

The Experiences of Family Members Witnessing the
Diminishing Drinking of a Dying Relative in Hospital:

A Narrative Inquiry

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I declare that this thesis is my own work and has not been submitted
for the award of a higher degree elsewhere.

Dedication

For my mother, Hilary Constance Pettifer (née Saint) SRN,

because I walk on your stepping-stones.

And for my daughters, Lucy Elspeth and Charlotte Kenyon Pettifer,

because I place stepping-stones for you.

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My father, John Pettifer, proofread this thesis. It has been a delight to share my work with him in this way. Philippa Hatch advised about intellectual property. Other family and friends have supported me too by 'keeping home' in my absence, chatting about my ideas, believing in my ability, listening to my frustrations, upholding me spiritually, valuing my work, connecting me, creating welcome diversion and bringing much needed fun and companionship into life as a PhD student.

Thank you all.

Abstract

Background

Palliative care aims to support the family members of people with life-threatening illnesses, alongside those who are ill. In the United Kingdom (UK), family members have expressed concern about the management of diminishing drinking and its consequences, particularly in the hospital environment, and the area is a priority for research.

Aim

This research aims to explore the experiences of family members when witnessing the diminishing drinking of a dying relative in order to identify areas in which professional support of family members might be improved. The exploration is framed within key notions of pragmatism as espoused by William James and John Dewey.

Methodology and Method

Thirteen family members who had witnessed diminishing drinking of a relative dying in hospital were recruited through the hospital bereavement service of one National Health Service trust in the UK. Their experiences were collected and analysed using narrative inquiry methodology, derived by Jean Clandinin and her colleagues from pragmatism.

Findings

Participants experienced diminishing drinking as an unfolding process which was part of overall decline associated with advancing illness. They all believed it to be detrimental. Three groups of responses were identified: promoting, accepting and ameliorating. Participants reported positive experiences of healthcare when staff actively supported relatives to drink, but they also found that staff could sometimes be too busy to attend to drinking. Tension occurred within families, and between healthcare staff and families over different approaches to managing aspiration risk and clinically assisted hydration.

Conclusion

This thesis offers a unique understanding of family members' experiences of diminishing drinking, which has the potential to inform new palliative endeavour in the field. It argues for a re-conceptualisation of diminishing drinking aligned to family members' experiences; for supporting family members through listening to their experiences with insight, and for supporting their agency within the management of their relatives with diminishing drinking. The thesis also offers an exemplar of how palliative care might be framed and executed through a pragmatic lens, enabling appraisal of its value to wider palliative research.

Keywords: pragmatism, narrative inquiry, drinking, fluid intake, dehydration, end of life care, palliative care, terminal care, family, caregiver, relative

Table of Contents

Dedication	2
Acknowledgements	3
Abstract	4
Table of Contents	6
List of Figures	10
List of Tables	10
List of Boxes	11
List of Abbreviations	11
Chapter 1: Introduction	12
1.1 The Research Puzzle	13
1.2 Justification of the Research	14
1.3 Location of the Researcher.....	17
1.4 Structure of the Thesis	19
Chapter 2: Philosophical Foundations: Pragmatism	22
2.1 Research Process	22
2.2 Pragmatism.....	23
2.2.1 Key ontological notions.....	26
2.2.2 Key epistemological notions	29
2.2.3 Key methodological implications	32
2.3 Narrative Research	33
2.3.1 The narrative inquiry of Clandinin	35
2.4 Summary.....	39
Chapter 3: Background	41
3.1 Terminology.....	41
3.2 Causes.....	43
3.3 Therapeutic Intervention	44
3.4 Controversies and Context	45
3.5 Supporting Family Members	51
3.6 Summary.....	52
Chapter 4: Existing Knowledge	53
4.1 Review Process	53
4.1.2 Scoping process.....	55

