al. 2006). However, the premise of the utility of developing systemic interventions for distress rests on another fundamental and yet frequently overlooked consideration, do families want professional help for their emotional distress?

Currently only a third of cancer patients who screen positive for distress receive psychosocial care (Mitchell, 2013). Moreover, the presence of distress does not necessarily correlate with a desire for help (Baker-Glenn et al. 2010; Clover et al. 2015; van Scheppingen et al. 2011). These findings signal that in tandem to understanding emotional distress in families it is imperative that we understand families' help-seeking behaviours for distress. In the context of this thesis it was expedient to grasp what was already known in the literature about the concept of help-seeking for distress in families. This goal forms the basis of the second phase of investigation of this thesis and is reported in the next chapter.

## **2.8 Chapter summary**

In this chapter I have situated the systematic review reported within paper one within the developmental stage of the MRC framework (Medical Research Council 2008) as a necessary pre-requisite to developing a systemic distress intervention. I have outlined the contribution of paper one to the field of knowledge in evidencing distress as a systemic construct. I have critically debated the research approach adopted during the conduct of the systematic review and considered the implications of choices made during the review process. I have shown the interrelationship of first phase and second phases of investigation in this thesis.



## Chapter 3

**3. Paper Two: Carolan, C.M., Smith, A., Davies, G.R. and Forbat, L. (2018) Seeking, Accepting and Declining Help for Emotional Distress in Cancer: Findings from a Systematic Review and Thematic Synthesis of Qualitative Evidence. *European Journal of Cancer Care*, 27(2): e12720. doi: 10.1111/ecc.12720.**

### 3.1 Rationale for paper two

#### 3.1.1 Why another systematic review?

Chapter two indicated that in tandem to understanding families' experience of emotional distress it was also important to understand families' help-seeking for distress. Thus, it was expedient to grasp what was already reported in the literature about the concept of help-seeking for distress in families. Preliminary examination of the research literature identified a recent pertinent systematic review. Dilworth et al. (2014) examined barriers perceived and experienced by health professionals and cancer patients in the delivery of psychosocial care. The review examined the experience of patients and staff but did not include family members. The review identified only one qualitative study reporting why patients did not seek help with their distress and thus provided limited insight into patients' attitudes, perceptions and experiences of help-seeking. Steele and Fitch's (2008) qualitative study reported that patients perceived they did not need help because of their existing support networks; their ability to self-manage; lack of awareness of resources; and perceived time constraints. Study limitations included: participants had single disease type (lung cancer); no cancer stage was reported; participants were recruited from a single Canadian regional cancer centre; and quantification and qualification of available help was poorly described. These limitations placed reduced transferability of findings to families living with advanced cancer receiving palliative care in a UK setting.

However, scrutiny of Dilworth et al.'s (2014) review indicated that the framing of their review may have constrained the numbers of qualitative studies retrieved. To clarify, I believe when designing their review, the authors had already made a value assumption about help-seeking

by framing their examination through the prism of simplistic deterministic barriers to help-seeking rather than seeking to explore the complexity of the help-seeking process. Indeed, one of the salient findings emphatically reported by the authors is *'The main barrier reported by patients is the perception that psychosocial care is not needed'* (Dilworth et al. 2014, p. 609). Reporting not needing help as a 'barrier' implies that patients' autonomous decision making is somehow at odds with superior professional wisdom that the presence of distress automatically implies a need for formal help. Adopting such a stance hints at medical paternalism and appears to denigrate alternative patient driven strategies such as seeking help from their social networks or using self-care and established coping strategies (Walshe et al. 2017).

Alternatively, one could posit that patients do not perceive any need for help because they do not conceive distress as an illness. Rogers and Pilgrim (2005) indicate that illness is a social construct in that *'Judgements about health and illness (physical as well as mental) are value laden and reflect specific norms in time and place.'* (p.11). Likewise, in their seminal text *'The Medicalisation of Misery'* Pilgrim and Bentall (1999) remind us that because illness is socially constructed, differences can exist between lay and professional constructions of distress and mental illness. Thus, if patients believe that their distress is not a genuine medical condition and/or reject a diagnostic category ascribed through distress screening, then they are unlikely to perceive a need for formal help for their distress.

Additionally, the search strategy used by the authors may have limited the retrieval of qualitative studies. The search terms were heavily influenced by a psycho-oncology perspective. Additionally, limiting data-bases to MEDLINE, CINAHL and PSYCH INFO risked omission from disciplinary perspectives such as medical sociology which might have produced a higher yield of qualitative studies.

As previously discussed in Chapter 2, it is good practice to review the evidence base before beginning any program of research (Evans et al. 2013; Medical Research Council 2008). Whilst on face value a recent pertinent systematic review had been conducted, I believed that the limitations of Dilworth et al.'s (2014) review placed considerable constraints on its utility in providing theoretical underpinning to this thesis. Therefore, I elected to undertake a systematic review of the qualitative evidence to examine why families living with advanced cancer seek formal help for their distress and what influences their help-seeking.

### **3.1.2 Expanding focus of the systematic review**

When developing the protocol for the proposed systematic review some preliminary pilot searches were conducted. Initial pilot searches were conducted at the end of 2014 and used a combination of purposefully broad search terms including: 'help-seeking' 'seeking help' 'desire for help' 'distress' 'anxiety' 'depression' 'palliative care' 'hospice\*' 'metastatic cancer' and 'advanced cancer'. Consistent with the approach taken in paper one inclusion criteria sought to include studies which examined the experience of patients and their family members and to exclude professional views. However, initial pilot searches yielded just under 100 hits with review of titles and abstracts indicating no studies of patients and their family members.

Appreciating that I would not be able to examine the literature on the experience of help-seeking from the narrow perspective '*the family in advanced cancer*' I believed it was justifiable to widen the search terms and inclusion criteria to capture the experience of cancer patients and/or family members throughout their cancer trajectory. I considered that such evidence would unquestionably still provide new knowledge to contribute to the aims of this thesis and inform the body of knowledge on help-seeking for emotional distress in serious illness. Thus, the aim of the second phase of investigation in this thesis was to understand why individuals affected by cancer seek, accept or decline help for emotional distress and what influences these actions. A systematic review and thematic synthesis of qualitative evidence was conducted and is reported in paper two.

## **3.2 Paper two**

This paper was submitted to the *European Journal of Cancer Care* in October 2016 and was accepted for publication in April 2017. It was published on-line in June 2017 and published in print in March 2018.

Paper redacted due to publisher restrictions

### **3.3 Critical review of the contribution of paper two to the field**

#### **3.3.1 Contribution of paper two to the field**

Paper two is the first systematic review and qualitative synthesis to investigate help-seeking behaviours for emotional distress during the experience of cancer and addressed an identified gap in our current understanding of why individuals choose to engage (or not) with help (Dilworth et al. 2014; Zwahlen et al. 2017). Moreover, paper two makes a meaningful contribution to the current field of psycho-oncology research by interrogating the synthesis within sociological understandings of illness behaviours. The paper provides several novel insights which contribute to our understanding of help-seeking for distress: advancing conceptions of normality in cancer experience; lay conceptions of distress; and the importance of family and lay networks.

##### **3.3.1.1 Advancing conceptions of normality in cancer experience**

The desire to experience a normal life when faced with the existential threat of cancer is well described within the cancer and palliative care literature and has been demonstrated for both patients and family members (Funk et al. 2010; García-Rueda et al. 2016). Existing literature clearly evidences that this desire for normality drives behaviours that patients and families employ in terms of day to day coping strategies (Pollock et al. 2007; Walshe et al. 2017). Paper two advances this notion because it suggests the desire for normality informs interactional behaviours within the mesosystem between the family system and the healthcare system in terms of help-seeking behaviours. Moreover, as paper two elucidates an individual's conception of normality is ideographic. Paper two makes a valuable contribution to practice by highlighting that assessing an individual's desire for help requires thoughtful exploration during each individual clinical encounter to understand how a patient's conception of normality informs their help-seeking preferences. Furthermore, it suggests that determination of need for help cannot be simply estimated nor predicated through adoption of mechanistic screening programmes which has implications for healthcare systems proposing to implement this approach as standard policy.

##### **3.3.1.2 Lay conceptions informing help-seeking**

Paper two indicates that help-actions for distress are ideographic and stresses the centrality of context dependent lay conceptions in shaping these actions. Importantly the synthesis reveals three closely interrelated lay conceptions: the meaning of distress; the meaning of help-seeking

and perceptions of help. In contextualising paper two's contribution to the field, I will refer to some seminal texts which have shaped sociological understandings of how lay interpretations shape illness behaviour.

The term illness behaviour was first coined in the early 1960's by Mechanic and Volkart (1961) with a later definition proposed by Mechanic in the mid 1990's. Mechanic's definition emphasises the centrality of lay interpretations of illness in shaping help-seeking behaviours.

*'Illness behavior refers to the varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilize various sources of informal and formal care. Such behavior is important because it shapes the recognition of illness, the selection of patients into care, the degree of compatibility between patient and physician attributions, patterns of health practice and adherence with medical advice, and the course of illness and the treatment process.'* (Mechanic 1995, p.1208)

In earlier work Dingwall (1976) signalled the importance of interpretation of symptoms as either 'normal' or 'deviant'. Specifically, the salience of these interpretations as deviations from normal informing help-seeking are a central tenet of Dingwall's illness action model. Therefore, Dingwall's model provided a fruitful means to interpret the findings of paper two. Dingwall's defines illness action as

*'the outcome of continuing efforts on the part of the sick person, and those with whom he (sic) associates, to make sense of what is going on in the light of the knowledge, resources and motivations available to them.'* (Dingwall 1976, p.121)

Dingwall's definition signals the importance of lay understandings of *knowledge, resources and motivations* informing help-seeking. Lay conceptions of help were vital to informing help-seeking in paper two which critically made distinctions between lay knowledge of help and lay beliefs about help (Pilgrim and Rogers 1997). The distinction is important for both researchers and professionals to appreciate. Lack of knowledge about help implies the existence of a realist objective measurable deficit, remedied with the provision of information. Whereas lay beliefs about help (and its value) are socially constructed and may clash with professional beliefs about help. Whilst lack of information has commonly been cited as a barrier to help-seeking for emotional distress within cancer care contexts (Dilworth et al. 2014; Schofield et al. 2006) it is simplistic and erroneous to assume that information provision is a panacea to enhance the uptake of psycho-social interventions. Lay beliefs about help are critical. Paper two clearly stresses the need for mutuality within clinical encounters to ensure that *'help desired and help offered are mutually understood'* (p.1). Hence paper two adds to the field by highlighting that it

is beliefs about knowledge rather than simply provision of knowledge which is critical to understanding why individual chose (or not) to engage with help.

Sociological contributions have advanced the debate about how the medicalised clinical gaze and its emerging dominance has shaped illness behaviours (Foucault 2003; Lupton 1997). The contested notion of the medicalisation of misery first described by Pilgrim and Bentall (1999) and the '*medicalization of life's problems*' (Conrad 2007, p.152) and has featured prominently within the general mental health literature for almost three decades (Kokanovic et al. 2013). Yet this contrasts sharply with a lack of a similar debate within the psycho-oncology literature in which lively debate about lay concepts of distress are conspicuously absent. In contrast, the current psycho-oncology literature is awash with a plethora of repetitive research on distress screening (Salander 2017) which instead preferences the epistemological authority of the professional as opposed to patient (Kokanovic et al. 2013; May et al. 2006; Salander 2017).

Salander (2017) has been a relatively solitary vocal critic of distress screening in cancer arguing that '*the research trend for 'screening' rests on an ontological and an epistemological mistake*' (p.859). Salander (2017) contends that the primary aim of any screening programme is to detect something which is hitherto unknown to the individual and for which there is a definitive assessment and treatment pathway which the individual is likely to accept (p.858). For example, detection of an abnormal smear indicative of cervical cancer. He questions the transferability of this presumption of utility in screening for emotional distress given that any positive screen for distress using a questionnaire is dependent on whether individuals make a conscious choice to disclose distress. Thus, he contends the likelihood of an individual actively choosing to seek help even if they are distressed is far from certain.

In a similar vein, Paul (2013) describes as a *professionally-driven paradigm* founded with a medical model whereby distress and desire for help is medically deliberated versus a *consumer-driven paradigm* whereby psychosocial health and need for help is determined by the individual. Clearly these two paradigms may clash. Importantly Paul draws attention to the pressing need for research to explore discordance between these paradigms. Paper two therefore clearly provides a nascent model specifically framed to provide emergent understanding of this consumer driven paradigm and contrasts with the current dominance of research in psycho-oncology informed from professional paradigms and understandings.

Returning to Salander's (2017) line of argument, he concludes that it is willingness to accept support rather than measured distress that is the most important metric and argues that that

clinicians should focus their energies on exploring and understanding the ideographic perspective of the individual in their care and whether they want help (or not) with their distress. Notably Salander's (2017) article was first published online in 2016 when paper two was already under peer-review and hence why no reference to his work is made within the paper. Salander's (2017) compelling rhetoric clearly illustrates both the currency of paper two in appreciating ideographic understandings and its value in giving voice to the importance of understanding lay conceptions in advancing the field of psycho-oncology.

### **3.3.1.3 Family and social networks informing help-seeking**

A second contribution paper two makes is that it clearly signals the importance of family and social networks as influencers of an individual's help-seeking for distress. Influences from family and social networks are operationalised in a plurality of ways: (i) by assisting interpretation and evaluation of distress; (ii) by sanctioning help; (iii) by inhibiting distress disclosure and through this inhibiting help-seeking; (iv) by being a source of informal help; (v) by not being a source of informal help; (vi) by having unsupportive attitudes to help; (vii) by facilitating access to formal help; (viii) and as a temporal influence to help-seeking via historical family scripts. Many of these influences are well described in the generic mental healthcare literature with the role of family and social networks critical in lay diagnosis of distress and facilitating access to formal help (Angermeyer et al. 1999; Vogel et al. 2007). Moreover, a programme of large population based studies in primary care settings in the Netherlands has demonstrated that family influences of socialisation and shared circumstances influence help-seeking behaviours in generic healthcare contexts (Cardol et al. 2005; Cardol et al. 2006).

The plurality of ways in which family and social networks influence help-seeking in paper two suggest that such networks form a relational and interdependent space in which help-seeking occurs. This notion aligns with Pescosolido's Network Episode Model which has been used to theorise help-seeking in the generic mental healthcare literature (Pescosolido 1991; Pescosolido 1992). Following Dingwall's recognition of the importance of the role of others informing help-seeking, Pescosolido (2013) similarly argues that help-seeking is not a solitary process but is socially constructed. Her model depicts illness behaviour and help-seeking as discrete episodes mediated via interaction within and between social systems as social networks. Over and above understanding the structure of these systems, she states that it is necessary to understand how context and sociocultural influences inform this interaction: first, *how* networks interact and second, the *content* of these interactions. Pescosolido's Network Episode Model clearly signals the complexity which underpins help-seeking behaviours. Framing

help-seeking for distress in this way can emphasise to clinicians the utility of adopting relational approaches to families; this will enable clinicians to appreciate the multiplicity of influences operating within the family system which can impact on engagement with emotional supportive care.

More recently Wyke et al. (2013) argue that reductionist research approaches which simply seek to understand nomothetic probabilities of help-seeking may not yield promise in providing tangible useful knowledge to inform care. Moreover, Wyke et al. argue that current approaches to advancing our understanding of help-seeking are unnecessarily constricted by researchers who continue to work exclusively from their own disciplinary silos. Paper two makes a valuable contribution to the field by illustrating that by using qualitative methods and drawing from different disciplinary perspectives deeper understanding of help-seeking was obtained.

### **3.3.2 Reception of paper two**

Paper three has been cited 3 times in Google Scholar (18th July 2018). Notably the review has attracted critique by Professor Janice Morse (2018) and will be responded to below.

## **3.4 Critical reflection of the methodology and methods used in paper two**

### **3.4.1 Why a qualitative thematic synthesis?**

This review sought to understand why individuals affected by cancer seek, accept or decline help for distress and what influences these actions. The goal of this research was interpretative in that the review sought to enhance our understanding of the phenomenon of help-seeking. Thus, a qualitative synthesis was chosen as a congruent approach to produce an interpretive translation of studies by deriving themes or constructs across studies rather than an aggregative summary of studies (Booth 2016; Grant et al. 2009). Several methods of synthesising qualitative evidence exist (Ring et al. 2011). Barnett-Page and Thomas (2009) reflect that thematic synthesis pioneered by Thomas and Harden (2008) was developed

*'out of a need to conduct reviews that addressed questions relating to intervention need, appropriateness and acceptability – as well as those relating to effectiveness – without compromising on key principles developed in systematic reviews.'* (p.6)

Given that the aim of this review related to the need for help it was considered that thematic synthesis presents the most appropriate choice of method available. Moreover, the clear and

unambiguous guidance of the method was attractive. Thomas et al.'s method of thematic synthesis advocates familiar techniques such as the use of computer software to facilitate data storage, coding and retrieval to simplify data management was appealing as I had never undertaken a qualitative synthesis before. Moreover, data analysis techniques borrowed from qualitative techniques such as an inductive approach using line by line coding and constant comparative methods with which I was familiar. (Barnett-Page et al. 2009). Hence, while the choice of method was congruent with the underlying aim of the study I found the method had appeal as I had never undertaken a qualitative synthesis before.

### **3.4.2 Search methods**

A recent criticism levied at qualitative synthesis is that authors have concentrated their energies on the technical aspects of the review i.e. searching, tabulating and displaying studies rather than focussing on interpretation of studies; this they argue produces an aggregative superficial product rather than synthesised novel integrated findings (Thorne 2015; Thorne 2017). Yet as Cooper argues, confidence in the conduct of meta-synthesis and sound retrieval of studies is vital (Cooper 2010). Furthermore, Britten et al. (2017) counter Thorne's criticisms by pointing out that currently in the absence of further definitive guidance on the conduct of qualitative synthesis prospective authors adherence to technical aspects of the search is a necessary pre-requisite to ensure publication. Britten et al. indicate that Thorne's criticism of searches which retrieve thousands of hits is not necessarily problematic but accept that further guidance is merited. Notwithstanding the pressing need for definitive guidance, Booth's (2016) recent structured methodological review highlights that poor empirical evidence informs current practice in search methods and inclusion of studies in qualitative systematic reviews or qualitative evidence syntheses.

The SPIDER tool was chosen as a preferred search strategy tool in paper two because tools such as PICO (Population, Intervention, Comparison, Outcome) may not necessarily *translate* to qualitative systematic reviews (Cooke et al. 2012). Indeed, reflecting on the generation of search terms used during this qualitative synthesis generating search terms using SPIDER was more intuitive than using PICO given that the domain of comparison is generally not a feature of qualitative studies. However, a recent study by Methley (2014) has questioned the assumption that intuitive use of SPIDER equates to empirical evidence to support its use.

Methley et al. (2014) compared the use of SPIDER and PICO tools to a modified version of PICO with added qualitative search terms (PICOS) across three databases, MEDLINE, EMBASE and

CINAHL. The study reported that while SPIDER had the greatest specificity it demonstrated a lower sensitivity than the other tools; PICOS tool demonstrated the greatest sensitivity of all the tools. Whilst accepting PICOS demonstrated greatest sensitivity given the relative resource and time constraints of the review within a program of PhD research the use of SPIDER probably remained a pragmatic choice to maximise specificity. Besides as Booth (2016) argues, qualitative data synthesis need not necessarily need exhaustive searches but rather they should be appropriate and comprehensive searches.

Paper two drew criticism by a leading expert in the field for not including 'enduring' in its search or reporting. In her recent article '*Theoretical Coalescence: A Method to Develop Qualitative Theory*' Janice Morse describes theoretical coalescence as a method of theory development. Morse chronicles the evolution of the lay concept of *enduring* to a scientific concept within her '*Theory of Suffering*' by drawing from 16 studies which she has authored. The theory of suffering delineates dual processes which occur in response to trauma such as cancer; namely *enduring* in which emotions are suppressed and *emotional suffering* in which emotions are released. Morse argues that advancing theory is a slow process with studies contributing to her theory spanning 23 years (1991-2014) and outlines several challenges in theory advancement. Morse (2018) then levies the following criticism of paper two in limiting advancement of theory development

*'Of greater concern, research that introduces new insights or concepts tends to be ignored by methods of meta-synthesis, perhaps because of the mechanics of research terms. For instance, a recent systematic review (2000–2016) of emotional distress and help-seeking in cancer, focused on emotional states of distress and ignored states of enduring (Carolan, Smith, Davies, & Forbat 2017)' (p.185).*

However, I consider that are salient reasons why 'enduring' did not feature within paper two. First, as Morse keenly points out in the very same article

*'Astonishingly, enduring is virtually absent from the scientific literature, including nursing' (p.184)*

I would argue that it is challenging to discover a concept if it is absent from the literature unless one has personal knowledge of an author's work. Secondly, the titles of the studies which Morse has derived her concept of suffering merit scrutiny. The titles of the studies include no easily discernible direct reference to or allude to concepts pertinent to our review, several do not relate to cancer populations, and finally many are not reported in peer-review journals but rather books. Taken together, I would argue that it is challenging to discover work which is not easily discoverable. Admittedly, I accept that Morse's programme of work was evolutionary

and hence why earlier titles do not readily incorporate or signal distress, suffering and enduring. Additionally, on reflection, paper two's subtheme of emotional space does resonate with Morse' subtheme of enduring and hence I accept that discussion of the findings of paper two with reference to Morse's theory of suffering would have strengthened paper two.

Nonetheless, such debates raise questions about authors' ethical responsibilities during research dissemination. I consider that within the ethical frameworks of beneficence non-maleficence and justice (Beauchamp and Childress 2003), authors should endeavour to publish articles which have easily discoverable titles. This will ensure that their work can contribute fully to the development of evidence-based care to ensure beneficence and non-maleficence in clinical care and to ensure justice to those who funded and participated in their research.

### **3.5 My contribution to paper two**

CC conceived and designed the study. CC developed the search strategy and devised the inclusion criteria and exclusion criteria. CC and GD independently screened all titles and abstracts with AS and LF resolving any discrepancies. CC quality appraised all identified papers. Data extraction and thematic synthesis was conducted by CC. AS and LF assessed the robustness of the analysis in their roles as PhD Supervisors. CC drafted and wrote the manuscript with amendments suggested by AS and LF. Estimated contribution to the paper: CC 85%, GD 5%, AS 5%, and LF 5%.

### **3.6 Choice of journal for paper two and journal standing**

The *European Journal of Cancer Care* is a highly respected international peer-reviewed journal that has wide academic and professional audience. The journal reports on a wide range of topics which affect the care of cancer patients and their family carers including supportive and psychosocial interventions and care. *European Journal of Cancer Care* has an impact factor of 2.409 (18th July 2018).

### **3.7 Progressing the thesis**

Reporting of phases one and two of this research chronicle the process of research and demonstrates the initial fluidity and iterative refinements which have necessarily shaped this thesis. So far, this thesis has produced new knowledge informing our understanding of distress as a systemic construct in families in palliative care (paper one) and why individuals affected by cancer seek help (or not) for distress and what influences their actions (paper two). Taken

together papers one and two demonstrate limited current understanding of the experience of emotional distress and help-seeking for distress in families living with advanced cancer. Thus, phases one and two of this thesis first, evidence the need for further research to address this knowledge gap and second, justify the claim that this thesis will make a necessary and original contribution to the field. The next phase of investigation was to design a research study to explore the experience of emotional distress and help-seeking for distress in families living with advanced cancer.

Central to this thesis is the ambition to understand how distress is experienced within the family system and families' help-seeking interactions with healthcare. As indicated in Chapter 1 family systems theories and ecological systems theories provided the initial theoretical underpinning to this thesis. Paper two keenly illustrates that the perception of self and the meaning of distress and the meaning of help-seeking critically informed conceptions of normality informing help-seeking. Given that interpretation of meaning was a central feature of paper two's findings, symbolic interactionism was considered as an additional theoretical lens to frame the next phase of investigation.