4.1.3 Searching process	55
4.1.4 Analysis and synthesis processes.....	59
4.2 Findings.....	60
4.2.1 Document characteristics	62
4.2.2 Narrative A: The experiences of family members witnessing the diminishing drinking of a dying relative	65
4.2.3 Narrative B: The experiences of family members regarding intervention for diminishing drinking.....	73
4.2.4 Narrative C: Professional support for family members of patients with diminishing drinking	91
4.2.5 Narratives A, B and C compared	93
4.3 Discussion	96
4.3.1 Limitations.....	98
4.4 Summary.....	98
Chapter 5: Research Design	100
5.1 Study Setting and Participant Population	100
5.2 The Sample and Recruitment Process.....	101
5.3 Consent Procedure	104
5.4 Telling Stories	104
5.5 Re-telling Stories.....	106
5.5.1 Field texts	108
5.5.2 Interim texts.....	108
5.5.3 Final texts	116
5.6 Rigour in Narrative Research.....	117
5.7 Ethical Considerations	119
5.8 Summary.....	121
Chapter 6: Findings.....	122
6.1 Recruitment.....	122
6.1.1 The participants	122
6.1.2 The relatives.....	129
6.1.3 The interviews.....	130
6.2 Strands.....	131
6.2.1 Strand A: Experiences of diminishing drinking	133
6.2.2 Strand B: Responses to diminishing drinking.....	140
6.2.3 Strand C: Experiences of healthcare and support	158
6.3 Summary.....	174

Chapter 7: Discussion	175
7.1 Temporality: Experiences over Time and in Sequence	176
7.2 Sociality: Experiences within Social and Personal Contexts.....	179
7.2.1 Personal beliefs and perceptions.....	180
7.2.2 Social and familial context	182
7.3 Place: Experiences within Hospital.....	184
7.4 Responses to Diminishing Drinking in Hospital	188
7.4.1 Behaviour	190
7.4.2 Approach.....	190
7.4.3 Reasoning.....	193
7.5 Conclusion of Discussion: Preserving Identity and Promoting Agency	196
Chapter 8: Conclusion.....	198
8.1 Instrumental Potential: Practice.....	198
8.1.1 Re-conceptualising.....	198
8.1.2 Listening with insight	199
8.1.3 Supporting agency	199
8.2 Instrumental Potential: Future Research	201
8.3 Instrumental Potential: Guidance and Policy.....	202
8.4 Strengths and Limitations.....	203
8.5 The Original Contribution of the Research.....	204
8.6 Reflecting Backwards and Forwards	205
8.7 Concluding Remarks	207
References	210
Appendices	224
Appendix 1: Glossary of Terms Used by Clandinin.....	224
Appendix 2: Health Research Authority Ethics Approval Letter	226
Appendix 3: Participant Invitation Letter	231
Appendix 4: Participant Information Sheet.....	232
Appendix 5: Expression of Interest Form	236
Appendix 6: Consent Form	237
Appendix 7: Confidentiality Agreement.....	240
Appendix 8: Interview Guide	241
Appendix 9: Distress Protocol	244

Appendix 10: Poster Presented at European Association of Palliative Care Research Conference, Bern, 2018	246
Appendix 11: Poster Presented at National Institute of Health Research and West Midlands Cares Research Conference, Birmingham 2018.....	247
Appendix 12: Poster Presented at European Association of Palliative Care Congress, Berlin 2019	248
Appendix 13: Poster Presented at European Association of Palliative Care Research Conference, Online 2020	249

List of Figures

Figure 1: William James, Houghton Library	24
Figure 2: John Dewey, Library of Congress	25
Figure 3: Jean Clandinin, University of Alberta	26
Figure 4: Plural ontology represented visually	27
Figure 5: Typology of terms relating to diminishing drinking.....	42
Figure 6: Weighted percentage response by place by bereaved family members to: 'in the last few days, he/she has support to drink or receive fluid if he/she wished'	49
Figure 7: Place of death in England in 2018 (Public Health England, 2019)	50
Figure 8: Narratives within research on family members' experience of diminishing drinking.....	55
Figure 9: PRIMA diagram	61
Figure 10: Commonplaces: The boundaries of narrative	107
Figure 11: Relationship of participating family members to their deceased relative.....	126
Figure 12: The responses of family members' experiences of diminishing drinking in hospital	189
Figure 13: The approaches to diminishing drinking of participants	191
Figure 14: Approach mapped to awareness of dying, beliefs about causation and reversibility, illness and awareness context	194
Figure 15: Underpinning assumption regarding the scope of family members' experiences of diminishing drinking in hospital.....	206

List of Tables

Table 1: Free-text search terms of each question area	57
Table 2: The narrative categories and key methodological features of included papers.....	63
Table 3: Key extracted data within narrative A	69
Table 4: Key extracted data within narrative B (Family members' perspectives)	80
Table 5: Key extracted data within narrative B (Professional's perspective)	86
Table 6: Key extracted data within narrative C.	92
Table 7: The tradition, key findings and limitations of each narrative	94
Table 8: Inclusion and exclusion criteria.....	101