Symbolic interactionism is a mid-range theory which seeks to understand how meaning is created through interaction. As Blummer (1986) describes

*'human beings interpret or 'define' each other's actions instead of merely reacting to each other's actions. Their 'response' is not made directly to the actions of one another but instead is based on the meaning which they attach to such actions. Thus human interaction is mediated by the use of symbols, by interpretation, or by asserting the meaning of one another's actions' (p.79).*

Therefore, interactional processes are constantly re-defined and re-interpreted through on going interaction, critically the influence of past knowledge, experience and societal norms and the importance of context are acknowledged (Blummer 1986).

Symbolic interactionism has been historically associated with grounded theory methodology. However, I rejected the use of grounded theory methodology in this research. First, I felt it would be untenable to adhere to the tenets of theoretical sampling and theoretical saturation. I considered that it would be difficult to predict with any certainty which families would provide contrasting experiences of distress or help-seeking necessary to fulfil the aims of theoretical sampling. Second, theoretical saturation means that it is not known at the outset of the research

how many families would need to be sampled. Given the time and resource limitations imposed by a PhD, I felt that it was untenable to commit to such an approach. Finally, I considered that the primary aim of this research was not theory generation but rather rich understanding of the phenomena of distress and help-seeking to provide *phronesis* (Flyvberg 2001) to inform clinical care. Despite my rejection of grounded theory, Handberg et al. (2015) keenly argues that symbolic interactionism can be used in a variety of qualitative methodologies '*to orient questions, inform design options, and refine analytic directions*' (p.1023), and is not exclusively wedded to grounded theory approaches.

In summary, the proposed research design needed to accommodate the theoretical perspectives of family and ecological systems theories and symbolic interactionism. Moreover, the proposed design must permit holistic examination of families and be expedient within palliative care settings. Taking these issues into account case study was chosen as the preferred research approach to this inquiry. First, case study embraces the study of the whole (Thomas 2011), thus it can permit holistic investigation of families and has been used in family research studies (Ayres et al. 2003; Gabb 2009; Ribbens McCarthy et al. 2003). Case study offers methodological flexibility and can accommodate differing theoretical lenses (Abma and Stake 2014) and provides a flexible research approach within palliative care contexts (Payne et al. 2007; Walshe et al. 2004). Walshe et al. (2004) contend that case study is particularly advantageous when situations are complex, multiple perspectives are involved, real world context is central to the investigation, and research needs to be congruent with clinical practice (p. 681). Clearly such reasoning applies to a case study of emotional distress and help-seeking for distress in families living with advanced cancer.

While I had determined that case study provided an approach which was congruent with the aims of this research, my initial readings of the literature left me somewhat confused about how to use case study. I therefore embarked on a critical review of case study. The following chapter, Chapter 4 outlines how I critically reviewed case study as a research approach and details how I then developed a new model to enhance the design, conduct, and reporting of case studies in healthcare.

### **3.8 Chapter summary**

In this chapter I have provided a rationale for undertaking a systematic review and qualitative synthesis exploring why individuals affected by cancer seek, accept or decline help with their distress and what influences these actions. I have justified why the review examined all cancer

populations. I have described the contribution of paper two to the field of knowledge. I have provided a critical reflection of the methodology and methods used in this systematic review. I have justified using case study as an approach by which to explore the experience of distress and help-seeking for distress in families living with advanced cancer. I have signalled that before proceeding with design of this case study I will interrogate case study as a proposed methodological approach.

## Chapter 4

### 4. Paper Three: Carolan, C.M., Forbat, L. and Smith A. (2016) Developing the DESCARTE Model: The Design of Case Study Research in Healthcare. *Qualitative Health Research*, 26(5), pp.626-639.

#### 4.1 Rationale for paper three

The many initial texts I consulted on case study spent numerous expansive paragraphs dedicated to descriptions of case study typology but provided limited useful guidance on *how* to do case study research. For example, Baxter and Jack's (2008) paper entitled '*Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers*' devotes pages of text to description of various types of case study design; yet has only three brief paragraphs devoted to analysis of data. After simply listing five possible types of analysis advocated by Yin (2003) and two by Stake (1995) the article asserts

*'Explaining each of these techniques is beyond the scope of this paper. As a novice researcher, it is important to review various types of analysis and to determine which approach you are most comfortable with' (p.554).*

The latter comment that researchers should employ the type of the analysis they are most comfortable with seemed at odds with my own understanding of research. In that rather than choosing methods based on comfort, that the choice of methods of data analysis should be congruent with the research aims, ontological and epistemological beliefs, methodology and if relevant, underpinning theory (Crotty 1998; Daly 2007).

While I was confident that case study was an appropriate methodological approach by which to investigate experience in families, I was less confident in my ability to use this methodology appropriately. From an ethical standpoint as a researcher I had significant concerns about proceeding with this research until I fully understood the methodological approach I had proposed. Thus, the aim of the third phase of this thesis was to critically review case study as a research approach. To achieve this aim, I undertook a rapid review of the literature. In doing so I identified significant shortfalls in the quality of reporting of case study in the healthcare literature. Given that a defining characteristic of case study is its use of multiple data sources I drew from the mixed-methods literature to devise a new model to enhance the design, conduct,

and reporting of case studies within the arena of healthcare. Paper three reports this process and presents the DESCARTE model: The **D**esign of **C**ase Study **R**esearch in Healthcare.

## **4.2 Paper three**

This paper was submitted to *Qualitative Health Research* in March 2015 and was accepted for publication in July 2015. It was published on-line in September 2015 and published in print in April 2016.

Paper redacted due to publisher restrictions

### **4.3 Critical review of the contribution of paper three to the field**

#### **4.3.1 Contribution of paper three to the field**

Paper three's significance is that it has proposed a new model to enhance the conduct and reporting of case study within healthcare. Importantly paper three addressed limitations of two earlier related reviews of cases study from the nursing literature (Antony and Jack 2009) and qualitative research literature (Hyett et al. 2014). In doing so the paper exposed significant deficiencies in the reporting of case study which catalysed development of the DESCARTE model. To illustrate the significance of the paper's contribution to the field it is necessary to first contextualise the rapid review reported considering these two earlier works.

##### **4.3.1.1 Identifying deficiencies in the reporting of case study in the literature**

Antony and Jack's (2009) integrative review examined case study in nursing between 2005-2007 from multiple data bases whilst Hyett et al.'s (2014) critical review examined case study between 2008-2013 from three qualitative journals. Antony et al. (2009) described qualitative case study methodology as

*'a research methodology grounded in an interpretive, constructivist paradigm, which guides an empirical inquiry of contemporary phenomena within inseparable real-life contexts.'* (p. 1172)

Antony et al. (2009) applied the inclusion criteria '*qualitative case study methodology*' (p.1172) in their review but did not indicate how they applied this. Given their definition one might assume that realist case studies were excluded from their review, but this is not explicit nor is a rationale for their decision making apparent. Given that case study characteristically uses multiple data sources and can employ mixed methods these earlier reviews did not represent the plurality of case study designs used within healthcare. In contrast, the review process in paper three was inclusive of all types of case study design and thus represented a fuller account of the conduct of case study in the literature.

The two reviews had evaluated the quality of case studies in different ways. Antony et al. (2009) used a numerical scoring system to evaluate the quality of studies and derived dual three-point scoring for authenticity and methodological quality with summated scores out of six. However, there was duplication within the scoring system and simply referring to a case study author such as Yin automatically attracted two points. Thus, the scoring system was hardly discriminatory

of quality. In contrast Hyett et al.'s (2014) used a 21-item checklist informed from Stake (1995), Merriam (2009) and Creswell (2013) however very few of the domains clearly focussed on design and analysis related to case study. Most items were derived from more generic qualitative standards of reporting e.g. '*Were sufficient raw data presented?*' (p.4) making the use of the checklist less discriminatory for specifically assessing the quality of case study. In their thematic analysis of included papers, they drew attention to the lack of methodological underpinning in studies but other than briefly highlighting omissions relating to the role of the researcher and ensuring triangulation of data, there was little exposition of methods of analysis and saliently how this was informed by ontological and epistemological positioning.

While building on these earlier reviews paper three made a novel contribution by focussing the critique of methodological reporting on alignment of philosophical positioning, detailed description of case study design and the reporting of data analysis procedures. Alignment of informing philosophical approach methodology and method is a critical consideration yet one which seems little addressed in the design of case study (Boblin et al. 2013). Boblin et al. stress that while most researchers cite the use of Yin's case study approach many researchers have not considered that Yin (2003; 2009) adopts a post-positivist stance as opposed to Stake's constructivist stance (1995; 2005). Thus, researchers may use a case study approach at odds with their underpinning philosophical positioning. The rapid review within the first half of paper three clearly demonstrates the poor quality of case study design and reporting and evidences a lack of attention to the congruence of philosophical positioning, methodological approach and execution of methods in case study design.

#### **4.3.1.2 Developing a new model of case study design**

Paper three makes an innovative contribution to the field because over and above identifying the poor methodological conduct of case study in the literature it proposes a new innovative approach to case study design to enhance current research practice. Saliently, the paper purposively drew from the mixed-methods literature to address deficiencies in the case study literature, particularly relating to data analysis technique. A cursory review of case study literature suggests a plethora of seminal textbooks on case study design which one would speculate would provide ample guidance on data analysis techniques in case study. However, closer scrutiny of these texts reveals weaknesses in their description of case study design which as paper three reports the DESCARTE model specifically seeks to address. In paper three I provided critique of Yin's case study approach. However, to advance the claim within this thesis that the DESCARTE model contributes to the field of knowledge I will support this argument

further by detailing what I think are salient omissions in the writings of several eminent case study authors.

Stake's writings are informed from a social constructivist perspective and there is minimal reference of the practice of case study informed by alternative paradigms. Stake's (1995) text *'The Art of Case Study Research'* describes data analysis in single case studies only. The chapter on data analysis (p.71-90) does not specifically debate how different data sources are integrated. Stake briefly suggests that quantitative data gathered should be analysed using categorical aggregation but omits further debate on how this data is then integrated with qualitative data gathered, he then signposts the reader to methods informed from Miles and Huberman (1984) for more complex analyses. In a later chapter (p.107-120) Stake discusses triangulation and briefly references Campbell and Fiske's (1959) work on multi-method. However, Stake's writings on triangulation do not provide a more detailed discussion of the purpose of multiple data sources within a study. This contrasts with the later writings of authors such as Greene et al. (1989) or Bryman (2006) who comprehensively and critically debate this issue as indicated in paper three. In Stake's later writings in his text (2006) *'Multiple Case Study Analysis'* discussion about variable based approaches to data analysis is omitted.

Simon's (2009) otherwise excellent text *'Case Study Research in Practice'* has two significant omissions. First, there is limited debate within Simon's text on philosophical positioning. Second, there are gaps in discussion of data analysis. Strategies for analysing multiple or collective case studies are not discussed in her text and akin to Stake, when discussing data analysis in case study there is minimal discussion of integration of mixed data sources with readers again signposted to Miles and Huberman (1984). Thomas' (2011) text *'How to do your case study'* is extremely insightful but the substantive part of his book, sections 1-2 (p.1-159) focuses on case study typology. Pages 170-193 of Thomas' book are devoted to data analysis but there is limited in-depth debate about how to analyse and integrate different data sources, the purpose of doing so and linkage to philosophical positioning. Moreover, there is scant reference to cross-case analysis. The positioning of the self and reflexive practices in data analysis are given limited attention in Thomas's book. Abma and Widderhoven's (2011) chapter *'Evaluation as Relationally Responsible Practice'* in Denzin and Lincoln's (2011) *'Sage Book of Qualitative Health Research'* only examines qualitative evaluative case study informed by social constructivism. While the chapter provides interesting insight into participatory research and issues of power and presents a design process, there is limited debate of methods in action and data analysis.

Paper three purposively seeks to address such omissions and thus makes a credible addition to literature which seeks to better explicate the application of research methods. While the three stages of the DESCARTE model mirror those of established case study authors, the strength of the model lies in the attentive and expanded description within each of the three stages of design. This will help ensure that there is clarity between philosophical positioning, methodology and method and moreover that regardless of the method of data analysis applied that this is critically considered, congruent and described in sufficient detail to allow judgements about the quality of the study. As such the DESCARTE model and accompanying questions to guide researchers will enhance the conduct and reporting of case study and thus makes an innovative and valuable contribution to the field of case study research.

### **4.3.2 Reception of paper three**

Paper three was presented as an oral paper at the Mixed Methods International Research Association, regional conference in Texas in August 2015 and was well received. Paper three has been cited 17 times in Google Scholar (18<sup>th</sup> July 2018). The DESCARTE model has been described and has been cited by Yin (2018) as an exemplar of case study research in healthcare in the new edition of his seminal text book '*Case study research and applications: Design and methods*'. The model was used by Palacios-Ceña et al. (2018) in their original research to inform their case study design.

## **4.4 Critical reflection of the methodology and methods used in paper three**

### **4.4.1 Why a rapid review?**

A rapid review was chosen as the methodological approach for this review because it would enable a knowledge synthesis within a timely manner whilst still permitting a systematic approach and explicit conduct of the review (Khangura 2012). While no current definitional parameters of a rapid review exist (Featherstone et al. 2015; Haby et al. 2016) paper three was positioned as a rapid review because of the following characteristics: rapid timeline focused questions; limited data sources; omission of grey literature; use of single screener; synthesis using narrative summary (Featherstone et al. 2015; Haby et al. 2016). No standardised quality appraisal tool was used within this review because the quality of the conduct of case study was the focus of the review. The pre-determined research questions of the rapid review thus negated the need for use of a specific quality appraisal tool in this instance.

Featherstone et al.'s (2015) observes that rapid reviews represent a 'spectrum of products' thus making the production of specific guidance in their conduct problematic. Acknowledging lack of standardised guidance Hay et al. (2016) recommends that authors should make their review methods explicit to enhance transparency. This would mean providing sufficient detail to enable replication of the review. On reflection I consider that sufficient detail was provided to enable replication of the review as a marker of transparency.

#### **4.4.2 Limitations of the review**

The rapid review in paper three might have been enhanced by inclusion of journals reflecting the conduct of case study within other domains of healthcare, for example organisational healthcare services and medicine. Three nursing journals were chosen in the first instance because I believed that the type of case studies reported within the nursing literature would align more closely with the research that I was proposing within my thesis. By this I mean that my exploratory case study of holistic family experience was underpinned by a relativist ontology which is dominant within nursing research whereas I considered that case studies within medical or organisational healthcare research are likely to be framed through a realist objectivist lens. Given that the original premise for the conduct of the review was to inform my own understanding of methodology for this thesis I considered that inclusion of such journals would be less fruitful and would unnecessarily extend the time needed to conduct the review and hence why a wider search of the literature during the rapid review was not pursued.

#### **4.4.3 Limitations of the evidence**

Paper three argues that authors may have used description of typology and reference to an informing case study author as a surrogate to detailed description of their case study design. Reflecting on my experience of writing up case study for publication I hazard that the practice of strict word limits in journal reporting articles may adversely influence the reporting of case studies within the literature. Certainly, my choice of journal of publication of papers five and paper six was partially influenced by the word limits applied by journals. Reflecting on my own experience, I would agree with Hyett et al. (2014) and Gillard et al. (2014) that adequate journal space would encourage more rigorous reporting of methods and might fruitfully encourage critical debate within the research community to enhance conduct of case study. In retrospect and if time had allowed it would have been useful to have contacted the authors from included studies within the rapid review to ascertain if limited journal reporting space had influenced how they reported their research studies.

Hyett et al. (2014) suggests that additional reporting of methods should be available within journals. Asking authors to critically reflect on their 'methods in action' should be actively encouraged by journal editors. I would argue that an optimal balance for the readership of healthcare journals would be an outline of methods with sufficient detail to enable busy practising clinicians to get to the 'bottom line' of a study content that was conducted in a rigorous manner but with additional detailed research methods appendices to promote debate and advance research methods innovation. While I accept that many authors produce subsequent related publications articles often reporting methodological insights the practice of reflection on methods used and subsequent peer reviewed publication this is not guaranteed and suggests potential wastage of accumulated methodological knowledge within the community of research practice.

#### **4.5 My contribution to paper three.**

CC conceived, designed and conducted all elements of the rapid review. CC reviewed the case study and mixed-methods literature. CC developed the DESCARTE model with AS and LF providing constructive critique during model development in their roles as PhD Supervisors. CC drafted and wrote the manuscript with amendments suggested by LF and AS. Estimated percentage contribution to the paper is: CC 90% AS 5%, and LF 5%.

#### **4.6 Choice of journal for paper three and journal standing**

*Qualitative Health Research* is an internationally respected peer-reviewed journal that provides a forum to further the understanding of qualitative research methods in healthcare. It has a wide range of readership from the speciality of healthcare and allied fields such as social work and education. *Qualitative Health Research* has an impact factor of 2.413 (18<sup>th</sup> July 2018).

#### **4.7 Progressing the thesis**

Informed by paper three I proposed a cross-sectional exploratory multiple case study of families living with advanced cancer. I planned to recruit 10-15 families living with advanced cancer in NHS Highland. In each family I wanted to conduct qualitative interviews with the patient and two family members, and a family nominated health or social care professional involved in their care. I proposed collecting the following data from each family recruited to the study: face to face semi-structured individual participant interviews with patients and two family members and a triadic family group interview, Family Relationships Index (Moos and Moos 1981) and

Emotion Thermometers Tool (Mitchell et al. 2010; Baker-Glenn et. al. 2010). I proposed conducting telephone interviews with the nominated health or social care professional nominated by families.

The aim of the case study was to explore the experience of emotional distress and help-seeking for distress in families living with advanced cancer receiving palliative care. The objectives of the case study were

- To describe and understand the experience of emotional distress in families living with advanced cancer
- To understand why families living with advanced cancer seek help (or not) for their emotional distress and what influences these actions

Subsequent chapters in this thesis will present papers four, five and six. Each publication presents an account of the case study design and methods. Chapter 8 will present a detailed critical reflection of the methodology and methods used in this case study research. Stage 1 of the DESCARTE model clearly articulates the need to outline the underpinning philosophical approach informing case study design. Thus, I will now detail how understandings of ontology and epistemology in family research have shaped the case study design.

Daly (2007) argues that families are ontologically a distinct focus of study. She contends that in order to understand the ontology of families it is necessary to shift thinking, from a structural question of *'what is a family?'* to a process question of *'what do families do?'* (p.71). Thus, it can be argued, families come into being by doing. Daly (2007) quoting Handel (1996) indicates that families are

*'Complex active agents in constructing their own family life, and we conceptualize each family member, each child as well as each agent whose actions contribute to shaping that family's interdependent life together – and apart'* (p.344).

Such actions create a meaning system which recursively shapes further action to promote collective identity, the private domain of family, relationships, emotions and family practices (Daly 2007). Accordingly, this family case study research assumes a relativist ontology assuming multiple constructed realities (Denzin and Lincoln 2005) created by inter-subjective construction of meanings and understanding by individuals achieved through social interaction and influenced by cultural norms (Benoliel 1996). A relativist ontology accepts multiple constructed realities and thus understanding of such realities are interpreted by the researcher

with knowledge constructed through negotiated dialogue between researcher and the object of investigation (Denzin et al. 2005). Thus, an inter-subjective epistemology acknowledges the role of the researcher in knowledge production.

Designing family research study poses questions such as 'how data will be gathered in families to facilitate knowledge construction about the experience of the family?' I believed that using a multi-perspective approach would enable exploration of the perceived meanings and actions of distress and help-seeking within the family system and would afford rich insight into family experience. Thus, I proposed using multi-perspective interviewing in as a method of data collection. The next chapter, chapter 5, critically examines the challenges of using this method of multi-perspective interviewing in this case study.

#### **4.8 Chapter summary**

In this chapter I have provided a rationale for the rapid review of case study that I conducted. I have presented paper three which describes a rapid review of the case study literature and describes the development of the DESCARTE model which I have presented as a new model of case study research design within the arena of healthcare. I have described the knowledge contribution of paper three to the field and the reception of the paper to date. I have provided a critical reflection of the methodology and methods used in the rapid review. I have described both the design of the case study of families used in this thesis and its philosophical underpinnings. I have explained that the case study uses multi-perspective interviewing methods. The next chapter, chapter 5 will critically examine the challenges of using multi-perspective interviewing in this case study.

## Chapter 5

### **5. Paper Four: Carolan, C.M. (2017) Researching Emotional Distress and Help-Seeking for Distress in Families in Palliative Care Using Multi-Perspective Interviewing. *SAGE Research Methods Cases*, SAGE Publications Ltd.**

#### **5.1 Rationale for paper four**

The rationale for inclusion of this publication is that it provides a reflective account of an aspect of methods in action used in the case study, namely the use of multi-perspective interviewing. This publication also introduces the case study and outlines some elements of the case study design, including the use of patient and public involvement and signals some of the complexities of data analysis. Paper four was a commissioned publication. I was approached by *SAGE Research Methods* following publication of paper three and asked to write a case for their *SAGE research methods cases* platform. I was initially asked to provide a 'methods in action' reflection on the use of the DESCARTE model. At that time, I had not yet completed data analysis and therefore I suggested to the editors that I write an article on multi-perspective interviewing.

The article underwent peer-review as part of the publication process. The article follows pre-defined structural template specified by *SAGE* including inclusion of learning outcomes and follow up exercise and discussion question. Thus, the article is designed to be an educational resource for research novices and student readers to learn about research methods rather than a conventional journal article. For simplicity, I focussed the publication solely on the use of multi-perspective interviewing in families. The objective of paper four was to critically examine the challenges of conducting multi-perspective interviewing in families. Paper four is therefore positioned in this thesis as a pedagogical paper reflecting on research methods used within the case study.

#### **5.2 Paper four**

This paper was commissioned by *SAGE Research Methods* in June 2016 and submitted on accepted for publication in August 2016. It was published on-line in the *SAGE Research Methods Cases* digital platform in January 2017. There is no print edition of this resource. Each case study is assigned a unique ISBN and DOI.



Paper redacted due to publisher restrictions

### **5.3 Critical review of the contribution of paper four to the field**

Paper four offers two allied contributions to the field. First, it presents a valuable contribution to the field because of its pedagogical value in explicating the use and application of a research method in action. Second, it contributes to a small but growing body of literature informing our understanding of how multi-perspective interviewing can be used to investigate and understand family experience.

#### **5.3.1 Pedagogy of research methods**

Wagner et al.'s (2011) systematic review identified a lack of critical debate within the literature about how research methods are taught and learnt in academic practice. Kilburn et al. (2014) contends that plethora of research textbooks do not necessarily furnish teachers of research methods with guidance on how to teach research methods nor do they reflect the messy realities of research (Lewthwaite and Nind 2016). Paper four describes the messy reality of research, it identifies potential pitfalls for neophyte researchers and suggests mechanisms to overcome issues that they might face. The value of this paper is that it presents an authentic account which is purposefully presented in clear and accessible language for student readers thereby addressing recognised negative attitudes of students to research methods teaching (Earley 2014).

#### **5.3.2 Multi-perspective interviewing**

Paper four provides a unique and innovative contribution to the field of knowledge of multi-perspective interviewing. This multi-perspective family case study is the first to have sampled family triads and to have used a combination approach of both individual and group family member interviews in palliative care settings. The use of more than two family members in multi-perspective interviewing in healthcare research is uncommon (Kendall et al. 2009) and research to date which used multiple family members has generally used family group interview methods only (Mollerberg et al. 2017; Ward-Griffin et al. 2012) rather than combining this with individual interviews. Thus, paper four provides a novel road map for researchers contemplating using multi-perspective interviewing methods using combined individual and family group interviews.

Paper four has utility in demonstrating the inter-relatedness of reflexivity and the ethical conduct of research in the field (Damianakis and Woodford 2012). Akin to many healthcare researchers, I had negotiated institutional and NHS ethical approvals prior to conducting this

case study. Yet, even such institutional review processes did not prepare me for encounters in the field. Guillemin et al. (2004) have coined the terms 'procedural ethics' generally relating to institutional ethics committee review and 'ethics in practice' describing unanticipated ethical issues arising in the field. Similarly, Pollock (2012) describes this latter process as micro-ethics. Pollock argues that micro-ethical practices are

*'based on judgement rather than rules, and relies on the cultivation of 'ethical mindfulness' on the part of individual researchers' (p.3)*

Paper four's value is that it helps illustrate to novice researchers that while not all ethical issues can be anticipated when conducting multi-perspective interviews in the field, sensitive and mindful attention to reflexive practices can help address any issues as and when they arise.