Table 9: Key characteristics of participants and key features they offered about their deceased relatives	124
Table 10: Table of strands, resonant threads and narrative threads	131

List of Boxes

Box 1: Example of a narrative account: Jane	112
Box 2: Example of a narrative thread: Brenda.....	115
Box 3: Vignettes of participants.....	127

List of Abbreviations

ANH: Artificial nutrition and hydration
CAH: Clinically assisted hydration
NICE: National Institute for Health and Care Excellence
UK: United Kingdom of Great Britain and Northern Ireland
USA: United States of America
LCP: Liverpool Care Pathway
VSED: Voluntarily Stopping of Eating and Drinking

Chapter 1: Introduction

In this opening chapter I introduce the philosophical commitment underpinning the research and the central puzzle or topic that it explores. I describe myself as a researcher and provide an overview of the structure of the thesis.

This study draws on pragmatism, specifically the understanding of knowledge and knowledge generation of William James (1907); the understanding of experience of John Dewey (1938); and the research methodology of narrative inquiry developed from James' and Dewey's thinking by Jean Clandinin (Clandinin, 2013; Clandinin & Connelly, 2000). It will apply these areas of pragmatic thinking to the exploration of the experience of family members witnessing the diminishing drinking of their dying relatives in hospitals. Pragmatism is a school of philosophy built on the central premise of Charles Peirce that knowledge is established by its practical effect (Peirce, 1878; Talisse & Aikin, 2008). This emphasis on practical endeavour makes it particularly pertinent to research which is driven by practical imperative (McCready, 2010) as is the case with palliative care.

Diminishing drinking is common among people who are dying (Royal College of Physicians and British Society of Gastroenterology, 2010). As people with advanced, life-limiting conditions become progressively less conscious and enter the last few days of their lives, their everyday drinking of liquids normally diminishes and sometimes ceases altogether (McAulay, 2001; Malia & Bennett, 2011). Family members of dying

people will inevitably notice the diminishing drinking of their relatives and may be troubled by it.

1.1 The Research Puzzle

Clandinin frames narrative inquiry as a process of wondering about a 'research puzzle'. The terminology reflects an iterative process involving 'a sense of search, a "re-search", a searching again' (Clandinin & Connelly, 2000, p.124). Clandinin expresses research puzzles as a series of open-ended questions that reflect the aspiration to explore an experience or group of experiences in order to generate new understanding which might enhance future experiences (Clandinin, 2013). The process of narrative inquiry does not involve answering a question definitively or testing a hypothesis; rather, it seeks to develop new insight leading to improved experiences. This research focuses on the following puzzle:

What are family members' experiences of their dying relatives' diminishing drinking in hospital? What sense do they make of the diminishing drinking and how do they react to it? What are their experiences of healthcare given to their relative and support offered to themselves? How might better understanding of their experiences lead to improved support of family members witnessing diminishing drinking?

The scope of the research puzzle is flexible in order for it to develop iteratively. I have used the key terms within it in the following ways:

Family members: those who are significant to dying people at the end of their lives, whether biologically and legally related to them or not.

Relative: the person dying, not the family member.

Witnessing: noticing the relative's deteriorating condition; not necessarily meaning that the family member was present at the death.

Diminishing drinking: continuing and significant reduction of the intake of liquids by a dying patient by mouth. (The term is discussed in detail in 3.1, p. 41.)

Dying and end of life: people whose death is imminent, usually within a few days to a week. These terms are commonly used in the literature, but their meanings are variable (Hui et al., 2014). Some participants used this term to denote a broader time period; when this is the case, their words are reproduced verbatim.

Palliative care: an overall approach to improving the quality of life of people with life-threatening illness and their families as per the World Health Organization (2016).

End of life care: care given at end of life (as defined above), but not the last year or so which is a common usage of this term in the UK (NICE, 2019).

Methodological terms used in this thesis are defined in Appendix 1.

1.2 Justification of the Research

Clandinin (2013) identifies three groups of justifications for the exploration of a particular research puzzle: its personal significance to the researcher, its practical significance and its significance to theoretical or socially just knowledge. I will consider each of these in turn.