## **5.4 Reception of paper four**

So far paper four has not received any citations. However, a related oral paper entitled '*Constructing Knowledge in Family Research: The Impact of Methodological Choices*' was presented at the International Institute for Qualitative Methodology's Qualitative Methods Conference in Glasgow in 2016 and was well received (Carolan et al. 2016 (b)).

## **5.5 Critical reflection of the methodology and methods used in paper four**

### **5.5.1 Pedagogy of research methods**

Paper four was judged during the peer-review process on its pedagogical value which enabled me to critically reflect on the choices I had made during my case study design. However, the guidance by the editors at *SAGE Research Methods Cases* was very prescriptive. Thus, paper four was not written in the same manner as a research-based journal article. I found writing in this style somewhat unnerving. Indeed, it reminded me of writing reflective accounts of clinical practice for my GP appraisal and revalidation. However, I recognise that this reflective style is intended to encourage student engagement and learning.

Paper four adopts two acknowledged pedagogical approaches to research methods teaching: first, making the research process visible by actively encouraging and engaging students in the aspects of the methods at hand; and second, by critical reflection on research practice (Kilburn et al. 2014, p. 197). Illustrating how methods operate in the field, including difficulties and challenges faced facilitates making the research process tangible to students, shifts students'

understanding to enable them to visualise application of theoretical constructs (Keenan 2012). Importantly, the paper presents clear learning outcomes and follow up discussion questions as it asks the student reader to critically engage with learning about the method rather than simply reading the text as they might do in a standard research textbook or journal article about methods. Adopting such an approach promotes active learning (Keyser 2000; Lewthwaite et al. 2016), fosters a student-approach and enhances the visibility of the research process (Keenan et al. 2012; Kilburn et al. 2014; Lewthwaite et al. 2016).

Using reflective practice (Schon 1983) was employed as a further pedagogical approach by demonstrating my own critical reflection on the research method of multi-perspective interviewing (Kilburn et al. 2014). The exercises and discussion section were carefully considered and asked student readers to critically appraise the approach to multi-perspective interviewing I had adopted and to help them unpick any assumptions they held or had not consciously considered. Including such exercises and discussions moves away for didactic methods of knowledge translation and promotes active learning (Keyser 2000). Moreover, reflectively sharing with fellow students the messiness and challenges that I had encountered in the field might prove a useful method of lessening concerns about their capability in using research methods (Pan and Tang 2004). In retrospect, I would hazard that as a novice family researcher I would have undoubtedly benefitted from participation of peer-group teaching using pedagogical papers such as paper four presents as method to enhance deeper understanding about research methods and promote a community of research practice for students.

### **5.5.2 Patient and public involvement**

Paper four clearly evidenced how patient and public involvement (PPI) shaped the process of research design in the case study approach and research methods used. Accordingly, reflection of paper four provides opportunity to further consider how PPI was used in the case study and to critically reflect on its contribution to study design. To recap, two user groups, the Lewis and Harris Breast Cancer Support Group and the Hebridean Men's Cancer Support Group were involved in the design of this research in a consultation model of patient and public involvement (PPI) (INVOLVE 2012). The groups comprised cancer survivors, patients living with cancer and family members of those bereaved by a cancer diagnosis, with many participants in the group identifying with dual perspectives. The user groups authenticated the definition of family and endorsed the use of the term emotional distress in preference to the term psychological distress and informed the design of the study documentation including the letter of invitation to

families, participant information leaflets, the '*Accessing further help and resources information sheet*' and consent forms. The user groups contributed to the sampling design by informing the choice of method of access to family members employed in this study and by informing the decision making to limit the sample to triads rather than whole families.

Access to these groups was facilitated through my professional role as local GP. Groups were offered involvement but were not pressured into participating, thus preserving their autonomy and mitigating concerns about the ethics of involving user groups in palliative care research (Johnston et al. 2008). Whilst accepting that ease of access was an influencing factor in the choice of user groups it was evident that the collective experience of both groups would enrich study design by drawing from their considerable expertise both as cancer patients but also family members. I already knew several users as patients in my role as a GP and I was concerned as to whether this could further augment potential risks of unequal power within the researcher-user group relationship (Occlou and Matthews 2016). I was pleasantly surprised that the user groups did not (to the best of my knowledge) perceive their involvement in this research as a tokenistic exercise (Johnston et al. 2008). Indeed, user groups actively challenged the epistemological premise of expert professional knowledge (Forbat et al. 2009), in their emphatic rejection of the term psychological distress and stated preference of the term emotional distress.

The importance of PPI in both clinical practice and research has been emphasised in Scottish Healthcare Policy for almost twenty years (SEHD 2000; SEHD 2001) with the explicit intent that user involvement will transform and improve services (Scottish Government 2007). Additionally, within palliative care research the use of PPI has been advocated as good research practice (Payne et al. 2005) with transformation of participants from passive objects of inquiry to active participants in research considered an ethical obligation (Scottish Partnership for Palliative Care 2011). Moreover, including service users at the outset is purported to ensure that research outcomes will be relevant and applicable service users (INVOLVE 2012). However, despite these laudable aims there has been limited evidence of user involvement in actual practice (Attree et al. 2008; Hubbard et al. 2007).

Hanley et al. (2004) differentiates between consultation, collaboration and user-controlled involvement in a hierarchy of involvement and reflects differences in the balance of power and control between researcher and user groups (Forbat et al. 2009). I considered that user-controlled involvement research was not appropriate for my research study given that it is part of a PhD which is an independent, assessed programme of study. I judged that a collaborative

method of involvement might be potentially problematic due to the necessary commitment both parties to engage in active, ongoing, partnerships (Hanley et al. 2004; INVOLVE 20012). First, several members of the group and their family members were living with cancer and may have been unable to commit to on-going partnership over a project which because of anticipated recruitment problems was likely to span a prolonged period. Second, good practice suggests that user groups should be prepared for this role and offered training to support them. As a novice researcher I did not feel I had the necessary experience nor skills to offer this support. Additionally, offering this through a third party would have been challenging due to the remote location of the user groups together with financial constraints of a resource limited PhD. Finally, living in a remote and rural geographical location can lead to blurring of roles between professional practice and other domains of life (Carolan and Campbell 2016 (c)). For part of the study I worked as locum GP across the isles of Lewis and Harris and so could potentially encounter users in my capacity as a GP and while not close friends with users I knew some well enough to stop and chat in the local supermarket. I had concerns that if I fostered closer relations in the *collaborative researcher-service user relationship* that this could also potentially lead to blurring of boundaries in *GP doctor-patient relationship* and impact on patient's future help-seeking behaviours (Farmer et al. 2006). I therefore chose a consultation model of PPI with this choice informed by the nature and aims of my study.

Benefits in shaping the research process as described in this case study have been similarly described elsewhere (Brett et al. 2014). Additionally, user groups expressed their willingness to be involved and as either historic, current or future users of healthcare services; users expressed that they were keen to "*give something back*" to healthcare services and "*improve future care to patients and their families*" consistent with existing literature (Johnston et al. 2008; Knighting et al. 2007). Brett et al. (2014) document that PPI can also pose challenges particularly if clashes occur between users wants in study design and the need to ensure academic rigour. However, this was not realised in the case study design as the method of sampling chosen by user groups was supported by the literature although I concede that the use of user groups informing study methodology was limited and hence perhaps why I did not encounter further significant challenges. However, the demographics of the user groups merits scrutiny, all members were white ethnic British and almost all users were of retirement age. Thus, the experiences of younger cancer patients and those from black and ethnic minority groups informing study design did not feature. This narrow composition of user groups mirrors existing PPI literature and potentially places some limits on the efficacy of PPI (Occlo et al. 2016).

Framing of the utility of PPI follows the premise that the findings of meaningful research shaped by services users is more likely to be implemented into clinical practice (Hanley et al. 2004). Involvement in health service planning and development indicates that the impact of change is poorly evaluated with outcomes of user involvement uncertain (Crawford et al. 2002). Similarly, Attree et al. (2008) found little evidence of the effectiveness of user involvement in the planning, commissioning and delivery of cancer care services. More recently while EPIC (Evidence base for Patient and public Involvement in Clinical trials) has evidenced positive impacts of PPI on the research process, translation of these outcomes into distal clinical impacts is not yet evident (Dudley et al. 2015). Nevertheless, from the context of the case study I conducted I am confident that PPI undoubtedly enhanced the research process and I believe this will have strengthened the findings of this thesis.

### **5.5.3 Multi-perspective interviewing and knowledge production in this case study research**

As paper four presents a critical reflective account of multi-perspective interviewing it is somewhat redundant to repeat an extensive critical reflection of methods here. However, within the exercises and discussion session of paper four I posed some discussion questions. These questions merit a response in relation to the conduct of interviews in this thesis. Some of these questions will be addressed here and others within the critical reflection of methodology and methods presented in chapter 8.

In nearly all the families I conducted the patient interview first, followed by individual family member interviews and then family group interviews. It was imperative when interviewing participants from one family that I did not carry forward with me any biases from interviewing one family member to the next (Reczek 2014). If this research had not been conducted as part of a PhD study, conducting concurrent interviews using multiple researchers may have negated this risk. Additionally, such concurrent interviewing may have minimised risks to confidentiality and ensured families had not prepared a unified account by sharing details about the interview schedule (Reczek 2014).

The sequencing of interviews merits further scrutiny. If I had conducted all family interviews first, I would have been able to follow up any issues raised at subsequent individual interview; this might have led to richer data being obtained. Conversely, some families described some initial concerns about participating in the family group interviews, however these were subsequently allayed because of rapport generated during individual interviews. Had I

conducted the family group interview first, it is possible that insufficient rapport with families would have been established; this might have equally impacted on the richness of data collected.

Paper four signals that philosophical assumptions are important in multi-perspective interviewing, however given that the paper's brief was to engage research novices, an expansive debate of ontology and epistemology was not fully explored. Without becoming overly embroiled in philosophical debates it is appropriate to provide some additional clarity to unpick nuances within this case study research relating to knowledge production from multiple perspectives. This is important to contextualise data analysis and reporting in the two findings papers (papers five and six) in this thesis.

The preceding chapter, chapter 4, signalled that this research was underpinned by a relativist ontology assuming multiple constructed realities and was informed by symbolic interactionism (Blumer 1986). Thus, it aligns with constructivist research approaches where meaning is created through interaction and interpretation (Reczek 2014). McNamee (2004) thoughtfully considers the differences between constructivism (with its orientation to internal cognitive processes of individuals) and social constructionism (with its orientation to discourse and joint activity between individuals). It could be argued that because this case study used individual participant interviews and family group interviews that I would be torn between what some perceive to be competing orientations between constructivism and constructionism. McNamee (2004) argues that rather than perceive constructivism and constructionism as competing perspectives, that these perspectives can be bridged because both focus on meaning making and how people co-create their experience and world together. Accordingly, within this case study research I have aligned with McNamee's (2004) co-constructed bridge which places focus on the meaning of distress and help-seeking for distress and seeks understanding of the co-creation of experience.

Paper four outlines some of the philosophical debates relating to the role of the researcher in knowledge production in multi-perspective family research studies. Throughout this research process I was torn between my constructivist beliefs and the pragmatic need to produce phronesis to inform clinical practice and care delivery to a healthcare audience who, for the most part, are firmly entrenched in positivist objectivist traditions (Greenhalgh et al. 2016). Therefore, Ribbens McCarthy et al.'s (2003) intermediate position of a reflexive bird's eye view held much appeal. While some authors have conceived this position through a post-positivist lens to produce the least false interpretation of family account (Warin et al. 2007) others have

located this position closer to a constructivist stance to interpret the meaning of convergent and divergent data (Zartler 2011).

Hence, as paper four describes I have adopted the reflexive bird's eye view to iteratively interpret convergent and divergent data. Adopting this stance enables me to balance my commitment to honouring the philosophical assumptions of a relativist ontology and intersubjective epistemology whilst producing findings which will be accepted by my medical and healthcare professional peers. Critically, acceptance of these research findings by my peers will mean that this research can influence clinical practice to enhance the care of patients and their families.

## **5.6 My contribution to paper four**

CC conceived the paper, wrote the manuscript and was the sole contributor. AS reviewed the manuscript before submission in her role as PhD supervisor.

## **5.7 Choice of journal for paper four and journal standing**

Paper four is published in *Sage Research Methods Cases*, a highly respected online platform, rather than a traditional journal. *Sage Research Methods Cases* is committed to the development of social science research methods (<https://uk.sagepub.com/en-gb/eur/sage-research-methods-cases>). Cases published examine a range of issues in research study design and application. The pedagogical design of the cases means *Sage Research Methods Cases* is of interest to students, academics and researchers from a wide range of disciplinary perspectives. It does not attract an impact factor but is internationally recognised for its excellence in furthering understanding and application of research methods in practice.

## **5.8 Progressing the thesis**

The next part of the thesis will report on the case study findings. The findings of this case study research are presented as two submitted publications. Chapter 6 will present paper five and Chapter 7 will present paper 6. Because these papers report findings from the same overarching case study design, the structure of the subsequent chapters differs slightly from preceding chapters to prevent unnecessary repetition. Thus, instead of providing a separate critical discussion of methodology for papers five and six within each chapter, a critical reflection of the case study methodology used will be presented in Chapter 8. The final chapter, chapter 9, will

demonstrate how these six publications have addressed the research aims and objectives before presenting the conclusions of the thesis.

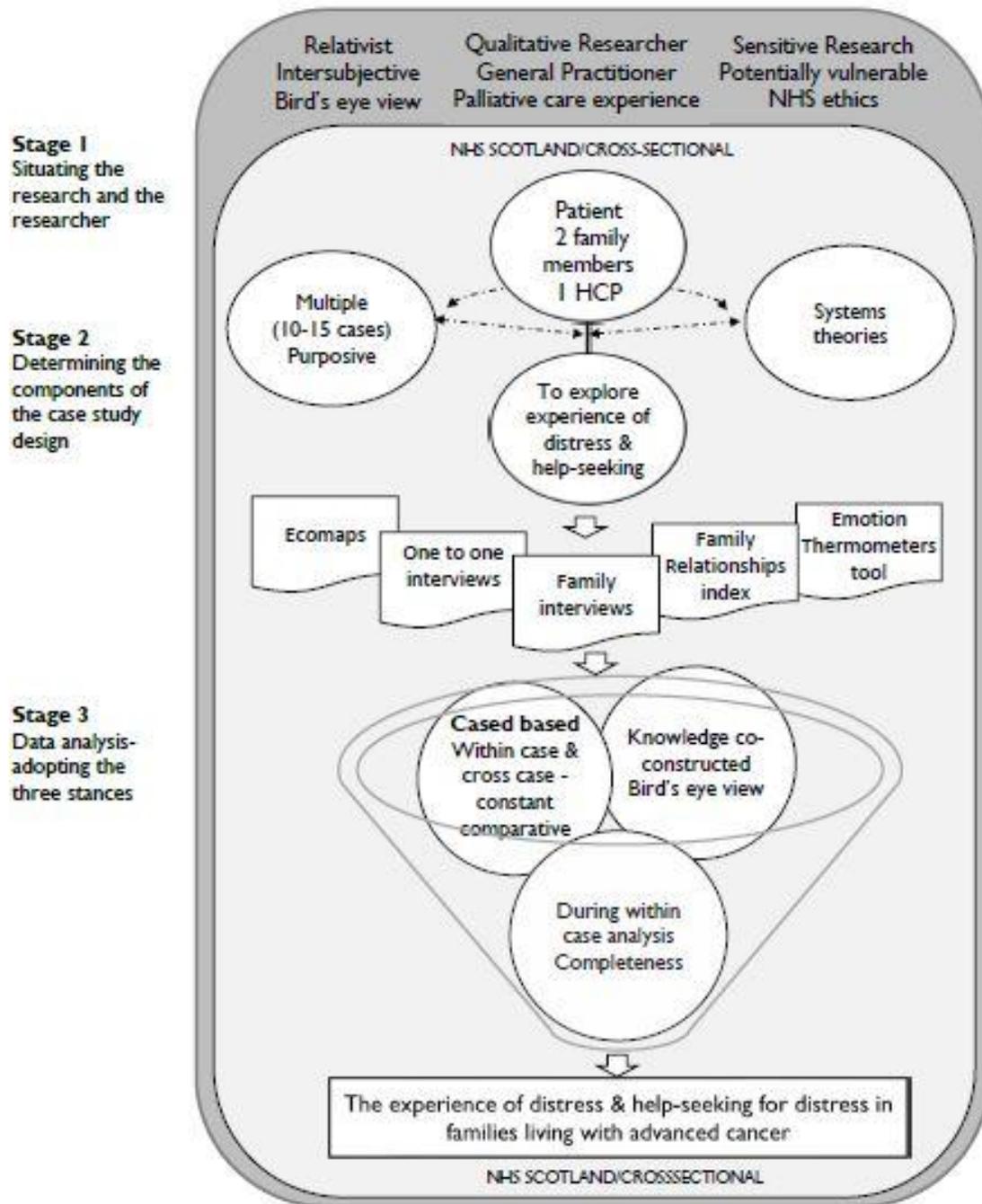
### **5.8.1 Ethical approvals and study documentation**

The ethical approvals for the conduct of this research are included as appendices (Appendix 1-3). The nature of this multi-perspective research and the subsequent conversion of this research from a single site study to a multi-site study meant that this study's supporting documentation extends to almost 30 documents. Word limits within this thesis includes appendices and has limited inclusion of all the supporting study documentation within the appendices (Appendix 4-14).

### **5.8.2 Schematic of the case study design**

As paper three suggests the DESCARTE model can be used to generate a schematic template to convey case study design. A schematic template for the overarching case study design is conveyed on the next page.

Figure 3: Schematic of the overarching case study design



## **5.9 Chapter summary**

In this chapter I have presented paper four which critically reflects on the use of multi-perspective interviewing used in this case study research. I have positioned paper four as a pedagogical paper and outlined its contribution to the pedagogy of research methods. I have critically reflected on the method of multi-perspective interviewing employed and I have described the contribution of public and patient involvement to the design of this case study research. I have signalled how my underpinning philosophical approach has influenced the subsequent analysis of multi-perspective interviews from families.



## Chapter 6

### 6. Paper Five: Carolan, C.M., Smith, A. and Forbat, L. The experience of emotional distress in families living with advanced cancer: a multi-perspective case study approach.

#### 6.1 Rationale for paper five

Paper one in this thesis has identified a gap in systemic understandings of emotional distress in families living with advanced illness. Such understanding is necessary to theorise the development of systemic distress interventions for families. The rationale for proposing a case study approach to investigate the experience of emotional distress in families has been already outlined in earlier sections of this thesis.

It is important to signal that while papers five and six are derived from the same overarching case study design, there are nuanced differences in how cases are constructed and thus how findings are reported within each paper. In this paper, paper five, the case is constructed as families living with advanced cancer and receiving palliative care. The purpose of the study is to explore the experience of emotional distress in families living with advanced cancer. Thus, this paper only reports from data gathered from within the family system and does not include data gathered from telephone interviews with healthcare professionals.

#### 6.2 Paper five

This paper is submitted to *Psycho-Oncology*. However, a related oral paper entitled '*Developing multi-perspective methodology: using triadic family interviews to understand experience in families*' was presented at the Palliative Care Congress in Glasgow in 2016 and was well received (Carolan et al. 2016 (d)).

Paper redacted due to publisher restrictions

### **6.3 Critical review of the contribution of paper five to the field**

Paper one evidenced the conceptualisation of emotional distress in families as a systemic construct but indicated that current understandings of distress were theoretically immature. Paper five's value is that it cements conceptualisation of distress as systemic and develops our understanding of distress as a relational phenomenon. Emotional distress as a relational phenomenon is operationalised in two interconnecting ways. First, as emotional distress relationally experienced within the family system. Second, as a product of relational interaction between the family microsystem and the healthcare exosystem. New understandings offered to the field are now explicated. Such understandings will have utility in the design of new interventions and shape current care to enhance the emotional wellbeing of families.

#### **6.3.1 Emotional distress within the family system**

Paper five advances understandings of emotional distress as relationally experienced within the family system distress in four novel ways: oscillatory distress, family conflict, private and shared distress, and total distress.

##### **6.3.1.1 Oscillatory distress: being towards life and being towards death**

Paper five is novel because it describes how families oscillate between dual perspectives of being towards life and being towards death and how this influences distress experience. The salience of these understandings is that it provides a new theoretical underpinning to inform the development of three possible systemic level interventions to ameliorate emotional distress in families living with terminal illness.

Being towards life describes efforts by families to maintain the integrity of family and the flow of family life. These findings build on individual level descriptions of the desire to maintain normality in the face of life limiting illness described by patients (García-Rueda et al. 2016) and caregivers (Penrod et al. 2012) and confirm similar family level findings described by Mollerberg et al. (2017) in their study of families with advanced cancer. In contrast, being towards death, means families describe how distress is provoked when the integrity of family is threatened by the disruptive impacts of illness. Paper five provides a fresh perspective on current understandings of cancer as biographical disruption. Cancer as biographical disruption is well described in patients (Broom and Cavenagh 2011; Carlander et al. 2010; Reeve et al. 2009) and caregivers (Duggleby et al. 2017; Martin et al. 2016; Ugalde et al. 2012). Paper five adds to understandings of cancer as biographical disruption by shifting conceptualisation of disruption

beyond the individual biographies of individuals to the collective biography of family. While Mollerberg et al.'s study cited above described biographical flow in families the study did not report disruptive threats to the integrity of family and contrasts with findings from paper five. Mollerberg et al. used family group qualitative interview methods only and it is possible that protective buffering operated during these family interviews and explains why this finding was not reported by families in their study.

As paper five indicates, the disruptive impacts of advancing illness were experienced by families in a plurality of ways and builds on existing literature describing the disruptive impacts of: bodily disintegration and physical decline (Ellis et al. 2015; García-Rueda et al. 2016; Hendriksen et al. 2015); loss of autonomy (García-Rueda et al. 2016; Hendriksen et al. 2015; Ventura et al. 2014); social isolation (Fletcher et al. 2012; Ventura et al. 2014; Ward-Griffin et al. 2012) and role and relational changes (Fletcher et al. 2012; García-Rueda et al. 2016). While loss and death posed the ultimate disruptive impact to the integrity of the family, some families described that activities such as legacy planning (which can aid the linear coherence and integrity of family) ameliorated the distress of being towards death. Findings from paper five thus support the utility of Dignity Talk (Guo et al. 2018) as a systemic level distress intervention in families living with terminal illness.

Reeve et al.'s (2009) Self Integrity Model depicts how distress arises when patients living with advanced cancer are unable to sustain biographical flow. As paper five illustrates, one respondent (wife 12) clearly describes how being unable participate in shared family activity which sustained their couple identity within their family system caused distress. In contrast paper five describes that setting family goals together helped maintain the integrity of family and ameliorated distress. Currently, goal setting is not routinely employed in palliative care settings, perhaps reflecting its cultural heritage in rehabilitation settings (Boa et al. 2014). A UK hospice study using goal setting and action planning [G-AP] was deemed acceptable to patients and demonstrated an increase in motivation and self-efficacy (Boa 2013). While Boa's (2013) study did not examine distress outcomes, findings from paper five help theorise the potential utility of systemic application goal setting and action planning [G-AP] as a family distress intervention and merits further investigation.

Findings from paper five indicate that unlike traditional conceptions of liminality, as a linear space betwixt life and death as a linear process through which individuals progress (Turner 1979; McKechnie et al. 2010), that families can hold dual perspectives of being towards life and being towards death. Paper five draws parallels and adds to Rodin and Zimmerman's (2008)

concept of double awareness. Double awareness describes how patients have *'the ability to shift flexibly between these multiple self-states pertaining to matters of living and matters of dying, according to the demands of the present situation'* (Colisimo et al. 2018, p.126).

Double awareness means that individuals can appear to simultaneously hold two contradictory self-states of living and dying (Rodin and Zimmerman 2008). Colisimo et al. (2018) have reflected on similarities between double awareness and Stroebe and Schut's (1999) dynamic dual-process model of grief in which adjustment to loss occurs between alternating perspectives of loss-orientated coping and restoration orientated coping (p.3).

Findings for paper five similarly show that families also described dual conceptions of being towards life and being towards death. However, in contrast to double awareness findings from paper five suggest that families can oscillate between states rather than hold simultaneous perspectives. Paper five is valuable because it can advance conceptualisation of double awareness to yield a systemic understanding. Borrowing from Colisimo et al. (2018) I would propose a systemic definition of double awareness in families as *'families' ability to shift flexibly between these multiple family-states pertaining to matters of living and matters of dying, according to the demands of their present situation'*.

Such understandings are important in helping to theorise family level distress interventions. 'Managing Cancer and Living Meaningfully (CALM)' therapy is brief psychotherapeutic individual-level patient intervention which fosters double awareness to reduce distress and promote emotional well-being in palliative care (Hales et al. 2015). Conceptions of oscillatory distress in families suggests the utility of dyadic and systemic application of CALM therapy and should be explored further.

### **6.3.1.2 Family conflict**

Paper five provides novel insight into current understandings of family conflict and consequent distress. Family function as a predictor of psychological morbidity in families is well established in the palliative care literature (Kissane 2017). To date, understandings of family conflict in palliative care have predominately adopted quantitative approaches to identify deterministic predictors of family conflict and typologies of family function (Kissane et al. 1994; Kissane et al. 1998, Ozono et al. 2005; Kramer et al. 2010; Schuler et al. 2014; Kraemer 2015; Nissen et al. 2016; Hamano et al. 2018; Dieperink et al. 2018). Currently, qualitative understandings of family conflict in palliative care are rare. Two studies have investigated caregiver and healthcare professional perspectives through qualitative survey data (Kramer et al. 2006) and qualitative

interviewing (Boelk et al. 2012). However, neither study included patient perspectives and therefore limits systemic understandings of conflict. Thus, paper five is novel and provides unique understanding of family conflict because of the underpinning study design.

Paper five indicates that intra-familial conflict is not a homogenous concept but can be experienced as safe or unsafe conflict. Data indicate how past and present family context, moral judgement and communication practices shape conflict within the family space. Thus, family space can be conceived as a physical space, a relational communicative space and a temporal space. The disruptive impacts of terminal illness within the family home are recognised (Morris et al. 2015; Milligan et al. 2016) with contentions about ownership of physical space within the home similarly described (Milligan et al. 2016). Paper five echoes these findings but moreover indicates how these changes to the physical space of home can produce unsafe conflict and distress.

Paper five's importance is that it illustrates how moral judgements about caregiving potentiated conflict and distress. Judgements within families about attribution of family roles (Hamano et al. 2018), gendered divisions of caregiving (Morgan et al. 2016) and sense of support within the family system (Miliberg et al. 2014) are not new. However, paper five provides additional insight into the consequences of these judgements. During unsafe conflict families hid concerns (Mollerberg et al. 2017) and used self-silencing (Jack 1991; Jack 1999) to limit unsafe conflict and prevent relational breakdown. However, such self-silencing engendered emotional distress which often remained undisclosed within the family system.

The use of self-silencing to avoid conflict within patient-primary caregiver dyads has similarly been described by Ussher and Perz (2010) and similarly described distress consequent on self-silencing. Paper five's worth is that in addition to describing how self-silencing occurs within the patient-family caregiver dyad it demonstrates this also occurs within the primary caregiver-secondary caregiver dyad with consequent distress caused. Ussher et al. (2013) argues that the inter-relationship between self-silencing and distress is why couple therapies (facilitating relational coping and communication) reduce distress. However, the tenets of couple therapy in spousal dyads may not necessarily apply to primary-secondary caregiver dyads. Further research to understand how best to promote relational coping and communication between family caregivers to prevent family distress, conflict, and relational breakdown is thus merited.

### **6.3.1.3 Private and shared distress**

Paper five contributes to understandings of family communication and draws attention to how communication patterns shape the experience of distress. This can be considered in terms of private distress as distress that is only known to the individual and not communicated to others; and shared distress as distress communicated to another (or others) within the family system. Shared distress which was freely communicated within the family system generally pertained to unnecessary distress consequent on adverse relational interaction with healthcare. In contrast, private distress was often the distress of being towards death. Such distress was considered difficult to share because of the threat of engendering recursive distress; such protective buffering is well described in the literature (Coyne and Smith 1991; Langer et al; Manne et al. 2007). Distress which remained private because of self-silencing (Jack 1991; Jack 1999) to prevent escalation of family conflict and has been explicated in the preceding section.

Allied to such protective buffering was informational communication practices in which information could also be held privately as information which was either hidden or withheld from others. Paper five shows that such informational communication practices contributed to the experience of familial uncertainty. This was particularly salient for distant caregivers with control of information often being held by either the patient or spouse. Such practices were similarly described in Mollerberg et al.'s qualitative study of families. Ngwenya et al. (2016) have recently described similar relational communication practices to paper five relating to how bad news is owned and controlled with the family system. Ngwenya et al. have interpreted their findings using Communication Privacy Management theory (Petronio 2002; Petronio and Reiersen 2009) to describe the flow of information in families. Paper five adds to understanding by revealing how these relational informational communication practices in families can generate distress. Appreciating this is vital to help professionals shape the support they can offer to families to help them share difficult new information within their family system.

Paper five is important in that it indicates substantial barriers to collectively sharing of emotional distress within families. Such understanding is vital for the design of any systemic distress interventions which are predicated on the need for disclosure and sharing of emotion within the family system. Clearly such barriers may limit the acceptability of some proposed intervention designs and therefore paper five provides useful insight for those contemplating systemic design.

#### **6.3.1.4 Total distress**

Paper five furnishes novel qualitative insight into the predominately quantitative description of distress as a systemic construct (Carolan et al. 2015). However, such studies which only focus on quantitatively demonstrating the interdependency of emotional distress are unable to convey the complexity of total distress experience in families. In contrast, paper five valuably describes how emotional distress is inseparable to other forms of distress including physical, functional, financial, social, and existential distress and is recursive within the family system. Additionally, paper five demonstrates that distress oscillates and fluctuates over time as it mirrors shifts in symptom experience, functional status etc. While fluctuation in distress is recognised as occurring across the cancer trajectory (Murray et al. 2007; Murray et al. 2010) paper five proposes that distress also fluctuates within the discrete trajectory of palliative care. If fluctuating distress is the natural history of distress within the period of palliative care this has inevitable implications for how the efficacy of distress interventions are judged. Longitudinal investigation of emotional distress in families is warranted to explicate understandings of distress oscillation over time.

Admittedly one could argue that findings in paper five simply align with the long-established concept of total pain in palliative care coined by Cicely Saunders (Clark 1999). However, the concept of total pain has been traditionally applied to individual patient experience within palliative care. Findings from paper five suggest that the concept of total pain should advance beyond individualistic application to encompass total distress of the family system. Reciprocally, this means that the holistic practice synonymous with palliative care necessitates a double holistic turn, meaning that professionals must simultaneously attend to the total pain of the patient and the total distress of the family.

#### **6.3.2 Emotional distress within the mesosystem**

Paper five provides new understanding as to how relational interaction and everyday acts by healthcare professionals occurring within the mesosystem between the families and healthcare cause emotional distress in families. Paper five's findings mirror a wealth of established literature which report on the experience of the uncertainty of living with terminal illness described by both patients and their family members (Brobäck and Berterö 2003; Carduff et al. 2016; Duggleby et al. 2016; Etkind et al. 2017; Hendricksen et al. 2015; Kimbell et al. 2016; Lobb et al. 2013; Mazanec et al. 2011; Schilling et al. 2017).

Paper five advances understandings of uncertainty in terminal illness because it describes how living with uncertainty provoked distress, particularly anxiety within the family system. Importantly paper five shows that healthcare practices which mitigate uncertainties about current and future illness experience and mitigate uncertainty about current and future care provision prevented emotional distress in families. These findings add to studies which demonstrate that a 'sense of security' in care (Milberg et al. 2012; Milberg et al. 2014; Sarmiento et al. 2017) and a 'sense of preparedness' (Henriksson and Årestedt 2013) mitigate uncertainty and enhance emotional well-being. Moreover, paper five emphasises that distress can be caused inadvertently by healthcare professionals if the pacing of care is not congruent with families' wishes. Paper five thus illustrates that while tenets of proactive and planned palliative care are to be advocated, preparedness for care decisions must be first assessed (Brighton and Bristowe 2016) and shared decision making employed (Belanger 2017). Paper five is therefore clinically important because it signals to healthcare professionals that care *done to* people and not *with* people can provoke unnecessary distress in families, with the ripple effect of this distress experienced recursively within family the system.

Paper five provides new understandings of how families perceive their worth and value by systems of care with perceptions of being second class patients because of their non-curative diagnosis. Such findings resonate with Collin et al.'s (2017) study describing palliative care as diminished care and Zimmerman et al.'s (2016) study describing the stigma of palliative care. Collins et al. (2017) argues that patients' and caregivers' understandings of palliative care have not progressed with professional understandings of palliative care. Both Collins et al. and Zimmerman et al. suggest the need for better education and public health initiatives to disentangle understandings of palliative care (Collins et al. 2017, p.825). While such aims are laudable, paper five proffers an alternative, if somewhat uncomfortable stance, that families perceive they are second class and receive diminished care because this reflects the reality of their lived experience. Whilst fully accepting that findings from paper five cannot provide nomothetic generalisations it does proffer an alternative conception which merits further investigation.

Paper five is valuable because it clearly reports how the absence of relational care to families by healthcare professionals causes distress which is perceived by families to be unnecessary and moreover adds to the distress of living with advanced illness. Relational care operates at both the individual level (with the need to validate personhood) and at the systemic level (with the need to validate familyhood). The importance of validation of personhood, relational

humanitarian communication, and personalised care is well described in the cancer (Thorne et al. 2005) and palliative care literature (Johnston and Smith 2006; Murray et al. 2015; Reeve et al. 2012). Validation of personhood is valued by both patients and family members (Aparicio et al. 2017) and has been recognised as a mechanism by which to promote resilience in caregivers (Roen et al. 2018). Conversely, failure to validate the individual personhood of patient or caregiver as described in paper five is recognised as causing distress (Reeve et al. 2012; Roen et al. 2018; Ward-Griffin et al. 2012).

Absence of relational care and healthcare professionals' lack of validation of 'familyhood' caused significant distress impacts throughout the family system. This was particularly salient for adult children who often felt remote or excluded from care even if they cohabited the same home as patients. Similar findings of distress in distant adult caregivers living remotely have been reported by others (Mazanec 2012; Mazanec et al. 2011; Oikonen 2015). Paper five adds to these understandings of distress in adult caregivers by emphasising that distress consequent on perceived remoteness from care is not necessarily predicated on geographical location but by the practice of relational care by healthcare professionals.

Paper five thus builds on Sampson et al.'s (2014) palliative care service evaluation which indicates that emotional aspects of care are of central significance in families' experience of palliative care and is embedded in relationships mediated by communication and tenor of care (p.291). Thus, findings from paper five progress theorisation of distress consequent on the lack of relational care beyond the individual to family focussed understandings.

Paper five is novel because it adds to our limited understanding of conflict with professionals in healthcare settings (Francois et al. 2017). Francois et al.'s (2017) qualitative study examining relationships between families and healthcare professionals in a specialist palliative care setting identified that emotional upset was consequent on conflict between families and professionals. Conflict was conceived as sub-optimal communication and mismatch in shared understanding and goals of care; systems issues, including professionals having limited time to care amplified conflict (Francois et al. 2017). Healthcare professionals predominated in Francois et al.'s study sample with only seven bereaved caregiver and no patients sampled. In contrast, paper five is of novel value because it contributes to understandings of the contemporaneous experience of conflict in families.

Importantly paper five shows that trusting relationships with Macmillan cancer nurse specialists mitigated causes of systemic conflict. Davies et al. (2017) has recently described such mitigation

of systemic conflict in their longitudinal study of relationships in paediatric cancer care. Drawing from attachment theory Davies et al. (2017) describe a process of 'containment' whereby a single trusting relationship with a healthcare professional can provide a secure base to mitigate systemic conflict. How such attachment operates within adult palliative care warrants further exploration.

#### **6.4 My contribution to paper five**

CC conceived the study. CC designed the study and all the study materials with constructive critique by LF and AS in their role as PhD supervisors and with input from two patient and carer support groups. CC obtained all the necessary ethical and research governance approvals. CC collected and analysed all the data. AS and LF assessed the robustness of the analysis in their roles as PhD Supervisors. CC drafted and wrote the manuscript with amendments suggested by AS and LF. Estimated contribution to the paper: CC 90%, AS 5%, and LF 5%.

#### **6.5 Choice of journal for paper five and journal standing**

*Psycho-Oncology* is a highly respected internationally acclaimed peer-reviewed journal devoted to furthering understandings of the psychological dimensions of cancer. It has a wide ranging multidisciplinary audience including those directly involved in clinical cancer care and service planning; this includes academics, clinicians and policy makers. *Psycho-Oncology* seeks to understand the psychological impacts of cancer throughout the cancer trajectory, including patients and their families who are living with advanced illness. *Psycho-Oncology* has an impact factor of 3.455 (18<sup>th</sup> July 2018).

#### **6.6 Chapter summary**

In this chapter I have reported the findings of the case study of emotional distress in families living with advanced cancer. I have proposed emotional distress as an interdependent relational phenomenon within the family system and as a product of relational interaction within the mesosystem. I have shown the interrelationships between distress and uncertainty, communication, intra-familial conflict and healthcare conflicts. In conceiving distress as an oscillatory distress, I have theorised three possible systemic distress interventions. The salience of unnecessary distress which arises as a product of relational interaction with healthcare professionals and systems of healthcare is described.

## **Chapter 7**

### **7. Paper Six: Carolan, C.M., Forbat, L. and Smith, A. Help-seeking for emotional distress in families living with advanced cancer: a multi-perspective case study approach.**

#### **7.1 Rationale for paper six**

Paper two in this thesis has identified a gap in systemic understandings of why families living with advanced cancer choose to seek help (or not) for the emotional distress and what influences these actions. Such understanding is necessary to develop family-focussed psychosocial care that will be relevant and acceptable to families. The rationale for proposing a case study approach to investigate the experience of help-seeking for emotional distress in families has been already outlined in earlier sections of this thesis.

#### **7.2 Paper six**

This paper is submitted to *BMC Palliative Care*.

Paper redacted due to publisher restrictions

### **7.3 Contribution of paper six to the field**

Paper six is the first qualitative study to investigate families' help-seeking behaviours for emotional distress and provides several new insights which contribute to our understanding of help-seeking for emotional distress in families living with advanced cancer. Paper six builds on two salient understandings proposed in paper two. First, congruent with the Attaining Normality Model, families choose not to seek help for emotional distress because they normalised and accommodated distress to maintain the normative flow of daily life; thus, they sought to maintain normality. However, as no families sought help for distress, conceptions of families' seeking help to achieve a new normality were not evident. While some individual participants described seeking help to reassert a perceived loss of control when distress could no longer be accommodated, unlike findings from paper two this was not conceptualised in relation to efforts to seek a new normality. It is possible that participants in paper six did not describe seeking help to attain a new normality because of their advanced cancer status, as opposed to paper two which was heterogeneous for cancer-stage.

Second, like paper two, paper six shows how interactions within the family system influence help-seeking including: (i) interpreting and evaluating of distress; (ii) coercing and sanctioning help-seeking; (iii) being a mutual source of help; (iv) facilitating access to formal help (v) inhibiting distress disclosure and through this inhibiting help-seeking (vi) and as a temporal influence on help-seeking via historical family scripts. Again, as already described in Chapter 3, paper six adds to existing knowledge of the importance of influence of social networks on help-seeking.

Paper six contributes to the field by proposing the Mutuality Model of Help-seeking for Emotional Distress. Critical to this model is the central positioning of mutuality in understandings between families and healthcare professionals. Paper six provides four new and important insights conceiving why distressed families living with advanced cancer choose not to seek help together as a family for their emotional distress: (i) the legitimacy of family as a candidate for help; (ii) mutuality in understandings of distress; (iii) the stigma of help-seeking; (iv) the perceived value of help.

#### **7.3.1 The legitimacy of 'the family' as a candidate for help**

Paper six demonstrates that the policy ideal of the family as the unit of care in palliative care is not always realised in clinical practice. Findings indicate that the reasons for this are complex

and pertain to how families and healthcare professionals interpret and apply differing conceptions of both the eligibility and legitimacy of the family unit as candidate for help. Particularly salient were distinctions made by families between their 'eligibility for help' and their 'legitimacy for help' in that families knowing that they could receive help did not necessarily translate into families seeking help. Families' prioritisation of care around the patient is well described within the literature (Morris and Thomas 2001; Funk et al. 2010). However, paper six importantly highlights that families' conceptions about their legitimacy and eligibility for help did not occur within a vacuum of their own lay interpretations but was informed through on-going interactions with healthcare professionals.

Paper six indicates that healthcare professionals described significant variation in whether they perceived families as legitimate co-recipients of care. Paper six thus builds on recent findings which highlight that although healthcare professionals working within palliative care purport that care is family focussed, that their own accounts of care highlight implicit contradictions in their day to day practice of inclusive care to families and that care practices remain centred around the patient (Austin et al. 2017; Nissim et al. 2017; Roen et al. 2018). If families are not validated as warranting help during on-going interaction with professionals, inevitably this will recursively impact on their perceived legitimacy for help. Paper six illustrates that families are not always perceived as legitimate candidates for help in day to day palliative care practices and illustrates the disparity between policy ideals and the care experience that families receive.

### **7.3.2 Mutuality in understandings of distress**

Paper six is valuable because it evidences that families' engagement with help is predicated on mutuality in understandings of distress i.e. that candidacy for distress must be asserted by families and recognised by professionals. Like paper two, paper six illustrates the importance of lay conceptions of distress and normalisation of distress by families. Paper six adds to existing understandings that patients and family members do not assert their candidacy for distress either by minimising their distress (Lambert et al. 2017) or not disclosing distress and emotional concerns (Bultz and Carlson 2006; Heaven and Maguire 1997; Okuyama et al. 2009; Ryan et al. 2005). Paper six adds to a wealth of literature demonstrating that candidacy for distress is not recognised because of the behaviours of healthcare professionals including: normalisation of distress (Granek et al. 2018); poor detection of distress and blocking communication behaviours (Griffith et al. 2010; Merckaert et al. 2008; Ryan et al. 2005; Sollner et al. 2001); being reliant on clinical judgement rather than validated tools (Carolan et al. 2016 (c); Ewing et al. 2016; Granek et al. 2018); being reliant on establishing relationships (Austin et al. 2017; Carolan et al.

2016(c); Ewing et al 2016; Granek et al. 2018 Griffiths et al. 2010); having limited time to assess distress (Dilworth et al. 2014); and professionals' own personal discomfort in distress assessment (Carolan et al. 2016 (c)).

Hill et al. (2014) have questioned the established view that familiarity is necessary to provide psychosocial support. Paper six advances this argument by showing that some patients and family members do not need to establish a relationship to disclose distress but rather that disclosure of distress and subsequent help-seeking are predicated on personal attributes and trust in the practitioner. Questioning this established view that distress disclosure is achieved through a process of relationship building is important as some evidence now suggests that established relationships might inhibit mutuality in understandings of distress. First, psychosocial support might be blocked rather than facilitated because of unwarranted assumptions made by professionals (Hill et al. 2014). Second, Lelorain et al. (2014) revealed that the presence of a good rapport with patients inhibited detection of emotional distress in highly distress patients; the authors postulated that this might be because of patients wanting to protectively buffer their healthcare professional.

Paper six's worth is that it clearly illustrates two important practitioner behaviours which negatively impact on mutuality in understandings of distress between families and healthcare professionals: non-explicit methods of distress assessment and person-centred consultation styles. Practitioners' over reliance on non-verbal assessment methods and relationship building over time meant that distress assessment was not made explicit to families within the consultation; thus, families could remain unaware that they were being assessed for emotional distress. Ewing et al. (2016) has recently reported similar disconnects between assessment behaviours described by professionals and perceived by families. Second, practitioners adopted a person-centred approach to distress assessment which meant that some families were uncertain about how to navigate the consultation and what to say to professionals. Person-centred distress assessment coupled with patients' and family members' uncertainties about what was a legitimate level of distress to disclose meant that some did not volunteer their distress during encounters with professionals. Such potential disconnects inhibit the promotion of mutual understanding of emotional distress and opportunities for families to seek help. Such distress assessment behaviours coupled with the variation in practice described by professionals in paper six calls into question how distress is currently assessed within palliative care settings. While clinical guidelines in cancer and palliative care currently promote a tiered model of distress assessment (dependent on practitioner expertise) actual guidance on how this

should be done is unclear (NICE 2004). Thus, paper six has utility in evidencing the pressing need to review current guidance on distress assessment.

### **7.3.3 The stigma of help-seeking**

Findings from paper six reveal that the desire to maintain an autonomous stoic identity inhibited help-seeking and clearly resonates with paper two which reported the meaning of self and the meaning of help-seeking influenced help-seeking behaviours. Paper six builds on these findings by indicating that an autonomous stoic identity inhibiting help-seeking can operate at the individual level of self and at the collectively level of family. The desire to maintain an autonomous stoic identity inhibiting help-seeking was reported in all families. While a few participants described the stigma of a mental health diagnosis inhibiting help-seeking, paper six clearly shows the stigma of help-seeking as a threat to an individuals' or families' autonomous stoic identities. Moreover, for some, the stigma of seeking help provoked shame, guilt and the desire to hide their help-seeking from others.

Current understandings of stigma within mental healthcare derive from Goffman's (1963) seminal work on stigma as a spoiled identity. Blaine (2000) describes stigma as the perception of being flawed because of a characteristic that is deemed as socially unacceptable. Corrigan has distinguished between public stigma and self-stigma; public stigma is a societal perception that an individual is socially unacceptable whereas self-stigma is when an individual internalises these public perceptions with resultant negative consequences for the individual (Corrigan, 2004; Corrigan et al. 2006; Corrigan et al. 2012). Vogel et al. (2007) has demonstrated that perceptions of public stigma can mediate self-stigma, which in turn can mediate attitudes towards help-seeking.

Tucker et al. (2013) used a suite of psychometric instruments to measure and distinguish between the public and self- stigma of mental illness, and the public and self-stigma of seeking psychological help. Tucker et al.'s study showed that the self-stigma of mental illness and the self-stigma of seeking help are two different constructs. Moreover, self-stigma of seeking help explained a larger amount of variance in the intention to seek help than self-stigma for mental illness. Moreover, both self-stigmas were associated with their corresponding public stigmas. Thus, efforts to enhance help seeking for distress by influencing stigma might therefore operate in several ways (Vogel et al. 2007; Tucker et al. 2013). First, healthcare professionals can influence the self-stigma of mental illness and the self-stigma of help-seeking by exploring an individual's or families' perceptions of self-stigma within the clinical encounter. Second public

health initiatives can be derived which can seek to influence the public stigma of mental health and the public stigma of help-seeking.

However, the collective works of Corrigan, Tucker and Vogel described above relate to generic mental healthcare contexts rather than advanced cancer and palliative care contexts. Nonetheless, paper six clearly describes the influence of the self-stigma of help-seeking and shows that in some instances self-stigma for help-seeking was actively addressed by professionals within healthcare encounters and promoted engagement with help. Moreover, findings from paper six suggest that public stigma for help-seeking and public stigma for mental illness may subtly operate within healthcare environments. First, the language used by both families and practitioners was pejorative and implied negative moral judgments about those who seek help suggesting public-help seeking stigma. Second, the prioritisation of physical care over emotional care and the apparent deficits within both the structure and organisation of care suggests that public-stigma about mental illness continues to permeate current systems of care. While the perceived stigma of lung cancer and psychosocial outcomes has been explored (Chambers et al. 2012) no studies with cancer or palliative care contexts have replicated Tucker et al.'s study to untangle the stigma of mental illness and the stigma of help-seeking. Such understandings are necessary to determine where efforts to address stigma might be most fruitfully employed and thereby enhance engagement with emotional supportive care in cancer.