In part, the research puzzle stems from my personal experience of teaching nurses. During the course of my work I am often approached by nursing students seeking my advice about how they might support family members concerned about diminishing drinking of their dying relatives. Many nurses have told me of feeling torn between the requests from family members to give dying people drinks and professional concerns that the dying person may not want or be able to drink, or may be adversely affected by choking or increased oedema. My interest developed further when I wrote an educational paper to support nurses with these dilemmas and considered the controversies involved in greater depth (Pettifer, 2015). While supporting family members with diminishing drinking may seem straightforward at first glance, it is a complex endeavour involving negotiating emotional, practical, clinical, policy and legal considerations.

The research puzzle is significant for palliative care. Palliative care includes the promotion of the quality of life of the families of people with life threatening illness (World Health Organization, 2016), so the exploration of their concerns lies within the scope of palliative care endeavour. Findings of a survey of patients, family members and healthcare professionals in the UK found that healthcare professionals, patients and family members identified issues relating to hydration as a research priority (Baillie et al., 2018). One bereaved carer stated:

I think families of dying patients would benefit from research on ways to support them in coming to terms with the withdrawal of IV (intravenous) drips and hydration in the last days of life. I'm convinced

this is the source of much dissatisfaction with end of life care. (Baillie et al., 2018, p. 8)

The preliminary literature review undertaken for this research found no research specifically exploring the experience of family members who witness dying relatives' diminishing drinking. However, there is some wider literature as follows. A small body of research literature describes family members' experience of diminishing oral intake (encompassing both food and drink) at the end of life, demonstrating that it concerns most families and can be distressing for them (Yamagishi et al., 2010; Raijmakers, Clark, van Zuylen, Allen & van der Heider, 2013; van der Riet, Brooks & Ashby, 2006; del Rio et al., 2012; Department of Health, 2013). There is literature exploring the impact of declining eating and associated distress by people with advanced cancer on family relationships (Hopkinson, 2016; Amano, Baracos and Hopkinson, 2019) and these include eating related distress in family members. In addition, some literature has described professionals' understanding of family members' concerns about the diminishing oral intake of dying relatives (van der Riet, Good, Higgins & Sneesby, 2008). The concerns identified in this wider literature indicate that diminishing drinking is an important area for further exploration.

Researching family members' experiences of diminishing drinking is commensurate with the pragmatic imperative to generate practical knowledge. Within pragmatic thinking, knowledge is differentiated from general information and belief on the basis of 'whether something is useful, whether it engages our interest, whether it helps us make better sense of the world around us' (Malachowski, 2010, p 6). Both the

literature review and my own experience suggest that family members' experiences of the diminishing drinking of dying relatives in hospital is an area in which there is potential to meet this criterion because new knowledge in the field may be useful to healthcare clinicians, engage the interest of those involved in contemporary palliative care and help make better sense of the experience of family members.

1.3 Location of the Researcher

The methodology of narrative inquiry emphasises the relational aspects of research so that the 'researcher' with their own experience and stories, is an integral and visible part of the research process (Clandinin, 2013).

I am a registered nurse, living and working within the UK. My specialist area of expertise is palliative care and I worked as a nurse specialist in hospitals and communities for six years. I developed an interest in the experience of involuntary weight loss from advanced cancer while working as a clinical nurse specialist in community palliative care and explored the impact of weight loss on patients with advanced cancer as part of a master's degree in 2001. I have cared for many dying patients with diminishing drinking and have endeavoured to support many of their family members who have witnessed it. This background in clinical palliative nursing gives me a personal and professional connection to the research. I have been part of both nursing and the specialist palliative care professional cultures and share their values and ethos. I inherently want these cultures to have a positive impact on patients and family. When this does not happen, I feel disappointed and driven to try to improve care.

I am now an educator in palliative care nursing and healthcare research with over 15 years' experience. This has been my primary professional role for the duration of the research process. As an educator, I am no longer directly immersed in the culture of clinical palliative nursing and have a more distant vantage point. I feel separate from clinical palliative care but inherently connected to it.

I am a member of a multi-generational family. I am a mother, daughter and sister, and have wider family and close friends and I value all these relationships. I have had two bereavements of older family members during the duration of the research. One died in a nursing home and experienced a few days of diminishing drinking. I felt comforted by offering her drinks and cleaning her mouth during this time. Another older family member expressed thoughts of limiting his own eating and drinking in order to hasten his death. This alerted me to a link between diminishing drinking and desire to die, which I had not encountered in my clinical practice. Reflecting on why this might be the case drew my attention to the potential for difference between the experience of professionals and family members regarding the diminishing drinking of dying people.