#### **7.3.4 The perceived value of help**

Paper six resonates with the findings reported in paper two which indicate variability in perceptions of the value and utility of help. Paper six is important because it reveals that the perception of the utility of help was influenced by the lens of terminal illness. This signals that caution should be exercised before making generalisations about the utility of interventions derived from heterogeneous cancer populations to the context of advanced cancer. Paper six is valuable because it indicates that the framing of help by healthcare professionals can influence perceptions of utility. Significantly paper six describes several barriers to families collectively wanting to seek help such as risks of generating distress, logistics of getting family together and differing concerns or needs within the family system. Clearly this may place limits on the perceived value and acceptability of any proposed systemic distress intervention. Taken together paper six suggests that mutual collaboration between healthcare providers and families is likely to have reciprocal benefits in shaping family-focussed psychosocial services and the development of systemic distress interventions.

## **7.4 My contribution to paper six**

CC conceived the study. CC designed the study with constructive critique by LF and AS in their role as PhD supervisors and with input from two patient and carer support groups. CC obtained all the necessary ethical and research governance approvals. CC designed all the study materials with constructive critique by LF and AS in their role as PhD supervisors and with input from two patient and carer support groups. CC collected and analysed all the data. AS and LF assessed the robustness of the analysis in their roles as PhD Supervisors. CC drafted and wrote the manuscript with amendments suggested by AS and LF. Estimated contribution to the paper: CC 90%, AS 5%, and LF 5%.

## **7.5 Choice of journal for paper six and journal standing**

*BMC Palliative Care* is a respected open access peer-reviewed journal that publishes original research on a variety of issues relevant to palliative care including ethical issues, clinical care, service issues and policy issues. Reflecting the multi-disciplinary nature of palliative care, the journal has a wide audience of clinicians also included academics, service providers and policy makers. *BMC Palliative Care* has an impact factor of 2.335 (18th July 2018).

## **7.6 Chapter summary**

In this chapter I have reported the findings of the case study of help-seeking for emotional in families living with advanced cancer. I have shown that help-seeking in families is conceived as relational phenomenon and occurs within a web of relationships within families, and between families and healthcare. Despite considerable distress in families, families do not seek help collectively for their distress. Currently there appears to be a disconnect in the policy ideal of holistic emotionally supportive care to families and the reality of family experience. The Mutuality Model of Help-seeking for Emotional Distress has been conceived as a nascent model to theorise help-seeking in families.



## Chapter 8

### 8. Critical review of the methodology and methods used in papers five and six

As the DESCARTE model aims to *'help researchers design and present their case study design accessibly, coherently, and transparently'* (Carolan et al. 2016 (a), p636) it seemed appropriate to use the model as a framework to structure this critical review.

#### 8.1 Stage 1: Situating the research and the researcher

##### 8.1.1 Philosophical approach

In presentation of the papers four, five and six and accompanying narratives I have provided a cogent description of my underlying philosophical assumptions and how these have shaped study design. While expansive discussion was not possible within the word limits of papers five and six that reported empirical findings, I am confident that application of the DESCARTE model provides readers with sufficient insight into my philosophical approach to judge methodological robustness.

##### 8.1.2 Situating my 'self' in this research

Reflexivity is an ongoing dynamic process (Hertz 1997) in which researchers must demonstrate an awareness of issues which can influence research design, data collection, analysis and write up to ensure the trustworthiness of findings (Finlay 2002; Finlay 2003). Reflexivity is a critical concern for any qualitative researcher and embarking on this research process I was self-aware of two important issues. First, my background as a practising healthcare clinician and second, my choice to employ multi-perspective approaches. Reflexivity must be considered more than simply self-awareness and requires conscious action across the entire research process Horsburgh (2003).

Nias (1993) in her study of personal and professional lives of primary school teachers makes the distinction between the 'substantial self' which has been moulded through past experiences and the 'situational self' which is malleable and is influenced by interaction within present contexts. My substantial self was as a daughter and sister within my own family system and my own familial experience of serious illnesses and death. It was important that during research design I questioned how my own beliefs, values and assumptions of death and family might

influence study design and subsequent interpretation of data gathered. Constructive challenge from my supervisors across the research process was invaluable in making me question any assumptions that I held.

It was important to be aware of my situational self when conducting interviews. When interviewing I was primarily my situational self as a healthcare researcher. However, I was aware that during interviews that my situational self was multiple: as a researcher, as a doctor and inevitably as another a human being responding to emotions generated in the field. These differing selves align with Reinharz's (1997) categories of the research self, the brought self (as a doctor) and the sectionally created self (as an empathic human being). Paper four critically reflects on my decision for families to disclose my brought self as a doctor during interviews patient. However, my brought self as a doctor had different implications for data collection from peers as it is possible that my healthcare professional peers might have perceived the interview as a test of knowledge (Chew-Graham et al. 2002; Coaar and Sim 2006). I was therefore mindful during these interviews to remind professionals that there was no 'correct or right answer' to any questions posed.

In paper four, I described being reflexive about how power operated during family interviewing (Warin et al. 2007) and described my efforts to avoid overly identifying with or taking sides with any one participant more than another (Forbat and Henderson 2003). Active listening to interview recordings, field notes and a reflective research diary enabled me to understand how these influences operated in the field.

During data analysis I maintained awareness that data generated in the field was context dependent and influenced by the '*the public that is being addressed*' (Morris 2001, p. 556). The goal of data analysis in this research was to produce understandings at the systemic level of the family. I was vital that I did not overly identify with or prioritise participant data which resonated with my own experiences (Forbat et al. 2003; Harden et al. 2010). Recording memos during transcription of interviews and subsequent data analysis together with regular research supervisory meetings helped me question any assumptions that I had made.

### **8.1.3 Ethical dimensions**

The necessary ethical approvals for this case study research were obtained from the School of Nursing, Midwifery and Health Research Ethics Committee (SREC), University of Stirling and the North of Scotland Research Ethics Committee (13/NS/0035) (Appendix 1-3). As a healthcare

researcher I had to comply with the conditions set by the authorising ethical committees. Throughout my medical career I have been guided by the four ethical principles which underpin professional conduct: autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 2003). Using these principles as my analytical framework I have reflected on the ethical challenges posed by this case study research.

### **8.1.3.1 Autonomy**

Autonomy within research relates to the individual's right to make their own choice to participate in research. Families in this study were living with advanced cancer, receiving palliative care and were emotionally distressed. Whether palliative care populations constitute a vulnerable population are well debated within the palliative care literature (Duke and Bennett 2010). Some earlier authors such as de Raevé (1994) have argued that research in palliative care is morally unjustifiable. However, subsequent studies have contested this view contending that palliative care populations are no more vulnerable than other groups (Addington-Hall 2002; Casarett and Karlawish 2000). However, Mount et al. (1995) assert that application of a global label to a heterogeneous patient group is inherently at odds with an individual's personhood at their right to self-determination. Similar arguments might apply to families in this case study if they were conceived as being vulnerable because they were possible consumers of mental healthcare (Du Bois 2008).

Whilst this is not to say that I did not recognise the need to safeguard against potential risks for individual families in this research I also believed that knee-jerkily applying a global label of vulnerable to these families was paternalistic (Berry 2004). Applying such a global label would be at odds with my ethical duty to uphold the autonomy of participants to be able to participate in this research and to exercise their choice to do so (Duke et al. 2010).

Aspects of the case study design which upheld families' autonomy are considered across the research process. The definition of family used in the study enabled patients to define their own family rather than have this imposed upon them, additionally families were able to self-determine whether they perceived they were distressed. Voluntary informed consent was taken, and process consent was employed (Beaver et al. 1999). Participants were free to decide what information they wished to share and importantly before family group interviewing families were able to move discussion along if they did not wish to share anything (Appendix 8). Patients were also free to decide if they wished their GP to be notified of their participation in the study.

The capacity to consent within palliative care populations can pose significant challenges as capacity may fluctuate because of changing clinician status related to symptom and treatment burden (Casarett et al. 2010; Duke et al. 2010). Clinicians identifying families used the inclusion criteria to screen eligibility and capacity. Although I did not formally re-assess capacity I applied my longstanding clinical judgment when taking informed consent. Moreover, consent is also predicated on whether individuals have exercised free-will in their choice to participate in this study. While not disclosed, there is always the possibility that some family members were influenced or coerced in taking part in the study by others within their family system (Agrawal 2003).

Gate-keeping by healthcare professionals has been readily identified in the palliative care literature as a potential threat to participant autonomy. Gatekeeping has been defined as *'the process whereby healthcare providers prevent access to eligible patients for research recruitment'* (Sharkey et al. 2010, p.363). Recruitment difficulties in palliative care are often attributed to gatekeeping by healthcare professionals. Significant recruitment difficulties occurred during this case study. Families in this case study were identified by clinicians involved in their care. This case study was initially a single site study of families in NHS Highland. After one year of data collection only three families had been recruited to the study. I was extremely concerned that I would not reach the recruitment target of 10-15 families. I thus applied to convert the study to a multi-site study. I spent several months working with additional sites in NHS Greater Glasgow and Clyde, NHS Lothian, NHS Tayside, NHS Grampian, and NHS Western Isles to develop new locality specific 'Accessing further help and resources information sheets' to support recruitment at these sites and progressed the necessary NHS ethics and local research governance approvals.

Over the entire recruitment period of the study (October 2013 - September 2015) almost 200 recruitment packs were provided to the varying participating sites. At the end of the recruitment period many sites were unable to tell me how many study packs had been given out. In total 15 families contacted me during the study recruitment period to express an interest in taking part in the study. One patient died suddenly a few days before I was due to meet the family, two patients clinically deteriorated and subsequently decided not to participate.

During informal feedback healthcare professionals described recognised gatekeeping issues (Kars et al. 2016) such as forgetting about the study, having insufficient time, and fears of generating distress in families (either from talking to families about study recruitment or from families taking part in the study). Kars et al. (2016) describe that the phenomenon of

gatekeeping has not been studied in depth. On reflection I believe that there were missed opportunities within study design to investigate the phenomena of gatekeeping in study design, for example by using an exit questionnaire of clinicians who identified families in this study which would have fully ascertained the nature of any issues which might have contributed to gatekeeping in this study.

### **8.1.3.2 Beneficence**

This study was not an intervention study and therefore therapeutic intent and demonstration of positive benefit for participants was not intended. Nonetheless several participants described positive benefits from participating in the study which included being able to share their story and by potentially influencing the future care of families in the future (Aoun et al. 2016; Duke et al. 2010; Kendall et al. 2007). I was mindful that participants knew I was a General Practitioner and that I needed to maintain clarity for participants (and myself) in managing boundaries appropriately (Dickson-Swift et al. 2008). During data collection I was asked several clinical questions. In response, I listened to patients and validated their questions and concerns but gently reminded patients that I was not there in a clinical capacity and accordingly signposted them to their own clinical team.

I have also considered the benefit to my own clinical practice. When analysing data to derive the theme unnecessary distress I would find myself lost in thoughts of “*Do I do that?*” and frequently questioned whether I had inadvertently caused unnecessary distress to families. Cognisance of unnecessary distress in families caused by the actions of healthcare professionals places personal value for me in terms of the future care I will deliver to families.

### **8.1.3.3 Non-maleficence**

The avoidance of harm is necessary in any research but especially during the conduct of ‘sensitive research’. Sensitive research can be defined in differing ways (Dickson-Swift et al. 2008). Renzetti and Lee (1993) define sensitive research topics as those which are ‘*intimate, discreditable or incriminating*’ (p. ix) or which are considered taboo and risk engendering emotion (Dickson-Swift et al. 2008). Framing this research as sensitive research is evident when the topic area involves: death and dying; emotional distress; and experience within the private sphere of family life (Dickson-Swift et al. 2008). Alternatively, Lee (1993) defines sensitive research as ‘*research which potentially poses a substantial threat to those who are or have been involved in it*’ (p.4). As Sieber (1993) argues that these threats are interpreted differently by those involved within the research process, for example: ethics committees, clinical

gatekeepers, researchers and above all participants. This was evident during the NHS ethical review process for this study where perceptions of risk between lay and professional members clashed and emotional expression of distress during interview was not equivalent to harm. Several strategies were used to manage risk and protect participants across the research process (Dickson-Swift et al. 2008).

#### **8.1.3.3.1 Recruitment**

Strategies were put in place to ensure that patients did not receive duplicate requests from different clinicians to participate in the study and that all families approached were cognisant of the patients' advanced cancer diagnosis. I was mindful that even discussions within families about whether to participate in the study might engender distress and this was why all families were able to access additional emotional support from local teams even if they decided not to participate in the study.

#### **8.1.3.3.2 Data collection**

It is recognised that interviews can be tiring for participants (Barnett 2001) and during interview I reminded patients that they could stop for a break or terminate the interview at any time if so desired. I responded to any distress that occurred during interview (Barnett 2001) and to manage any un-identified distress after interviews (Gysels et al. 2008) participants were provided with information about further sources of information and support. Although a letter was sent to patients' GP about their participation in the study in retrospect I have now questioned whether I had privileged patients over family members and whether I should have offered this to all family members.

Whilst confidentiality was assured during the data collection period I remained conscious of my position as an inside researcher (Ferdinand et al. 2007). Whilst I did not encounter any circumstances which gave serious concerns about risks to participant safety (e.g. issues pertaining to risks to patient safety from professional misconduct; participants expressing thoughts of suicidal ideation with active intent) I had detailed in the study ethics application that I would adhere to my standards of conduct of my professional regulatory body (General Medical Council 2010), consult with my PhD supervisors and apply ethical the principles (Beauchamps et al. 2003) to determine if confidentiality should be broken.

### **8.1.3.3.3 Data analysis and reporting**

Several strategies were used to protect the identity of participants to prevent harm (Damianakis and Woodford 2012). All data was anonymised using codes with identifiable material removed from the transcripts. Data recorded on paper was stored in locked cabinets with electronic data password protected. Ensuring anonymity of participants can be especially challenging when reporting case study data when one must balance providing sufficient detail while avoiding possible identification of participants (Damianakis et al. 2012). Ellis (2007) argues that researchers must report findings ethically and actively consider '*the ethics of what to tell*' (p. 24).

When reporting participant characteristics in papers five and six, I decided to omit detailed demographic description. I also used classifications to make identifying families and healthcare professionals less likely, for example I used the rurality classification to provide further description of context as opposed to geographical locality by health board area. During data analysis I actively interpreted data including divergent and dissonant data to provide essential understandings to derive the themes presented in papers five and paper six (Damianakis et al. 2012). I believed that this approach was congruent with the ethics of '*what to tell*' as it minimised the risks of identifying families which might have occurred if I had reported findings by describing individualised case studies of each of the families.

The avoidance of harm for the researcher has been described already in paper four. I transcribed 36 interviews with 16 interviews transcribed by an approved transcriber. The transcriber chosen was familiar with transcribing interview data of a sensitive nature and was fully cognisant of the potentially sensitive and emotional nature of the transcripts (MacLean et al. 2004).

### **8.1.3.4 Justice**

The overall intent of this design was to treat all participants equally. In retrospect there were two potential threats to justice in the study design. Although the letters of invitation were addressed to families, the primary point for identifying families was through identification of the patient. Additionally, only patients were asked if they wanted their GP to be notified of their participation in the study, family members were not also asked if they wished to do this. In many instances families had the same GP but this was not always the case and in retrospect this could have been considered. Input from the two user groups about this would have been invaluable in informing such decisions in study design.

## **8.2 Stage 2: Components of case study design**

### **8.2.1 The case-purpose dyad**

Given the lack of existing theories informing understandings of distress and help-seeking for distress in families the overarching research design was descriptive and exploratory (Yin 2009). The DESCARTE model describes realist and constructivist approaches to casing (Sandelowski 2011). Although derived from the same overarching research design, the case-purpose dyad in papers five and six were constructed differently to reflect nuanced differences in the research aims of each respective paper. In paper five the case is constructed as families living with advanced cancer and receiving palliative care with the purpose of the study to explore the experience of distress in families. Whereas in paper six the case is constructed as families living with advanced cancer and their nominated health or social care provider with the purpose of the study to understand the experience of help-seeking for distress.

Three aspects of case construction ensured the primacy of families participating in this research. First, families were able to self-determine which family members they wanted to include. Second, families could self-determine whether they perceived themselves as distressed. Mitchell (2013) contends that emotional distress remains poorly operationalized; this assertion was further supported by the findings of paper one which demonstrated that there was no consensus on how to capture or measure distress. Given the exploratory nature of this research I considered that imposing a minimum distress measure score within the inclusion criteria would presuppose the nature of emotional distress in families. This would introduce assumptions made by the researcher which could risk introducing bias. Detection of psychological distress by healthcare professionals in cancer care is poor (Sollner et al. 2001) and thus identifying distressed families using recruiting healthcare professionals could introduce a further source of bias. Casing families in terms of distress attributes was simply based on families perceiving that a single member and /or multiple family members are distressed. Finally, families were able to freely nominate a health or social care professional involved in their care to participate.

### **8.2.2 Context**

Context was clearly defined as palliative care in NHS Scotland. The context of the case study changed during study recruitment. Initially families were recruited from NHS Highland, thus the

initial context of the study was palliative care in NHS Highland. However significant recruitment issues meant the study was converted to a multi-site site. The justification for this decision was to ensure completion of this PhD research. Table 2 in paper five describes the geographical contexts of families and indicate 5 out of 12 families were sampled from rural areas. While this research does seek to produce nomothetic generalisations, it could be argued that the findings from paper five have limited transferability to large urban populations. In contrast the diversity of contexts sampled including remote and rural areas is indicative of the wide range of geographical contexts within NHS Scotland and thus it could be alternatively argued that the sample is representative of wide range of experience of palliative care within NHS Scotland.

### **8.2.3 Theoretical considerations**

Justification for using family and ecological systems theories and symbolic interactionism has been outlined in early chapters. Symbolic interactionism as an analytical frame was particularly useful in enabling interpretations of the meanings, actions and processes which occurred during help-seeking for distress. While it is essential to describe a theoretical position at the outset of research it is important to appreciate that it can be useful to draw from additional theoretical perspectives as analysis proceeds. As reported in paper six, cross-case analysis employed an abductive approach (Timmermans and Tavory 2012) using multiple theoretical lenses to interpret data; this will be described later in section 8.3 Data Analysis.

### **8.2.4 Sampling**

#### **8.2.4.1 Sampling approach**

Purposeful sampling of distressed families provided information rich data (Patton 2002) and is a recognised sampling approach in case study (Denscombe 2003). A maximal variation sampling approach (Patton 2002) using patient related characteristic of age (18-65 yrs. and 65yrs +) and gender (male and female) was initially proposed. However, significant recruitment difficulties meant that this approach to sampling was abandoned. In retrospect, this initial choice of patient characteristics reflected my naivety as a family researcher as there are innumerate ways maximal variation can apply to family cases. While I accept that the final sample included a predominance of male patients the sample contained a wide range of different primary and recurrent cancer diagnoses, a wide variety of both familial relationships and geographical settings. Thus, I believe that the final sample comprised of a wide range of contrasting experience of distress necessary to promote rigor to the findings of the research (Mays and Pope 1995).

#### **8.2.4.2 Sample size**

Single case studies are expedient when a unique or extreme case merits in-depth investigation or to test existing theory (Yin 2009). A single case study was not chosen as it would have been difficult to predict from the outset which families would provide a unique case and there was no existing theory to test. Instead, a multiple case study design was chosen (Yin 2009). Additionally, findings from a multiple case study are more compelling than a single case study (Herriott and Firestone 1983).

Sample size is a contentious issue within qualitative research (Baker and Edwards 2012). No new data had emerged from interviews with family 12; data was deemed to be saturated and thus data collection was stopped (Baker et al. 2012; Guest et al. 2006). The sample size in this case study was analogous to a comparable research design on the experience of fatigue in palliative care patients (Krishnasamy 2000). While I was content methodologically that data was saturated the decision to stop data collection also reflected pragmatic considerations (Baker et al. 2012; McDonnell 2000). I was acutely aware of warnings in case study literature of neophyte case study researchers becoming overwhelmed by data (Yin 2009). I was also conscious of the ethical imperative to ensure completion of the study within the confines of a time and resource limited PhD.

#### **8.2.5 Data sources**

Paper three indicates that multiple data sources characterise case study. The rationale for using combined multiple perspective interviewing in families has already been described in Chapter 5. At the beginning of individual interviews (excluding healthcare professional interviews) participants were asked to describe their family to enable construction of a very simple family ecomap to provide contextual understanding of the family structure. Additionally, this proved to be very useful in building rapport. I rejected using social networks methods such as the Pictor technique (Hardy et al. 2012) because of the possible risks of excessive participant burden.

Interviews conducted with health and social care professionals sought to understand their perceptions of distress and help-seeking within families. Healthcare professionals can have significant time constraints from pressure of work and unpredictable shift patterns which can make face to face scheduling of interviews problematic. Telephone interviews were a pragmatic choice to ensure participation of professionals and demonstrate similar efficacy to face to face interviews (Sturges and Hanrahan 2004).

The Family Relationships Index (FRI) is a 12-item measure developed from 3 subscales (cohesion, expressiveness and conflict) of the Family Environment Scale (Moos and Moos 1981). The FRI is a validated measure of relational functioning and psychosocial risk in palliative care families (Edwards and Clarke 2005; Kissane et al. 1998). The Distress Thermometer is as a single item tool with a visual analogue scale of 0 -10 allowing patients to self-rate their distress (Roth et al. 1998) and it has been established that a cut-off score of 4 denotes significant distress when measured against established tools (Jacobsen et al. 2005) and its use has been validated in a UK palliative care setting (Gessler et al. 2008). Its use has been advocated by the National Comprehensive Cancer Network as a patient self-report measure of psychological distress. Building on the Distress Thermometer the Emotion Thermometers Tool © has been developed which combines five visual-analogue scales in the form of four predictor domains (distress, anxiety, depression, anger) and one outcome domain (need for help) and has been validated in a UK population (Baker-Glenn et al. 2010; Mitchell et al. 2010). The 7 item Emotion Thermometers Scale which includes two additional domains of impact and overall health and was used with the permission of the tool's developer Dr AJ Mitchell.

The rationale for using the FRI and ET tool © was to provide additional measures of distress and relational functioning. However, I soon realised during data collection and during the preliminary stages of data analysis that the quantitative data I had gathered from families during data collection had less utility than I had initially presumed. In part, this related to my status as a neophyte family researcher. To explain, the aim of this research was to understand family level experience of distress and help-seeking within the family system with early findings signalling temporal oscillation of distress. Thus, a single objective numerical measurement of individual level experience contributed little to my understanding of the family's experience of distress over time. The FRI as a more stable measure did provide some contextual understanding of relational function in families.

Taking these issues into account I used the quantitative data to provide contextual description of the sample. Some research peers, particularly those who are informed from objectivist research traditions might have questioned my choice to allow families to self-determine distress for inclusion in the study. As findings from papers five and six demonstrate, if a prism of objective measures is applied to families in this study, all families reported at least one member with significant distress with a distress score  $\geq 4$  (Mitchell et al. 2010) and nine families were deemed at some degree of risk with FRI  $< 9$  or cohesiveness score  $< 4$  (Kissane et al. 1998). This

data can justify to research peers who have an objectivist stance that this research does report the experience of distressed families.

### **8.3 Stage 3: Data analysis and adopting the three stances**

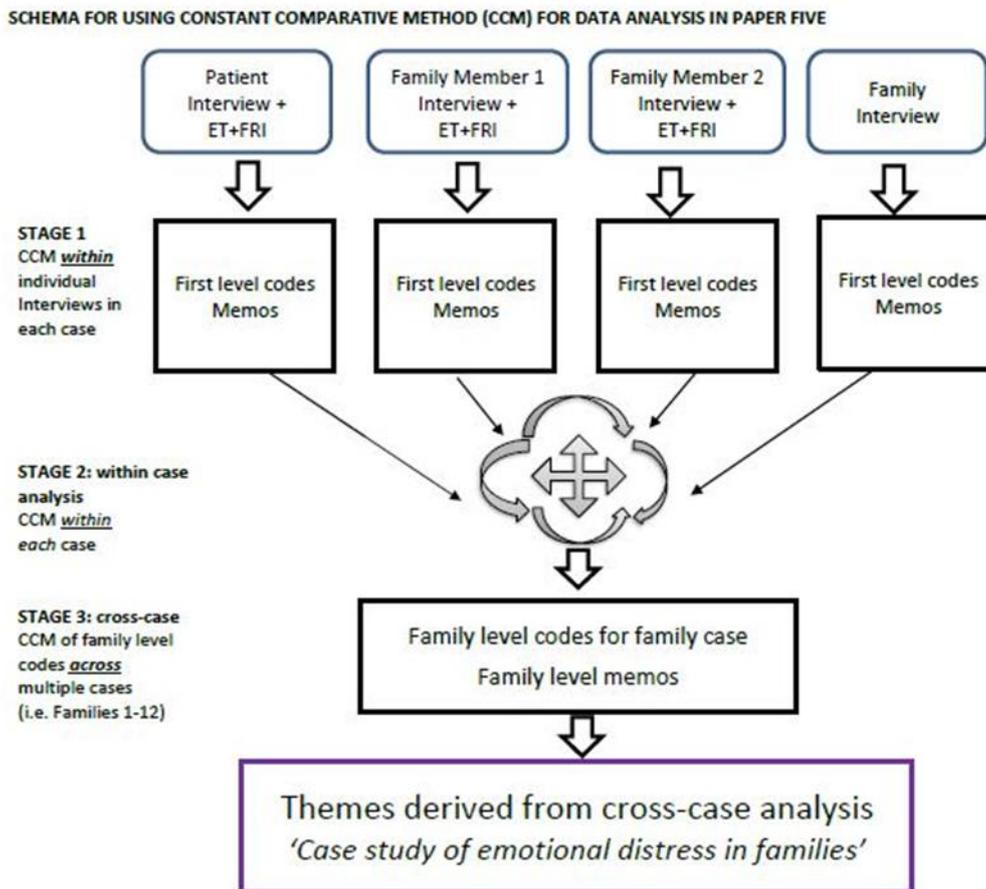
The DESCARTE model indicates that during data analysis researches must describe their three stances of philosophical, strategic and integrative (Carolan et al. 2016 (a)). Data analysis was congruent with the philosophical underpinnings described in earlier chapters. Data analysis in both papers five and six described their strategic approach as a case based approach using within-case analysis followed by cross-case analysis (Byrne and Ragin 2009). In both papers five and six data was integrated during within-case analysis with completeness the purpose of integration (Bryman 2006; Greene et al. 2009).

As highlighted earlier in this chapter, there was nuanced difference in case construction in paper five and six. While the initial stages of data analysis were the same for papers five and six, latter stages of data analysis differed slightly. To provide a transparent a fuller account of the method of data analysis used in each.

#### **8.3.1 Within-case and cross-case analysis for paper five**

Data was first analysed within-case and then across-case using a constant comparative method. In deriving my approach to data analysis, I drew from the following works: Ayres et al. (2003), Bazeley (2013), Boeije (2002), Daly (2007), Charmaz (2006), Fram (2013), Ribbens McCarthy et al. (2003), Perlesz et al. (2003). Data analysis was considerably more complex than I had initially anticipated. First, due to the volume of data I had collected and second, because of my desire to report family level findings and I readily admit that there were times that I felt overwhelmed by data (Yin 2009). The schema below provides an overview of how the constant comparative method was used during data analysis in paper five.

Figure 4: Data analysis and the use of the constant comparative method in paper five



However, the reality of data analysis was somewhat messier than the schema suggests and to give a transparent account as possible I will describe the process of data analysis below.

### Initial data familiarisation and data organisation

I familiarised myself with the data by reading and re-reading all the interview transcripts. Realising the amount of data that I had collected I constructed a coding framework to enable data organisation. To do this I inductively coded all individual and family transcripts from two cases and from this I developed the inductive coding framework. At this initial stage the framework contained several broad coding bins enabling data organisation (Appendix 15). During data analysis I used a prompt sheet to help me think about the data (Appendix 16).

### Stage 1: Constant comparison within interviews

All interviews were line by line coded and within interview analysis used a constant comparative method to develop first level codes and memos. These codes were then organised within the

coding framework but held within a hierarchical coding framework in that each family was assigned a parent coded of Family 1 with 4 child codes of patient 1, family member 1, family member 2, 'family interview' 1. Subsequent child nodes for each of these codes (e.g.) patient 1 contained all inductively derived first level codes from each interview that were germane to the broad coding bin in which they were contained. This was repeated for all twelve families.

## **Stage 2: Constant comparison during within-case analysis**

During this stage I compared and contrasted first level codes from all interviews from each family case (i.e. patient, 2 family members and family interview) to derive family level codes for each family case. During within case analysis, it was important to identify and interpret convergent and divergent data (complementary or dissonant data). I had numerous false starts during this stage of data analysis. I initially attempted within case analysis within n-vivo. However, I found it almost impossible to 'see' data which was convergent, divergent and importantly what had not been said. Whilst cumbersome I constructed a discrete simple word document for within case analysis of each family (e.g. Within Case Analysis Family (WCA) Family 1, WCA Family 2, etc.). In each within case analysis word document I made a very simple within case analysis matrix. I used colours to represent different participant's first level codes:

- Family group interviews red
- Patient individual interview green
- Wife individual interview dark yellow
- Sister individual interview light yellow
- Daughter individual interview pale pink
- Son individual interview purple
- Male partner individual interview brown
- Female friend individual interview dark pink

The matrix was sectioned horizontally in rows according as per the coding bins in the coding framework (e.g. uncertainty, open communication etc.). Level one codes contained within the respective coding bin were aligned vertically in columns. At the level of each coding bin (e.g. uncertainty) levels one codes pertaining to this coding bin were compared and contrasted. Data that was convergent was cut and pasted from the individual column and moved to the first family column on the left with colouring of the codes unchanged. Data was then compared and

contrasted within this column to produce family levels codes. Family levels codes were entered in a new row, directly below. Convergent family levels codes assigned on the left in black. Divergent family codes assigned on the right as: (i) complementary in grey (ii) dissonant in dark red. As illustrated below.

**Table 2: Within-case analysis matrix**

<b>Uncertainty (coding bins from broad coding framework)</b>			
Level 1 codes from family interview	Level one codes from individual patient interview	Level 1 codes from individual wife interview	Level one codes from individual son interview
Convergent family level entered here		Divergent codes entered here <ul style="list-style-type: none"> <li>• Complementary codes</li> <li>• Dissonant codes</li> </ul>	
<b>Open Communication (coding bins from broad coding framework)</b>			
Level 1 codes from family interview	Level one codes from individual patient interview	Level 1 codes from individual wife interview	Level one codes from individual son interview
Convergent family level entered here		Divergent codes entered here <ul style="list-style-type: none"> <li>• Complementary codes</li> <li>• Dissonant codes</li> </ul>	
Etc...repeated for all coding bins from coding framework			

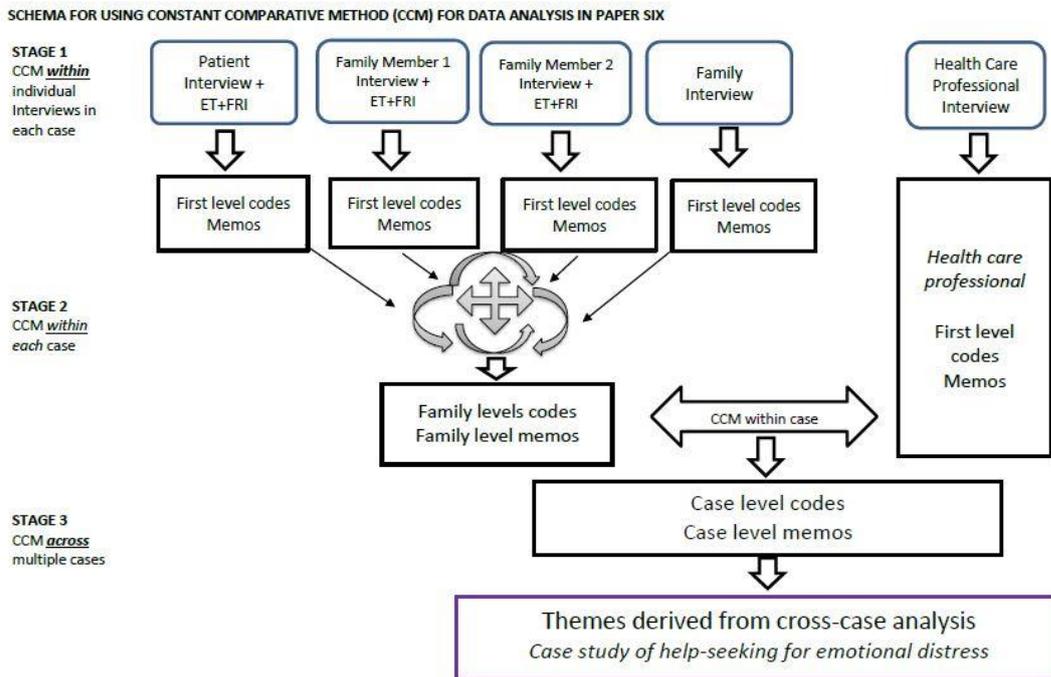
### STAGE 3: Constant comparison during cross-case analysis

Family level codes were imported back into N vivo and with codes compared and contrasted across cases. During this stage I utilised memos and field notes to inform my data analysis. From this cross-case analysis themes were derived as findings for the case study of emotional distress in families as reported in paper five.

### 8.3.2 Within-case and cross-case analysis for paper six

The initial stages of data analysis for paper six mirrored paper five until the point of within case analysis where family level codes were produced. At this point during within case analysis, family codes were then compared and contrasted with first level codes derived from individual healthcare professional individual interviews to derive case level codes. Subsequently during cross-case analysis these case level codes were then compared and contrasted across the twelve cases (families and their healthcare professional). The schema below provides an overview of how the constant comparative method was used during data analysis in paper six.

**Figure 5: Data analysis and the use of the constant comparative method in paper six**



Data analysis for the findings reported in paper six had further nuanced difference to paper 5 in that an abductive approach to data analysis was employed during cross-case analysis. In abductive analysis multiple theoretical sensitiser are used to enable researchers puzzle out and interpret the data through revisiting, defamiliarisation and alternative casing (Timmermans et al. 2012). I used the following models of help-seeking as theoretical sensitiser: (i) the Attaining Normality Model (Carolan et al. 2018); (iii) the Network Episode Model (Pescosolido 1991; Pescosolido 1992); and the Candidacy Framework (Dixon-Woods et al. 2006). While findings were derived inductively from the data I believe that using an abductive approach enabled me to interpret data cognisant of other disciplinary perspectives (Wyke et al. 2013).

## 8.4 Chapter summary

In this chapter I have critically reflected on the methods used during the conduct of this case study research and have done so using the DESCARTE model of case study research in healthcare (Carolan et al. 2016 (a)). The next chapter, chapter 9, is the final chapter of this thesis. In this chapter I will demonstrate how the six publications and associated narratives have addressed the aims and objectives of the thesis and describe their collective contribution to the literature and the implications for clinical practice, policy, research and education.

# Chapter 9

## 9. Discussion and conclusions

### 9.1 Introduction

This research is located in the pre-clinical phase of the MRC guidance for the development and evaluation of complex interventions (Medical Research Council 2008). The aim of this thesis was to identify the evidence base and to theorise the development of systemic interventions for emotional distress in families living with advanced cancer. A tandem and important part of implementing any proposed systemic distress intervention in clinical practice is understanding why families seek help (or not) for their distress. Thus, this thesis additionally aimed to identify the evidence base and to theorise help-seeking for emotional distress within cancer and palliative care contexts.

In this thesis I have presented a collection of six publications, comprising four published papers and two submitted papers. The accompanying narratives in this thesis have clearly outlined how each publication makes an original contribution to the field with the strengths and limitations of each publication critically debated. In this concluding chapter I will demonstrate how the aims and objectives of this thesis have been addressed. I will state the how the collective contribution of these publications informs our understanding of emotional distress and help-seeking for distress in families living with advanced cancer. I also describe how this thesis has advanced methodological understanding in case study and family research methods. Implications of this thesis for clinical practice, policy, research and education and personal professional development are then considered.

### 9.2 Addressing the aims and objectives of the thesis

To re-iterate the aim of this thesis was to begin to theorise the development of systemic distress interventions for emotional distress in families living with advanced cancer and to understand families' help-seeking behaviours for distress. Necessarily this concluding section will focus on explaining how the publications have provided systemic understandings of family experience to address these research objectives.

### **9.2.1 Objective 1: To ascertain how emotional distress in families is conceptualised in the palliative care literature.**

This objective was wholly met by the findings of paper one. Distress in families is conceptualised as a multi-dimensional construct but is poorly defined with no apparent consensus on how to quantitatively measure this construct. Paper one endorses the conceptualisation of distress as a systemic construct by evidencing that distress in one member of the family is related to another. Distress is influenced by communication practices, relational functioning, dyadic coping and adjustment, family support and hardiness. Thus, paper one identifies mechanisms which might be amenable to manipulation and can thus inform future intervention design. A new tiered model of distress to aid conceptualisation of distress was derived. The tiered model of distress shows individualistic non-interactive depictions of distress which progress through gradations of interaction to convey a systemic account of distress within the family system.

### **9.2.2 Objective 2: To describe and understand the experience of emotional distress in families living with advanced cancer**

This objective was met by the findings of papers two, five and six. Paper five cements conceptualisation of emotional distress as systemic construct. Emotional distress is depicted as an interdependent relational phenomenon which is recursively experienced within the family system. This recursive interrelationship between individuals' differing distresses (e.g. physical, functional, emotional etc.) means that distress in families is conceived as total distress and can fluctuate over time.

Paper five conceives emotional distress in families as oscillatory distress. Families describe oscillating between dual perspectives of being towards life (describing efforts to flow of normal life and maintain the integrity of family) and being towards death (describing how advanced illness and death threaten the integrity of the family). Being toward death provoked distress whereas being towards life and efforts to maintain the integrity of family ameliorated distress. This finding suggests systemic conceptualisation of double awareness (Rodin et al. 2008).

Paper five shows how emotional distress, communication practices and intra-familial conflict are intertwined. Intra-familial conflict can be experienced as either safe everyday family conflict or unsafe conflict. Changes to the physical space of home and to structural caregiving, moral judgements about caregiving and the historical context of family relationships could provoke conflict. During unsafe conflict families used self-silencing to prevent escalation but this generated further distress. Distress from relational breakdown was described.

Paper five shows families affected by cancer living in uncertainty with consequent distress evoked. While families and social networks can alleviate uncertainty by sharing knowledge, informational communication practices within families can augment uncertainty within the family system. Healthcare professionals' actions which addressed uncertainty could prevent and mitigate families' emotional distress and included: provision of tailored personalised knowledge; anticipatory care planning; and safe, seamless, accessible and certain care. Such actions provided a sense of security in the present and preparedness for the future. In contrast, healthcare professional behaviours which amplified families' uncertainty such as delays in care augmented families' distress.

Paper five demonstrates that families can experience unnecessary distress because of interactions with healthcare professionals and systems of healthcare. Unnecessary distress arises because of deficient relational care and is recursively experienced within the family system. Deficient relational care operates at the individual level (with the need to validate personhood) and at the systemic level (with the need to validate familyhood). Unnecessary distress also arose from conflict with healthcare due to poor interpersonal communication skills and systemic issues in care. Trusting relational attachments with cancer nurse specialists helped mitigate systemic healthcare conflict. Perceived inequalities in care provoking unnecessary distress were also described.

Papers two, five and six provided rich understanding into the reciprocity of distress and family communication practices. Distress within families can be conceived as private distress (known only to the individual) and shared distress (communicated to others within the family system). Distress can be expressed as displays of emotions (including non-verbal, verbal and behavioural change) or communicated as a topic. Unnecessary distress was freely communicated within the family system. In contrast distress experienced by being towards death was generally held as private distress. A myriad of factors influenced distress disclosure in families and included: protective buffering, moral judgements, power and emotional norm setting, patterns of existing familial communication, historical family scripts, maintaining familial roles, avoidance of conflict, lack of opportunity, geographical constraints, lack of time and temporal influences.

### **9.2.3 Objective 3: To understand why families living with advanced cancer seek help (or not) for their emotional distress and what influences these actions**

Papers two, five and six provided rich understandings of why families did not seek help with their distress. First, families' reluctance to disclose distress within their family system operated to inhibit collective help-seeking for distress. Importantly clashes and gaps in understandings between families and healthcare professionals inhibited collective help-seeking and were related to: perceived candidacy for distress; perceived candidacy for help; the influence of identity and the meaning of help-seeking; and the perceived value of help. No families in the case study collectively sought help for their distress thus, objective 3 is only partially met

Variable lay conceptualisations of distress in families informed help-seeking. Distress was normalised via social comparisons, rationalised through the lens of terminal illness and influenced by moral reasoning including whether a legitimate level of distress necessary to seek help had been reached. Mutual shared everyday coping and informal help from social networks enabled families to accommodate distress and maintain the flow of daily life. Thus, families did not necessarily perceive distress as a problem that needed formal help and thus families did not assert candidacy for distress. In some families' mutual understandings of distress between families and healthcare professionals was never realised because of healthcare professionals distress assessment practices, communication behaviours and consultation styles. Thus, families' candidacy for distress was not recognised.

The legitimacy of the family unit as warranting help was a contested concept by families and healthcare professionals. Both families and professionals prioritised patients' physical needs because of perceived limited resources. Variability in healthcare professionals' perception of the eligibility and legitimacy of family as co-recipients of care was described and influenced by professionals' personal comfort and skills in family distress assessment.

Help-seeking was perceived as a threat to families' collective autonomous stoic identity. Pejorative language suggests that the public-stigma of help-seeking informs self-stigma and family-level-stigma of help-seeking within the family system. Maintaining autonomy in advancing illness, maintaining sociocultural hegemonic masculinity or stoic persona of the good caregiver together with historical family scripts further influenced the autonomous stoic identity. The self-stigma of mental illness was also described. Moreover, prioritisation of physical symptoms and perceptions of the limited value placed on emotional care within the

organisation and culture of healthcare suggests the pervasive influence of the public-stigma of mental illness within systems of care.

Lay beliefs held by families about help inhibited help-seeking and included perceptions of limited efficacy and possible risks of help. All families described the perceived risk of collective help-seeking. Families believed that the disclosure of distress which would arise from collective help seeking would generate recursive distress within the family system. These beliefs placed limits on the perceived value of collective help. Disconnects between help offered and help desired were evident, with some families describing services as too cancer focussed and too feminised. Differences in issues of concern, levels of need, desire for help, limited time and opportunity were perceived as barriers to collective help-seeking with generic barriers such as limited availability of help and physical access to care described.

Help-seeking was recursively experienced over time and influenced by historic family scripts and past and present interactions with healthcare. In particular the experience of stigma relating to past help-seeking for mental health issues and/or alcohol dependency together with erosion of trust from cancer care experience inhibited help-seeking. While no families had sought help collectively for their distress, language used by families suggests that help-seeking preferences might be malleable to change over time.

#### **9.2.4 Objective 4: To critically review case study as a research approach**

This objective was met by paper three. In the current healthcare literature there is significant variability in the quality of the reporting of case study; methods of data analysis procedure are poorly described and often insufficient to enable study replication. The three-stage DESCARTE model of case study design was developed as a flexible inclusive model to enable researchers to conduct and report case study in a transparent, coherent, and accessible way to enhance study rigour.

#### **9.2.5 Objective 5: To critically examine the challenges of conducting multi-perspective interviewing in families**

This objective was met by paper four. The challenges of conducting multi-perspective interviewing in family research are interrogated. The nuanced methodological choices faced by researchers using this method of data collection are critically examined. Ethical issues are deliberated, including unforeseen issues arising during fieldwork. Recommendations for novice researchers contemplating using this method are made.

## **9.3 The collective contribution of this thesis and its implications**

The collective contribution of works in this thesis is now considered. The implications of this collective work for clinical practice, policy, research, education and personal professional development has already been described in the publications and in their accompanying narratives. Key implications are re-iterated here.

### **9.3.1 Collective contribution of this thesis**

This thesis proposes that the care of families living with advanced cancer can be improved by understanding emotional distress and families' help-seeking for distress as a socially constructed, context dependent, relational phenomenon. How distress is experienced and communicated within the family system is proposed as a recursive phenomenon, with distress shaping communication and communication shaping distress. This thesis has demonstrated distress as an interdependent relational experience within the family system and has theorised how systemic application of dignity therapy, (Guo et al. 2018), goal setting (Boa 2013) and CALM therapy (Hales et al. 2015) might ameliorate distress within the family system. Although emotional distress is relationally experienced many families do not communicate their distress to one another which can place limits on how application of systemic distress interventions might be realised in clinical practice. While accepting that distress is relationally experienced by families, this research also demonstrates how families and social networks self-organise to mutually support one another.

Distress in families is relationally experienced between families and healthcare professionals. Emotional distress in families can be caused by interactions with individual healthcare practitioners and the healthcare system. Families describe this distress as unnecessary; this unnecessary distress is recursively experienced and openly communicated within the family system. Unnecessary distress occurred when families did not experience relationally centred care because their personhood and familyhood was not validated. This deficit in relational care indicates a chasm between the rhetoric of the policy ideal of palliative care and the reality of care experienced by families. Conversely, families described that care embedded in relationships mitigated the distress of living with advanced illness and ameliorated distress *if* the pacing of formal healthcare was congruent with families' needs. Secure trusting relational attachments with individual healthcare practitioners mitigated distress arising from systemic healthcare conflict.

The goal of this thesis was to theorise the development of systemic distress interventions. While this goal has been met, findings suggest significant and likely constraints on the implementation of systemic distress interventions in clinical practice. However, the finding of unnecessary distress from this research offers an alternative mechanism to improve the emotional wellbeing of families living with advanced illness. This thesis proposes that efforts to embed relational care in day to day clinical practice and systems of care must be prioritised (Wright et al. 2004). This action will serve a dual purpose; first, enhancing relational care will prevent unnecessary distress and second, in the longer term it will likely enhance the acceptability of any systemic distress intervention derived.

To explain; that emotional distress in families is a relationally experienced phenomena has been cogently argued. Likewise, this thesis proposes that help-seeking for distress is a socially constructed, context dependent, relational phenomenon occurring within the family system and the mesosystem. Help-seeking is relationally experienced within the family system, with families influencing help-seeking in a plurality of ways. Within the mesosystem mutuality in understanding between families and professionals is needed to facilitate help-seeking. Some families did not seek help for their distress because the candidacy of the family as a legitimate unit of care was not mutually understood by families and professionals. Efforts to embed relational care in day to day practice will legitimise families' candidacy for help and will ensure their candidacy for help is recognised by professionals.

Thus, care practices foregrounded in relationships and which are embedded in everyday healthcare will first, prevent and mitigate unnecessary distress and second, will ensure families candidacy for help to facilitate families help-seeking if so desired. In order to embed relational care in day to day clinical practice, families, clinicians, service providers and policy makers must critically question why disconnects and gaps between the policy ideals of palliative care and the practice of palliative care currently exist, and importantly how this can be remedied.

In the interim the implications of this thesis for clinical practice, policy, research, education and personal professional development are presented. Findings from this thesis illustrate interacting influences within the microsystem, mesosystem, exosystem, and macrosystem. While these implications for this thesis are now listed, it must be stressed that implementing change to enhance the emotional wellbeing of families at the end of life must be cognisant of the complexity of palliative care (Pask et al. 2018) and the need to adopt a systems thinking approach (Peters 2014).