I have undertaken this research as a part-time doctoral student in palliative care. Hence, it has been a process of experiential learning about research and the thesis has been written for doctoral assessment. At times, this learning has been joyful, even playful as I have toyed with choices and delighted in discovery. At other times, learning has been elusive and difficult. It has also been frustrating, particularly when my inexperience has limited my decisions and, with hindsight I have wondered seen

whether different choices may have improved the work. These limitations are reviewed in Section 8.5, p.20. Aspects of this research have been published (Pettifer, Froggatt & Hughes, 2019) and presented (Pettifer, Hughes & Froggatt, 2018; Pettifer, Hughes & Froggatt, 2019; Pettifer, Bevan, Chaplin et al., 2018; Pettifer, Bingley, Brearley & Hughes, 2020) (see Appendices 11–14 for poster presentations).

1.4 Structure of the Thesis

This thesis has an unusual structure. It is customary to start a thesis with the background and context of the research topic. However, in this case it starts with pragmatic philosophy, as this is what has driven the research and pervades throughout its findings and conclusions.

I introduce the research in Chapter 1 by explaining its aim, purpose, justification and approach. I explain the research puzzle and the key terms used throughout the research. I also introduce myself as the researcher.

I explain the process used to undertake this particular piece in Chapter 2, presenting the view that research may be guided by the philosophical commitment of the researcher rather than the research hypothesis or question. Since this study is guided by pragmatism, I trace the implications of key notions in pragmatic thinking for research ontology, epistemology and methodology. I present narrative research methodology and I justify the particular narrative inquiry of Clandinin (2013) as the methodology of choice for this study since it is philosophically aligned to pragmatism.

I review the background relevant to the research puzzle in Chapter 3. I analyse how diminishing drinking has been conceptualised within the speciality of palliative care by drawing on research and discursive literature. I go on to present the causes, consequences and therapeutics of diminishing drinking focusing on the complexity and controversy inherent in its clinical management. I reflect on the approaches to supporting family members with regard to the diminishing drinking of their dying relatives that are evident within the research and discursive literature.

In Chapter 4 I present a systematic meta-narrative review of what is known about family members witnessing diminishing drinking in research published since 1982, when issues surrounding hydration at the end of life first appeared in discursive literature. The review establishes that there is a paucity of knowledge specific to diminishing drinking. However, some knowledge can be surmised from related research into family members' experiences of diminishing oral nourishment and clinically assisted hydration (CAH). This knowledge provides a foundation for this research.

I present the narrative inquiry design and working methods of the research in Chapter 5. I detail how family members of recently deceased relatives were recruited as participants through hospital bereavement services in three hospitals. I explain the narrative interviewing process which I used to collect participants' stories and the method of analysis which I used to re-tell these stories. I also consider the ethical and rigour issues encountered during the research.

I present the research findings in Chapter 6. I start by describing the participants, their deceased relatives and the interviews. I present the narrative threads that resonated across the participants' stories within three strands or groups pertinent to the foci within the research puzzle. The strands are: experiences of diminishing drinking, responses to diminishing drinking and experiences of healthcare staff regarding diminishing drinking.

I discuss family members' experiences of the diminishing drinking of a relative in Chapter 7. I consider the coherence of these experiences with understanding in the existing research and in relation to wider relevant literature. I then proffer an explanatory model of how participants respond to the diminishing drinking of their dying relatives in hospital. I conclude this discussion by arguing that family members' experiences of diminishing drinking are rooted in their notions of personal and social identity and that they seek to assert these in the face of diminishing drinking and advancing illness.

I conclude the thesis in Chapter 8. I discuss the potential of these findings to improve the care of family members through their implications for practice, research and policy. I reflect on the strengths, limitations and contribution of this research within the aspiration of pragmatism. I end with some reflexive thoughts and a final summary.

Chapter 2: Philosophical Foundations: Pragmatism

In this Chapter I describe the philosophical foundations underpinning this research. I start by explaining the research process arguing, contentiously, that research should be driven by philosophical imperative rather than by the question or hypothesis under inquiry. I go on to present key ontological, epistemological and methodological notions within American pragmatism as espoused by William James and John Dewey, since these are the philosophical drivers of this research. I argue that pragmatism is commensurate with palliative care philosophy and critically explore its implications for palliative care research. At the end of this chapter I present narrative inquiry, the chosen methodology for this research.