### 9.3.2 Implications for clinical practice

Central to this thesis is the need for clinicians to foreground relational care to validate the dual perspectives of personhood and familyhood in those living with advanced illness. Simple measures can be transformative, for example core to Kate Granger's 'hellomynameis' campaign was the desire for relational care valuing the primacy of relationships. Clinicians must embrace the tenets of shared decision making to facilitate relational autonomy (Belanger 2017; Laidsaar-Powell et al. 2017) and achieve personalised and family-focussed care to mitigate unnecessary distress.

Clinicians must seek to foster trust within their relationships with families and understand how their communication and practices can engender conflict and unnecessary distress for families. Clinicians must be cognisant of how erosion of trust can engender distress and inhibit help-seeking and seek to remedy this. Implementing 'Duty of Candour' (Scottish Government 2018) will support these efforts.

Clinicians must be cognisant of the inseparability of emotional distress and other distresses (Salmon and Young 2017). Application of the tiered model of distress in practice can ensure that clinicians can attend to the total distress of the family. Clinicians must be mindful of how historical family scripts, role changes, relational autonomy, division of caregiving, family information and communication practices, together with changes to the physical space of home influence intra-familial conflict and offer support as desired.

Clinicians must mitigate, where possible, the uncertainties experienced by families when living with terminal illness. Etkind et al. (2017) have proposed a typology of patient responses to uncertainty which include: patients' engagement with their illness, patients' temporal focus (in terms of present or future), and patients' information preferences. While useful, this thesis suggests that this typology would provide greater utility if '*patients*' was replaced by '*families*' and '*information*' was replaced by '*knowledge*'. Clinicians could use this framework during collaborative anticipatory care conversations with families. This would align well with current anticipatory care models such as Scotland's House of Care Model (Health and Social Care Alliance Scotland n.d). Derived anticipatory and advance care planning choices can then be formalised in Key Information Summaries to help ensure that families receive the safe, seamless, accessible and certain care they desire and alleviate distress.

### 9.3.3 Implications for policy

This thesis has two key implications for policy. First, the need to advocate policy shifts to affect the practical achievement of relational care and second, the need to tackle stigma associated with mental illness and help-seeking. This thesis does not dispute that many family members perceive they are co-workers in care and do not perceive themselves as co-recipients of care (Payne 2010). Equally, this thesis does not advocate that death in families automatically equates with a need for help. Rather, this thesis proposes that care embedded in relationships can prevent emotional distress in families and that the practice of relational care can facilitate help-seeking help for families who want formal help for their distress.

This thesis shows that the WHO policy ideal of palliative care to the family unit is not currently translated into clinical practice. The recognition of such disconnects between policy and practice are not new and reflect longstanding cultural practices of healthcare. As King (2006) over a decade ago reflects

*'Much of Western medical training emphasizes an individualistic approach focused on patient autonomy to the relative neglect of the social system that shapes the patient's identity and values. Thus, many medical professionals working in palliative or hospice settings have little or no training in family systems approaches, leaving them unprepared for the challenges of providing family-inclusive care' (p.704)*

Similarly, referring to palliative care nursing Ward-Griffin et al. (2012) states the need for nursing to break free from the dominance of individualistic care and execute *'family nursing as a relational practice'* (p.508). However, individual practitioners do not work in a vacuum but within systems of care shaped by healthcare policy. Thus, the execution of relational palliative care practice can only be fully realised through policy shifts.

While Scotland's new Strategic Framework for Action on Palliative and End of Life Care 2016-2021 (Scottish Government 2015) acknowledges the need to support families in advanced illness, inspection of the documents reveals a dominant narrative to advance the status of families from taken for granted resources (Twigg and Atkin 1994) to co-workers in palliative care (Payne 2010). Explicit commitment to relational family-focussed care is woefully absent in the ten Government commitments to palliative care within the Strategic Framework (Scottish Government 2015). It is unknown whether there would be an additional cost to configuring services to deliver family-focussed care. However, prevention of unnecessary distress would mitigate the significant negative adverse impacts on patients' and caregivers' quality of life and related healthcare costs previously outlined in Chapter 1. Cost benefit analyses of differing

models of care are necessary and will ensure any policy shifts are evidenced based. Moreover, collaborative deliberation with all relevant stakeholders (inclusive of families) is necessary to ensure that policies shaped will be acceptable in practice.

Findings from this thesis support arguments made by Salmon et al. (2015) of the pressing need to adopt public health initiatives to shift socio-cultural perceptions related to mental illness and help-seeking. Recent drivers within Scotland to promote public health approaches to promote openness about death and dying such as 'Good Life, Good Death, Good Grief' help de-medicalise death and dying. Good Life, Good Death, Good Grief's overriding emphasis is to promote community resilience emphasising that *'formal services are a small part of people's lives and deaths'* (Good Life, Good Death, Good Grief n.d). However, such laudable efforts might have unintended consequences if families interpret that it is socially unacceptable to seek formal help for the emotional distress of dying; such initiatives might inadvertently risk perpetuating the public stigma of help-seeking. Thus, policies should employ dual approaches which emphasise that while death and dying are part of normal life that it is acceptable to ask for help for distress if so desired.

### **9.3.4 Implications for research**

This thesis has important implications for research in two differing domains. First, by indicating further empirical research necessary to enhance our understandings of emotional distress and help-seeking for distress and second, by its contribution to case study and family research methods.

#### **9.3.4.1 Implications for empirical research on distress and help-seeking for distress**

Clearly, the tiered model of distress presented in paper one has implications for researchers conceiving family research designs with the need for consensus on the use of distress measures evident. Papers one, two, five and six and their accompanying narratives have already outlined further research needed to advance understandings of distress. While all are arguably merited, the following areas of research should be prioritised.

##### **9.3.4.1.1 To conduct further qualitative family research**

Further qualitative family research is merited. While this thesis makes a substantial contribution to qualitative understandings of distress in families and their help-seeking there were limitations described in the conduct of this case study. First, findings relate to NHS Scotland and therefore might not necessarily be transferable to different sociocultural contexts

and systems of healthcare. Thus, this research should be replicated in differing contexts of care. Second, the Mutuality Model of Help-seeking for Emotional Distress could not be fully developed because families in this case study had not sought collective help for their distress. Thus, this research should be replicated in families who have sought help to determine if the model has theoretical consistency.

#### **9.3.4.1.2 To develop systemic application of goal-setting and action planning in generalist community palliative care settings**

Paper five theorised three possible systemic interventions for distress. Research to develop systemic application of goal-setting and action planning in generalist community palliative care settings is justified by this thesis. First, families described how collaborative family goal setting and being towards life ameliorated distress. Second, the practice of relational care also mitigated distress. Goal setting and action planning would be predicated on what matters to families. If systemic family goal setting and action planning was embedded within community nursing care practice it would shift current care practices from task led care dictated by professionals and centred around patients to family-centred goals of care directed by families' wishes. Thus, systemic family goal setting might be one mechanism to attain the policy goals of relational family-focussed care.

#### **9.3.4.1.3 To understand and address the causes of healthcare conflict generating unnecessary distress.**

Given that a large proportion of NHS complaints relate to end of life care (Department of Health 2008) healthcare-conflict and its impacts on the emotional well-being of families merits further attention. Research about conflict in palliative care is potentially fraught with challenge and research about how best to investigate healthcare conflict is scarce (Van Keer et al. 2015). Given that systems issues influence conflict, different evaluation methodologies might have utility. For example, using existing local care reporting structures such as Care Opinion (n.d) or national care reporting structures such as the annual Scottish Cancer Patient Experience Survey (Cunningham and Wells 2016) might usefully inform quality improvement activities to address systems issues identified.

#### **9.3.4.1.4 To untangle the stigmas of help-seeking for emotional distress in cancer and palliative care contexts.**

The need for public health policy approaches to address the stigma of help-seeking for emotional distress in cancer has been argued above. Replicating Tucker et al.'s (2013) study could help untangle the stigmas of mental illness and the stigmas of help-seeking in cancer and

palliative care contexts; this would better inform spending on public health initiatives to address stigma. Given that some families report palliative care as diminished care, incorporating measures to determine the influence of the stigma of palliative care should be considered.

#### **9.3.4.2 Implications for research methodology**

This thesis has introduced the DESCARTE model to inform the practice of case study research. The model has already been used to inform the design of other empirical research. As paper three indicates research practice is enhanced through meaningful debate, thus it would be useful to share reflections about the use of the DESCARTE model in this research in publication format. In the future it would be useful to critically review whether research articles employing the DESCARTE model demonstrated enhanced quality of study reporting.

#### **9.3.5 Implications for education and personal professional development**

Implications for clinical practice can be supported by Scotland's new education framework '*Palliative and end of life care: enriching and improving experience*' (NHS Education for Scotland 2018). Collaboration is needed between Higher Education Institutions within Scotland to design undergraduate curricula to ensure that students appreciate how unnecessary distress in palliative care can be caused and how the practice of relationally centred family-focussed palliative care can be achieved. Considerable variation in clinical assessment of distress in families was shown by healthcare professionals. Some professionals also described a perceived lack of organisational support for education. This suggests a possible lack of robust frameworks to support personal and professional development within healthcare organisations and warrants further exploration.

#### **9.3.6 Final statement**

This thesis began with an aim to produce pronesis to inform clinical practice and to enhance the well-being of families living with advanced illness. Dissemination of research is critical to achieving this aim. On reflection, the journey of PhD by publication has been somewhat bumpy at times, with additional detours, which has prolonged the journey time somewhat. However, this thesis has affected my personal practice as a GP, on my teaching to students as a nurse lecturer and as a confidant peer as a GP appraiser. My task ahead is to continue on my journey as a healthcare researcher and to work with families and professionals to enhance understandings of distress in families by which to improve care.

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## 11. Appendices

### 11.1 Appendix 1: University of Stirling ethical approvals

JP/SG

26 March 2013

Clare Carolan  
Clinical Academic Fellow  
School of Nursing, Midwifery and Health  
Western Isles Campus  
Macaulay Road  
Stomoway  
HS1 2AF



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SCHOOL OF  
NURSING, MIDWIFERY  
AND HEALTH

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Web: [www.nm.stir.ac.uk](http://www.nm.stir.ac.uk)

John Paley  
Chair  
School Research Ethics Committee

School of Nursing, Midwifery and Health  
University of Stirling  
Stirling FK9 4LA

Tel: +44 (0) 1786 466399  
Fax: +44 (0) 1786 466333  
Email: [john.paley@stir.ac.uk](mailto:john.paley@stir.ac.uk)

Dear Clare

#### **The Experience of Distress and Help-seeking for Distress in Families Accessing Palliative Care**

Thank you for submitting your proposal to SREC and responding to queries and clarifications.

I can now confirm the study has now been approved.

May I take this opportunity to remind you that a site-file of *all* documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website. Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Paley', written over a large, stylized circular flourish.

John Paley  
(Chair)

School of Nursing, Midwifery and Health Research Ethics Committee

Highland Campus:  
Centre for Health Science  
Old Perth Road  
Inverness IV2 3JH

Tel: +44 (0) 1463 255655  
Fax: +44 (0) 1463 255654

Stirling Campus:  
Stirling  
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Western Isles Campus:  
Western Isles Hospital  
MacAulay Road  
Stornoway Isle of Lewis HS1 2AF

Tel: +44 (0) 1851 708243  
Fax: +44 (0) 1851 706070

## 11.2 Appendix 2: NHS initial ethical approval

NRES Committees – North of Scotland  
Summerfield House  
2 Eday Road  
Aberdeen  
AB15 6RE

Telephone: 01224 558458  
Facsimile: 01224 558609  
Email: nosres@nhs.net



04 June 2013

Dr Clare M Carolan  
University of Stirling (Western Isles Campus)  
Western Isles Hospital  
MacAulay Road  
Stornoway  
HS1 2AF

Dear Dr Carolan

**Study title:** The experience of emotional distress and help-seeking for distress in families accessing palliative care  
**REC reference:** 13/NS/0035  
**IRAS project ID:** 124297

Thank you for your letter of 03 June 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Scientific Officer.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Karen Gauld, kgauld@nhs.net.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		28 May 2013
Evidence of insurance or indemnity		10 April 2013
Interview Schedules/Topic Guides - Patient	v1	26 March 2013
Interview Schedules/Topic Guides - Health or Social Care Professional	v1	26 March 2013
Investigator CV – Dr Clare Carolan		26 March 2013
Letter from Sponsor		10 April 2013
Letter of Invitation: Health or Social Care Professional	1	26 March 2013
Letter to GP	1	26 March 2013
Interview Schedule: Family Member	1	26 March 2013
Interview Schedule: Group Family	1	26 March 2013
Response to SREC Peer Review		22 March 2013
SREC Approval Letter		26 March 2013
Dr Liz Forbat - CV	1	14 February 2013
Dr Liz Forbat - Master of Science Certificate		18 November 2011
Dr Anetta Smith - CV		03 June 2013 *
Letter from Dr Jeremy Keen - Highland Hospice		23 May 2013
Letter of Invitation to Patient & Family	2	30 May 2013
Letter of Invitation to Patient & Family - Track Changes	2	30 May 2013
Participant Information Sheet - Patient	2	30 May 2013
Participant Information Sheet - Patient - Track Changes	2	30 May 2013
Participant Information Sheet - Family Member	2	30 May 2013
Participant Information Sheet - Family Member - Track Changes	2	30 May 2013

Document	Version	Date
Accessing further help & resources Information Sheet	2	30 May 2013
Accessing further help & resources Information Sheet - Track Changes	2	30 May 2013
Consent Form - Patient	2	30 May 2013
Consent Form - Patient - Track Changes	2	30 May 2013
Consent Form - Family Member	2	30 May 2013
Consent Form - Family Member - Track Changes	2	30 May 2013
Consent Form - Health/Social Care Professional	2	30 May 2013
Consent Form - Health/Social Care Professional - Track Changes	2	30 May 2013
Protocol	1	02 April 2013
Protocol	LF	01 September 2010
Questionnaire: Emotion Thermometers Scale		18 April 2013 *
Questionnaire: The Family Relationships Index (FRI)		18 April 2013 *
REC application	124297/438263/1/666	18 April 2013
Referees or other scientific critique report		15 March 2013
Response to Request for Further Information		03 June 2013

\* Date received

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

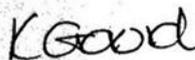
13/NS/0035

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Alex Johnstone  
Chair

Enclosures:

"After ethical review – guidance for researchers" [SL-AR2]

Copy to:

Ms Carol Johnstone – University of Stirling

## 11.3 Appendix 3: NHS ethical approval for conversion to a multi-site study

### NRES Committees - North of Scotland

Summerfield House  
2 Eday Road  
Aberdeen  
AB15 6RE

Telephone: 01224 558458  
Facsimile: 01224 558609  
Email: nosres@nhs.net



25 June 2014

Dr Clare Carolan  
Clinical Academic Fellow  
University of Stirling  
Western Isles Hospital  
STORNOWAY  
HS2 9NH

Dear Dr Carolan

**Study title:** The experience of emotional distress and help-seeking for distress in families accessing palliative care  
**REC reference:** 13/NS/0035  
**Amendment number:** AM03  
**Amendment date:** 17 June 2014  
**IRAS project ID:** 124297

The above amendment was reviewed by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter for Substantial Amendment		17 June 2014
Notice of Substantial Amendment (non-CTIMP)	AM03	17 June 2014
Marie Curie Cancer Care Approval Letter		23 May 2014
Appendix 16 - Letter of Invitation - Patient and Family - all sites	1	9 June 2014
Appendix 17 - Participant Information Sheet - Patients - all sites	1	9 June 2014
Appendix 18 - Participant Information Sheet - Family Member - all sites	1	9 June 2014
Appendix 19 - Participant Information Sheet - Health or Social Care Professional - all sites	1	19 June 2014

<i>Document</i>	<i>Version</i>	<i>Date</i>
Appendix 20 - Accessing Further Help and Resources Information Sheet - Grampian	1	9 June 2014
Appendix 21 - Accessing Further Help and Resources Information Sheet - Dundee	1	9 June 2014
Appendix 22 - Accessing Further Help and Resources Information Sheet - Perth and Kinross	1	9 June 2014
Appendix 23 - Accessing Further Help and Resources Information Sheet - Angus	1	9 June 2014
Appendix 24 - Accessing Further Help and Resources Information Sheet - Lothian	1	9 June 2014
Appendix 25 - Accessing Further Help and Resources Information Sheet - Greater Glasgow & Clyde	1	9 June 2014
Appendix 26 - Accessing Further Help and Resources Information Sheet - Western Isles	1	9 June 2014
Appendix 27 - Letter to GP - all sites	1	9 June 2014
Research protocol or project proposal	2	9 June 2014
Summary CV for Chief Investigator (CI): Clare Carolan		9 June 2014

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

#### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

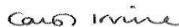
#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>13/NS/0035:</b>	<b>Please quote this number on all correspondence</b>
--------------------	-------------------------------------------------------

Yours sincerely



**pp'd on behalf of  
Mr Gary Cooper  
Alternate Vice-Chair**

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Carol Johnstone

**NRES Committees - North of Scotland (2)**

**Attendance at Sub-Committee of the REC meeting by correspondence**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Gary Cooper	Lay Member - Alternate Vice Chair and Quality Assurance Manager	Yes	
Dr Jeremy Morse	Manager of Clinical Skills	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Carol Irvine	Senior Ethics Co-ordinator

## 11.4 Appendix 4: Accessing further help and resources information sheet

Appendix 4  
Accessing further help and resources information sheet: The Experience of Emotional Distress and Help-seeking for Distress  
in Families Accessing Palliative Care. 13/NS0035  
Version 2 30/5/13



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### Accessing further help and resources information sheet

You may find that there are issues that you would like to discuss further with someone else. You may want to consider using one or more of the following:

- Talking to family and friends
- Talking to any of the doctors or nurses involved in you or your family members care
- Talking to your own GP or your local community nursing services. They will be able to give you direct support and further information. They will also be able to refer you to specialist support such as Macmillan Nursing or Marie Curie Nursing service
- Contacting the Highland Hospice, Inverness\*
- Contacting Maggie's Highland, Inverness
- Contacting local support groups or local branches of national agencies or visiting National Support and Information Websites

\*Dr Jeremy Keen from Highland Hospice is aware of this study and he can be contacted to provide emotional support and further help. He can be contacted both during and after taking part in the study. He can be contacted through the Highland Hospice contact details below.

You might find the following list of contacts helpful:

#### Highland Hospice

Hospices offer supportive palliative care to patients and their families. Highland Hospice is based in Inverness and has in-patient and day patient facilities. It also has an outreach day service in Skye, Fort William, Thurso and Dornoch. The Hospice also offers a Family Support Service. You can visit their website ➔ <http://highlandhospice.org/contact> or contact the service ➔ Highland Hospice  
Ness House, 1 Bishops Road, Inverness, IV3 5SB  
Tel: 01463 243132

#### Macmillan Cancer Support

Macmillan Cancer Support provides practical, medical and financial support for cancer patients and their families. You can visit their website ➔ <http://www.macmillan.org.uk/Home.aspx>  
You can also contact them by telephone ➔ 0808 808 00 00

#### Macmillan Citizens Advice Bureau Partnership

Macmillan Cancer Support work in partnership with Citizens Advice Scotland to ensure patients and families can access information and support from the services available to them. You can contact the service ➔  
Macmillan Citizens Advice Bureau Partnership  
Raigmore Hospital, Inverness, IV2 3UJ.

Appendix 4

Accessing further help and resources information sheet: The Experience of Emotional Distress and Help-seeking for Distress in Families Accessing Palliative Care. 13/NS0035

Version 2 30/5/13

Tel: 01463706178

**Macmillan Nursing Service, Inverness**

Macmillan nurses specialise in caring for cancer patients and their families. You can be referred to their service by doctors and nurses already involved in your care. You can also contact the service ☞

Macmillan Nursing Service, Inverness

NHS Highland

Netley Centre, Bishop's Road, Inverness, IV3 5SB.

Tel: 01463 233659

**Maggie's Highlands**

Maggie's centres offer support to anyone who is affected by cancer and provides access to high quality, evidence based psychological, emotional and informational support in a relaxed setting.

You can visit their website ☞ <http://www.maggiescentres.org/centres/highlands/introduction.html>

or contact the service ☞

Maggie's Highlands

Raigmore Hospital, Old Perth Road, Inverness IV2 3FL

Tel: 01463 706306

**Crossroads Caring Scotland**

Crossroads Caring Scotland is a national charity which provides home based support for carers. You can visit their website ☞ <http://www.crossroads-scotland.co.uk/>. You can contact the service ☞

Crossroads Caring Scotland Inverness

5, Charles Street, Inverness, IV2 3AQ

Tel: 01463 242112

**Marie Curie Cancer Care**

Marie Curie Cancer nurses provide care to terminally ill patients in their own homes while offering support to their families. If you would like to find out more please speak to the doctor or nurse involved in you and your family's care or visit their website ☞ <http://www.mariecurie.org.uk/>

**Cancer Support Groups**

You can visit the Cancer Support Scotland website ☞ <http://www.cancersupportscotland.org/> or you can contact them by telephone ☞0800 652 4531

A list of local cancer support groups in the area can also be found by visiting the NHS Inform Website ☞<http://www.nhsinform.co.uk/Support-Services/Topic?letter=C&topic=Cancer>

**Living Life**

Living Life is a free telephone service available to anyone over the age of 16 who is suffering from low mood, mild to moderate depression and/or anxiety and is provided by NHS Scotland. You can ask your GP to refer you to this service or you can contact them directly by phoning the free, confidential phone line ☞0800 328 9655 (Mon-Fri 1pm to 9pm). You can visit this website for further information ☞ <http://www.nhs24.com/UsefulResources/LivingLife>

**End of Life Care Information**

You may also find the following website helpful to help you and your family discuss issues about the future ☞ <http://www.goodlifedeathgrief.org.uk/>

If you would like to have this information sheet sent to you electronically please contact me at ☞ [clare.carolan@stir.ac.uk](mailto:clare.carolan@stir.ac.uk)

## 11.5 Appendix 5: Letter of invitation to the family

Appendix 1.  
Letter of invitation to Patient and Family: The Experience of Emotional Distress and Help-seeking for Distress in Families  
Accessing Palliative Care. 13/NS0035  
Version 2.30/05/13



UNIVERSITY OF  
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Dr Annetta Smith,  
Associate Head of School,  
School of Nursing Midwifery & Health  
University of Stirling  
(Western Isles Campus)  
Macaulay Road  
Stornoway HS1 2AF  
Tel: 01851708250  
E:mail:annetta.smith@stir.ac.uk

Dr Liz Forbat,  
Reader and Co-Director,  
Cancer Care Research Centre.  
University of Stirling  
(Stirling Campus)  
Stirling  
FK9 4LA  
Tel: 01786 466103  
E:mail:elizabeth.forbat@stir.ac.uk

Dr Clare Carolan  
PhD Student & Clinical Academic Fellow  
School of Nursing Midwifery & Health  
University of Stirling  
(Western Isles Campus)  
Macaulay Road  
Stornoway HS1 2AF  
Tel:01851 70849  
E:mail clare.carolan@stir.ac.uk

Date: 7/10/2013

Dear Patient and Family,

Dr Clare Carolan is carrying out a research study about the experience of emotional distress in cancer patients and their families. We know that cancer patients and their families may experience emotional distress and we would like to understand more about such feelings, worries and emotional symptoms. We would also like to know about any help families may have wanted or may have received for their distress from health and social care professionals. We would like to ask families who feel they have experienced distress to consider taking part in this study. This study is being undertaken as part of Clare's PhD and is being supervised by Drs Forbat and Smith from the University of Stirling.

Clare has asked doctors and nurses working in NHS Highland to tell you about this study. For each family who agrees to take part in the study she will need to talk to the patient and two other members of their family. How people describe families can vary widely and may include individuals that they are related to either by blood or by marriage or may include those individuals that they have longstanding relationships and close friendships with. For the purposes of this study Clare will ask you to consider family to be those individuals who '*share closely in your illness experience*'. So this could include relatives, partners, friends or carers or any other individual who you feel shares closely in your experience of your illness.