2.1 Research Process

It is common for the research process to adhere to Trow's dictum that 'the problem under investigation properly dictates the methods of investigation' (Trow, 1957, p. 33). When adhering to this axiom, the researcher normally starts with a problem expressed as a hypothesis or question which addresses a gap within existing knowledge. The researcher selects a research methodology and working method for its suitability to address this problem and positions the research within a philosophical paradigm which is congruent with the problem, the chosen methodology and working method (Bryman, 1984). In this way, the problem drives the research process. The expertise and world view of the researcher and the intended audience are important drivers, but are secondary to the problem (Creswell, 2013).

The above approach has largely become common practice in health research. However, in 1984 Bryman argued that the use of Trow's dictum as an approach to research assumes that working methods, methodologies, epistemologies and ontologies are both distinctive and can be convincingly aligned, which is not always the case. Additionally it prioritises predominantly technical considerations over philosophical ones in research design. Bryman (1984) offered an alternative approach to Trow's dictum in which 'it is not so much a problem that determines the use of a particular technique but a prior intellectual commitment to a philosophical position' (Bryman, 1984; p. 80).

While recognising the importance of choosing a philosophical paradigm that is appropriate for the research problem and intended audience, I have taken up Bryman's (1984) proposition, privileging philosophy in relation to research endeavour (Creswell, 2013). This approach is commensurate with the temporality of my doctoral learning journey since I explored my philosophical allegiance before settling on a topic or question. In so doing I discovered my personal alignment to pragmatism. The key aspects of the ontological, epistemological and methodological insights of pragmatists James, Dewey and Clandinin are described and critiqued in the following sections.

2.2 Pragmatism

Pragmatism is a relatively young school of philosophical thought, starting around 1870 in the United States of America (USA) (Malachowski, 2010). While there is divergence and diversification within it, pragmatism is usually typified by commitment to the view that experience can be judged by its practical effect; in other words, by its ability to

address difficulties (Bertman, 2007; Talisse & Aikin, 2008). It is commonly understood to have been developed by three key philosophers: Charles Peirce, William James and John Dewey.

William James (1842–1910) (Figure 1) was an academic psychologist and philosopher at Harvard University (Bertman, 2007). James is widely credited as co-founding pragmatism by developing the principle of Charles Peirce (1878), a logician, scientist and philosopher at Johns Hopkins University, into a comprehensive philosophy with widespread implications for knowledge and research.

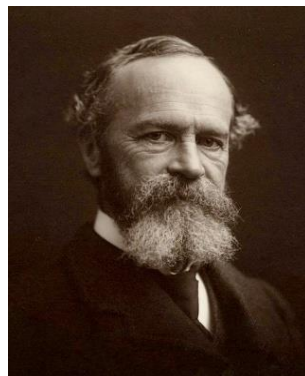


Figure 1: William James, Houghton Library

James cites Peirce's principle 'to develop a thought's meaning, we need only determine what conduct it is fitted to produce: that conduct is for us its sole significance' (James, 1907, p. 25). That is, that the meaning of something is determined by the effect that it has (McCready, 2010).

John Dewey (1859–1952) (Figure 2) was a student of James. He described himself as an anthropologist, though he also taught philosophy, education and psychology

(Bertman, 2007). Dewey developed his ideas from those of James and Peirce and applied them to education and other spheres of life (Rescher, 2003).

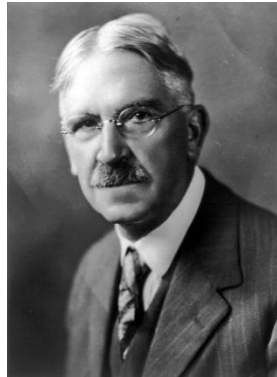


Figure 2: John Dewey, Library of Congress

Both James and Dewey were prolific writers and thinkers who refined their ideas throughout their lifetimes. There were differences in their thinking: James was more psychologically and personally orientated while Dewey was more concerned with society as a whole (Talisie & Aikin, 2008). Later philosophers, particularly Richard Rorty, have revived and redeveloped their ideas, spawning new interpretations and applications so that pragmatism is now broad in scope (Malachowski, 2010; Talisie & Aikin, 2008). While this eclecticism may engender difficulties in precisely defining pragmatism, Talisie and Aikin (2008, p. 3) purport that this is a positive state of affairs since pragmatism is a relatively new and 'living philosophy' which can be utilised in different ways.