We would like to invite you to take away the accompanying information pack which contains some information leaflets and further copies of this letter for you to share and discuss with your family. If you and/or your family have experienced distress then we would like to invite you, the patient, and two members of your family to participate in the study. The study will involve Clare interviewing you individually and then together and Clare will also ask you to complete two very brief questionnaires. The information sheets contained in the study information pack provides you with detailed information about the study and how to contact Clare if your family would like to participate in the study. Thank you for taking the time to read this letter and the accompanying material in the study information pack.

Appendix 1.

Letter of invitation to Patient and Family: The Experience of Emotional Distress and Help-seeking for Distress in Families Accessing Palliative Care. 13/NS0035  
Version 2 30/05/13

There are some frequently asked questions at the end of this letter which may help answer any questions you have but if you need more information about the study before deciding whether you wish to participate then please contact Clare either by [email or phone to Clare Carolan](mailto:clare.carolan@stir.ac.uk) ☎ 01851 708249 ☎ [clare.carolan@stir.ac.uk](mailto:clare.carolan@stir.ac.uk) . You are also able to contact Drs Forbat and Dr Smith using the contact details above.

Yours sincerely,

pp 

Dr Liz Forbat & Dr Annetta Smith

**Frequently asked questions**

- 1. Does everyone in my family need to be distressed for our family to take part in the study?**  
No. We are interested in the different ways distress affects families. So it might be that only one member of your family is distressed or it might be that everyone is distressed. What is important is whether you feel that distress affects at least one member in your family. If this is the case then we would like your family to consider taking part in the study.
- 2. Who decides which member of our family takes part in the study?**  
Clare will need to speak to your family member who has cancer (the patient) but it will be up to you as a family to decide who will be the other two family members taking part in the study.
- 3. Several members of our family are distressed will you talk to all of them?**  
While Clare would value speaking to everyone in your family about your family's distress Clare is only able to speak to the patient and two family members. She does not necessarily need to speak to the person who you feel is the most distressed particularly if they are either unable or do not want to take part in the study. However, she will ask your family members who do take part in the study to tell her about how distress affects the whole family.
- 4. Why didn't you ask the doctors and nurses to choose families who they feel are distressed to take part in the study?**  
The doctors and nurses looking after you and your family may not always see everyone in your family and so may not be able to pick up on distress in the family. Research also tells us that doctors and nurses sometimes don't pick up on emotional symptoms that affect families. If we only ask families chosen by doctors and nurses we may miss some families who are distressed and they would not get the opportunity to take part in the study.
- 5. Our family doesn't want to take part in the study but we would like to speak to someone about how distress affects our family. What should we do?**  
You can speak to any health care professional involved in the care of your family member who has cancer or your contact your own GP. There is a support leaflet included in the study information pack which has contact numbers that you may also find helpful.

## 11.6 Appendix 6: Interview schedule (patient)

Participant interview schedule – patient  
Version 1 21/02/2013

**1. To begin with can you tell me a little about yourself? If I use the definition of family as ‘those who share closely in your illness experience’, can you tell me who your family are?**

*Prompts:*

*Brief demographics about patient age, marital status, employment status and how long they have lived in the area.*

*Details of family members: who they are, relationships to patient and their location.*

**2. Can you tell me about your cancer? Can you tell me about your feelings and emotions at diagnosis and since this time?**

*Prompts:*

*Consider contextual changes in physical health, Quality of Life (QOL), social context (work/hobbies)*

*What do you feel influenced your feelings/emotions/mood?*

*If not raised ask about issues around breaking bad news and any perceptions around the time of diagnosis.*

**4. How are you feeling at the moment?**

*Prompts:*

*Do you feel emotionally distressed?*

*Can you tell me about this emotional distress (including triggers, precipitants, perceived impact on their QOL, responses to distress?)*

*Are you experiencing any other emotions? For example some people describe feeling down; anxious, worried, angry, guilty (omit from list those that the patient has already discussed). Can you tell me about your experience of these?*

**5. How do you feel the diagnosis of cancer has affected your family?**

*Prompts:*

*Can you tell me about emotional distress in other family members?*

*Including triggers, precipitants, perceived impact on their QoL, responses to dealing with their own distress?*

*Can you tell me about any affect it has had on relationships within the family?*

**6. Do you and your family share your experiences of emotional upset and distress with one another? Can you tell me about this?**

*Prompts:*

*Consider verbal and non-verbal communication; behaviour; communication through third parties; issues around remote caregiving.*

*What influences how emotional worries and distress are communicated / talked about?*

*How do you feel about how you talk about emotions in your family?*

*Is there anything you would like to change about how your family talks about emotions?*

**7. When bad or difficult things have happened in the past how have you and your family coped?**

*Prompts:*

*Are there any differences within the family in how family members respond and cope?*

*Have you ever been troubled with anxiety or depression in the past?*

**8. Who do you think has recognised/noticed any distress affecting your family? Can you tell more about this and what happened?**

*Prompts:*

*Friends/Work/Health and social care services/ voluntary groups/ religious groups*

*Did they offer help? What was this? How did you feel about this?*

**9. (i) Have you or any member of your family asked for help with emotional distress such as anxiety, worry, depression etc. from any health or social care professionals (such doctors/nurses/social workers)? Can you tell me about your experience of this?**

*Prompts:*

*Who did you seek help from?*

*Why-what led to this?*

*How did you seek help?*

*What influenced your decision to seek help?*

*Did you get the help you wanted?*

*Was it helpful?*

*Would you ask for help again?*

**(ii) Have there been times when you and your family have been distress but decided not to ask these professionals for help? Can you tell me more about this?**

*Prompts:*

*Why this was this?*

*What influenced this?*

*Is there anything that health care/social care should change to make it more likely for families to ask for help?*

**10. Is there something else you would like to say?**

## 11.7 Appendix 7: Interview schedule (family member)

Participant interview schedule – family member  
Version 1 21/02/2013

**1. To begin with can you tell me a little about yourself? If I use the definition of family as ‘those who share closely in your illness experience’, can you tell me who your family are?**

*Prompts: Brief demographics about patient age, marital status, employment status and how long they have lived in the area.*

*Details of family members: who they are, relationships to patient and their location.*

**2. Can you tell me your story – what has happened to you since [INSERT PATIENT’S NAME] was diagnosed with cancer? Can you tell me about your feelings and emotions at diagnosis and since this time?**

*Prompts: Consider contextual changes in physical health, Quality of Life (QOL), social context (work/hobbies)*

*What do you feel influenced your feelings/emotions/mood?*

*If not raised ask about issues around breaking bad news and any perceptions around the time of diagnosis.*

**4. How are you feeling at the moment?**

*Prompts: Do you feel emotionally distressed?*

*Can you tell me about this (including triggers, precipitants, perceived impact on their QOL, responses to distress?)*

*Are you experiencing any other emotions? For example some people describe feeling down; anxious, worried, angry, guilty (omit from list those that the patient has already discussed). Can you tell me about your experience of these?*

**5. How has the diagnosis of cancer affected the family?**

*Prompts: Can you tell me about emotional distress in other family members including [Insert patient’s name]*

*Including triggers, precipitants, perceived impact on their QoL, responses to dealing with their own distress?*

*Can you tell me about any affect it has had on relationships within the family?*

**6. Do you and your family including INSERT PATIENT’S NAME share your experiences of emotional upset and distress with one another? Can you tell me about this?**

*Prompts: Consider verbal and non-verbal communication; behaviour; communication through third parties; issues around remote caregiving.*

*What influences how emotional worries and distress are communicated/talked about?*

*How do you feel about how you talk about emotions in your family?*

*Is there anything you would like to change about how your family talks about emotions?*

**7. When bad or difficult things have happened in the past how have you and your family coped?**

*Prompts: Are there any differences within the family in how family members respond and cope?*

*Have you ever been troubled with anxiety or depression in the past?*

**8. Who do you think has recognised any distress affecting your family? Can you tell more about this and what happened?**

*Prompts: Friends/Work/Health and social care services/ voluntary groups/ religious groups*

*Did they offer help? What was this? How did you feel about this?*

**9. (i) Have you or any member of your family asked for help with emotional distress such as anxiety, worry, depression etc. from any health or social care professionals (such as doctors/nurses social workers)? Can you tell me about your experience of this?**

*Prompts:*

*Who did you seek help from?*

*Why-what led to this?*

*How did you seek help?*

*What influenced your decision to seek help?*

*Did you get the help you wanted?*

*Was it helpful?*

*Would you ask for help again?*

**(ii) Have there been times when you and your family have been distressed but decided not to ask these professionals for help? Can you tell me more about this?**

*Prompts:*

*Why this was this?*

*What influenced this?*

*Is there anything that health care/social care should change to make it more likely for families to ask for help?*

**10. Is there something else you would like to say?**

## 11.8 Appendix 8: Interview schedule (family group interview)

Participant interview schedule – group family interview  
Version 1 16/01/2013

### Notes

The family interview will seek to produce an interactional space to explore how families co-construct their experience of distress and help seeking and to explore how they communicate distress. During the family interview the researcher will use circular questioning. For example during the interview family members will be asked to reflect on and respond to one another's responses using prompts such as: 'X, can you tell me how you feel about what Y has said?' 'X, what do you think Y means by this?' 'X has said .....Does anyone else identify with this?' Any differences in perceptions from individual family members will be explored and perspective taking will be encouraged. This will be undertaken sensitively and the researcher will be mindful of and responsive to non-verbal and verbal cues throughout the interview process.

Before starting the interview the researcher will say the following to the participants:

*'I would like to start by thanking you all for taking part in this family interview. During this interview I would like you all to feel able to contribute to the discussion and for you all to feel comfortable about doing this. During the interview I may ask you about what you think or feel about what someone else has said or why they might have these feelings or views. When I ask you a question you can tell me as little or as much as you want to. It is also important for you to know and understand that it is OK if you don't want to say anything at all and we can simply move on to another question. Please feel free to tell me if any of you want to stop the interview at any point.'*

**1. Some families describe very different experiences of help they have received from health care workers or social workers when they become distressed.**

**(i) Can you tell me about any help your family has received from health or social care workers? Can you share some examples with me?**

*Prompts:*

*Explore whether help **offered** or **sought** and what were the triggers for this? Ask family where possible to preferably share an example of where help was sought if this was applicable.*

*If help was **sought**, how did this come about in terms of decision making and what influenced this decision making. If help had been **offered** without the family asking, explore whether they would have asked for help if it had not been given and the reasons for this response.*

*(Explore any differences in responses between members and perspective taking)*

**(ii) Has there ever been a time when you have had a difference of opinion as a family on whether to ask for help or not? Can you tell me about this and why there was a difference of opinion?**

*(Explore any differences in responses between members and perspective taking)*

**(iii) If you've not asked or received any help for your distress from health or social care workers what would influence you to make you ask for help?**

*(Explore any differences in responses between members and perspective taking)*

**2. What do you feel about health and social care workers asking you about your emotions and feelings?**

*Prompts: Perceptions about role of professionals. If families perceive no or limited role for HCP –why is this?*

**3(i) Have any health or social care workers involved your family's care helped your family communicate and talk about your emotions and feelings as a family?**

**If yes – what happened and how did this change the way your family communicate?**

**If not – can you tell more about this?**

*(Explore any differences in responses between members and perspective taking)*

**(ii) How does your family currently talk about worries or emotional upset?**

*Prompts:*

*How have conversations begun? Who recognises distress?*

*What are the triggers, who is involved, outcomes?*

**(iii) Have there ever been times since [Insert patient's name's] diagnosis when you've felt that as a family you didn't talk about your worries, concerns or emotional upset when you feel you might have done? Can you tell me about this?**

**Looking back what do you feel influences why as a family you didn't talk about your worries, concerns or upset at this time?**

*(Explore any differences in responses between members and perspective taking)*

If families do not describe any such instances of where distress wasn't discussed then ask the following.

**(iv) You describe that your family seem to be able to freely discuss and talk about your distress. Why do you think this is?**

**4. Is there something else anyone would like to share?**

## 11.9 Appendix 9: Interview schedule (health/social care professional)

Appendix 12 Participant interview schedule – health or social care professional: The Experience of Emotional Distress and Help-seeking for Distress in Families Accessing Palliative Care. 13/NS0035  
Version 1 26/03/2013

**1. Can you tell me how you have been involved about the care of [INSERT PATIENT'S NAME] and their family?**

*Prompts:*

*When did you become involved and why? Have you been involved since diagnosis?*

*What's your relationship with the patient/family? Do you see them often, who arranges, how do you get on? What do you know about the family's relationship with other professionals?*

*How do you perceive your role in the care of the family of [INSERT PATIENT'S NAME]?*

**2. In general terms what is your approach to assessing emotional symptoms and distress in palliative care patients and their families?**

*Prompts:*

*Thoughts, feelings and perceptions*

**3. Can you tell me about your experience of assessing emotional symptoms and distress in [INSERT PATIENT'S NAME] and their family?**

**4. Do you feel there is distress in this family? Can you tell me more about this?**

*Prompts:*

*Who is affected; thoughts and perceptions about this; communication of distress within the family?*

**5. Do you know of any help this family has received to help with emotional symptoms? What can you tell me about this?**

**6. Do you feel you have helped this family with their emotional distress? Can you tell me about this?**

*Prompts:*

*Either as individuals or collectively*

**7. Can you think of instances when this family hasn't sought or taken up help for their distress? Why do you think this is?**

*Prompts:*

*Have you experienced any barriers (individual/family/your own practice)? If so what do you think they are and how does this affect help-seeking?*

**8. Do you feel this family's level of distress will change over time? Can you tell me more about your thoughts on this? What do you feel your role will be?**

*Prompts:*

*Individuals and family.*

**9. Is there something else you would like to say?**

# 11.10 Appendix 10: Emotion Thermometers Tool

## Emotion Thermometers Scale 7-items Alex Mitchell ©

Instructions in the first four columns, please mark the number (0-10) that best describes how much emotional upset you have been experiencing in the past two weeks, including today. In the next three columns please indicate how much impact this has had on you and how much you need help for these.

Emotional Upset				Burden		
<b>1. Distress</b> Please mark how severe is your distress? Distress means feeling stressed, upset, hurt or preoccupied	<b>2. Anxiety</b> Please mark how severe is your anxiety? Anxiety means feeling worried, tense, agitated	<b>3. Depression</b> Please mark how severe is your depression? Depression means feeling down, low, withdrawn	<b>4. Anger</b> Please mark how severe is your distress? Anger means feeling annoyed, irritated	<b>5. Impact</b> How much has this affected you? To what extent can you still do normal activities?	<b>6. Need Help</b> How much do you need professional help for these concerns?	<b>7. Overall Health</b> Please indicate how good or bad your own health is today. 10 is the best state you can imagine and 0 the worst
10 = Extreme	10 = Extreme	10 = Extreme	10 = Extreme	10 = Cannot function at all	10 = Desperately	10 = Best Health
0 = None	0 = None	0 = None	0 = None	0 = No Effect on me	0 = Can manage myself	0 = Worst Health

## 11.11 Appendix 11: Family Relationships Index

### The Family Relationships Index (FRI)

The following statements help us understand your family. Please read each statement below and place a tick in the column marked TRUE, if you think the statement is true of your family, or a tick in the column marked FALSE, if you think this statement is not true of your family.

		TRUE	FALSE
1.	Family members really help and support one another		
2.	Family members often keep their feelings to themselves.		
3.	We fight a lot in our family		
4.	We often seem to be killing time at home		
5.	We say anything we want to around the home		
6.	Family members rarely become openly angry		
7.	We put a lot of energy into what we do at home		
8.	It is hard to 'blow off steam' at home without upsetting somebody		
9.	Family members sometimes get so angry they throw things		
10.	There is a feeling of togetherness in our family		
11.	We tell each other about our personal problems		
12.	Family members hardly ever lose their tempers		

## 11.12 Appendix 12: Consent form (patient)

Appendix 5  
Patient Participant Consent Form: The Experience of Emotional Distress and Help-seeking for Distress in  
Families Accessing Palliative Care. 13/NS0035  
Version 2 30/05/13



UNIVERSITY OF  
STIRLING

Study Number:

Participant Identification Number for this study:

### PATIENT CONSENT FORM

**Title of Project:** The Experience of Distress and Help-seeking for Distress in Families Accessing Palliative Care

Name of Researcher: Clare Carolan

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version .....) for the above study.	<input type="checkbox"/>
2. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	<input type="checkbox"/>
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected.	<input type="checkbox"/>
4. I understand that research data collected during the study may be looked at by individuals from The University of Stirling, from regulatory authorities or from the NHS Trust/Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this research data.	<input type="checkbox"/>
5. I agree to be audio recorded.	<input type="checkbox"/>
6. I understand that what I say in my individual interview will not be shared with family members.	<input type="checkbox"/>

7. I agree to the use of quotations of my anonymised responses from the audiotaped interview which may be presented in the dissertation report or any subsequent publication that comes of this research study	<input type="checkbox"/>
8. I agree to my GP being informed of my participation in this research study	<input type="checkbox"/>
9. I agree to take part in the above research study.	<input type="checkbox"/>

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Name of Participant	Date	Signature
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Researcher	Date	Signature
------------	------	-----------

Researcher contact details:

Name: Clare Carolan

Address: University of Stirling (Western Isles Campus)  
MacAulay Road  
Stornoway HS1 2AF

Email: clare.carolan@stir.ac.uk

Telephone: 01851 708249

## 11.13 Appendix 13: Consent form (family member)

Appendix 13  
Family Member Participant Consent Form: The Experience of Emotional Distress and Help-seeking for Distress  
in Families Accessing Palliative Care. 13/NS0035  
Version 2 30/05/13



UNIVERSITY OF  
STIRLING

Study Number:

Participant Identification Number for this study:

### FAMILY MEMBER CONSENT FORM

**Title of Project:** The Experience of Distress and Help-seeking for Distress in Families Accessing Palliative Care

Name of Researcher: Clare Carolan

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version .....) for the above study.	<input type="checkbox"/>
2. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	<input type="checkbox"/>
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected.	<input type="checkbox"/>
4. I understand that research data collected during the study may be looked at by individuals from The University of Stirling, from regulatory authorities or from the NHS Trust/Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this research data.	<input type="checkbox"/>
5. I agree to be audio recorded.	<input type="checkbox"/>
6. I understand that what I say in my individual interview will not be shared with family members.	<input type="checkbox"/>

7. I agree to the use of quotations of my anonymised responses from the audiotaped interview  
which may be presented in the dissertation report or any subsequent publication that comes of  
this research study.

8. I agree to take part in the above research study.

---

Name of Participant

Date

Signature

---

Researcher

Date

Signature

Researcher contact details:

Name: Clare Carolan

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MacAulay Road  
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## 11.14 Appendix 14: Consent form (healthcare/social care professional)

Appendix 14  
Health/Social Care Professional Participant Consent Form: The Experience of Emotional Distress and Help-seeking for Distress in Families Accessing Palliative Care. 13/NS0035  
Version 2 30/05/13



UNIVERSITY OF  
STIRLING

Study Number:

Participant Identification Number for this study:

### HEALTH/SOCIAL CARE PROFESSIONAL CONSENT FORM

**Title of Project:** The Experience of Distress and Help-seeking for Distress in Families Accessing Palliative Care

Name of Researcher: Clare Carolan

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version .....) for the above study.	<input type="checkbox"/>
2. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	<input type="checkbox"/>
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected.	<input type="checkbox"/>
4. I understand that research data collected during the study may be looked at by individuals from The University of Stirling, from regulatory authorities or from the NHS Trust/Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this research data.	<input type="checkbox"/>
5. I agree to be audio recorded.	<input type="checkbox"/>

6. I agree to the use of quotations of my anonymised responses from the audiotaped interview which may be presented in the dissertation report or any subsequent publication that comes of this research study.

7. I agree to take part in the above research study.

---

Name of Participant

Date

Signature

---

Researcher

Date

Signature

Researcher contact details:

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Telephone: 01851 708249

## 11.15 Appendix 15: Initial inductive coding framework

Nodes			
Name	Sources	References	
a INITIAL CODING FRAMEWORK		95	5371
ZMISC		7	11
TRUTH		27	189
WHAT IS NOT SAID		6	7
HONESTY IN INTERVIEW		9	37
CLARITY OF TRUTH		23	145
TEMPORAL		33	385
POWER		30	292
POWER EXERTED WITHIN		13	57
POWER EXERTED UPON		14	65
POWER - EXERTING CONTROL SPECTRUM		24	170
OBSERVABLE EMOTION IN INTERVIEWS		23	256
I, ME , WE, US F1		26	168
HELP-SEEKING AND CARE		52	1947
CATEGORIES OF HCPS		28	295
BEING INCLUDED & EXCLUDED		17	125
BEING PERMEABLE TO HELP		31	640
INTERACTIONS AT DIAGNOSIS		16	253
HEALTHCARE INTERFACE		32	634

Name	Sources	References
HEALTHCARE INTERFACE	32	634
FAMILY SPACE	45	541
HISTORICAL SPACE	27	133
PHYSICAL SPACE	18	97
RELATIONAL SPACE	14	63
CARING SPACE	14	66
OCCUPATIONAL SPACE	14	51
SOCIAL NETWORKS	7	57
SOCIETAL NORMS	12	63
FINANCIAL SPACE	3	11
EMOTIONS AND EMOTIONAL SPACE	35	456
AMPLITUDE (INTER AND INTRA)	16	82
MISC EMOTION (inc.hope and strength)	14	49
EMOTIONAL SPACE	12	60
BEING DISTRESSED	27	265
EMBODIMENT	43	417
INTEGRITY (trans-death, personhood identit	29	184
EMODIMENT CANCER	18	113
EMBDODIMENT EMOTIONAL	17	101

## Nodes

Name	Sources	References
EMBODIMENT		43 417
INTEGRITY (trans-death, personhood identit		29 184
EMODIMENT CANCER		18 113
EMBDODIMENT EMOTIONAL		17 101
EMODIMENT OTHER PHYSICAL		10 19
COMMUNICATION		34 346
OPEN COMMUNICATION		16 54
MISC FAMILY COMMUNICATION CODES		14 54
HUMOUR		5 28
CLOSED COMMUNICATION		28 210
CERTAINTY AND UNCERTAINTY		16 246
AGREEMENT & DISAGREEMENT IN FAMILY INTE		5 117

## 11.16 Appendix 16: Data analysis prompt sheet

### General things I need to keep at the front of my mind during data analysis

- NO SINGLE OBEJECTIVE TRUTH /NO VERIFICATION
- SEEK TO CAPTURE SHARED MEANINGS AND PROCESSES- ANSWER WHY IS THIS SHARED?
- SEEK TO CAPTURE DIVERGENT MEANINGS AND PROCESS – ANSWER WHY IS THIS DIVERGENT?
- PAY ATTENTION TO WHAT PEOPLE ARE DOING - GERUNDS
- PAY ATTENTION TO LANGUAGE AND LINGUISTICS
- PAY ATTENTION TO WHAT IS NOT SAID
- PAY ATTENTION TO HOW OTHERS ASCRIBE MEANINGS AND ACTIONS TO THOSE IN THE FAMILY THAT WERE NOT INTERVIEWED
- PAY ATTENTION TO TAKEN FOR GRANTED/ NOVEL/ ANOMALOUS EXPERIENCES
- **WHAT AM I DOING DURING DATA COLLECTION AND ANALYSIS? WHAT INFLUENCES MY POSITION; how does the various facets of who I am influences the process?**
- HOW DO WE CO-CONSTRUCT THE EXPERIENCE OF THE FAMILY/FAMILY SYSTEM?
- KEEP CLOSE 'EMIC PERSPECTIVE' WHEN CONDUCTING WITHIN CASE ANALYSIS
- INCORPORATE ETIC PERSEPCTIVE AND ABDUCTIVE ANALYSIS WHEN CONDUCTING CROSS CASE ANALYSIS (HELP-SEEKING)