Jean Clandinin (Figure 3) has interpreted and applied pragmatism to research. She is a contemporary Canadian educationalist and narrative scholar who, together with her

colleagues, has drawn on the thinking of James, and particularly Dewey, to develop a specific methodological approach to narrative inquiry (Clandinin & Rosiek, 2007).



Figure 3: Jean Clandinin, University of Alberta

2.2.1 Key ontological notions

Ontology is concerned with the form and nature of being. When applied to a research context, Guba and Lincoln (1994) frame ontological enquiry as: ‘What is the form and nature of reality, and therefore what can be known about it?’ (p. 108). In adopting an epistemological position, a view is taken about the nature of what we are trying to know. Two pragmatic ontological notions are central to this research: plurality and fluidity.

James argued that reality is plural, that it comprises multiple or plural forms, not monist, i.e. unified in one single form. In his essay *A pluralistic universe*, James termed these ‘each-forms’ (1907, 1909a). He maintained that ‘each-forms’ of reality not only co-exist but are interdependent and influence each other (McCready, 2010). These many forms of reality may converge in what James called the ‘all-form’ reality but, if so, it would be beyond human reach (James 1907, 1909a). James’ notions of each and all forms of reality are illustrated in Figure 4 below:

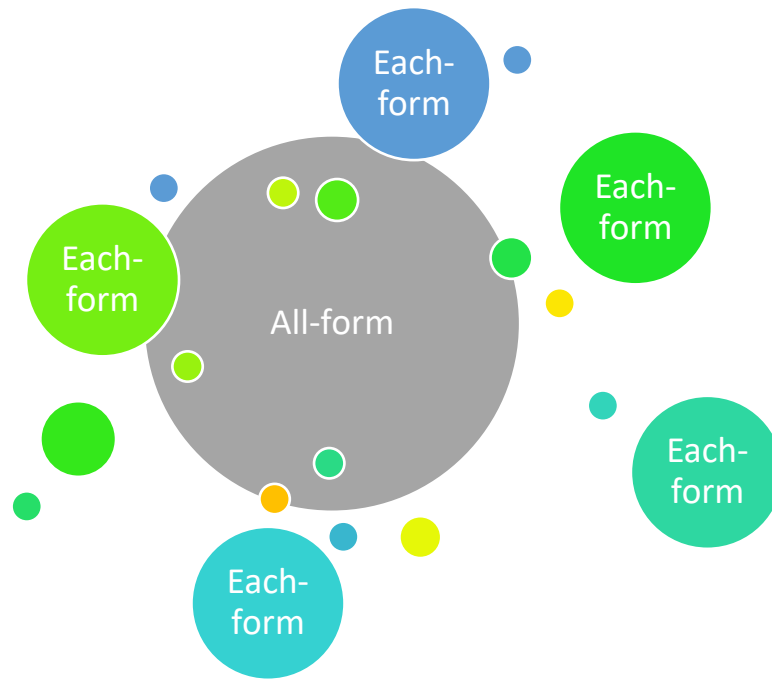


Figure 4: Plural ontology represented visually

He wrote, 'We are invincibly parts, let us talk as we will, and must always apprehend the absolute as if it were a foreign being' (James 1907, p. 13).

As well as being plural, James saw reality as fluid and changeable through the application of new understanding. He emphasised the potential of human experience to change. He wrote,

if you follow the pragmatic method, you cannot look on any such word as closing your quest, you must bring out of each word the practical cash-value, set it at work with the stream of your experience. It appears less as a solution, then, than as a program for more work and, more practically, as an indication of the ways in which existing realities can change. (James, 1907, p. 28)

The pragmatic conceptualisation of ontology as plural and fluid invites criticism. In comparison to positivism where reality is understood to be singular and fixed, the implication of pragmatism that reality can be construed in many different ways that are neither exclusive nor fixed is unhelpful because it is elusive (Talisie & Aikin, 2008). Furthermore, pragmatic ontology is not unique: critical realism shares the ontological view of pragmatism that reality is plural and fluid (Clandinin & Rosiek, 2007). However, the two diverge in their motivations. Pragmatism privileges individual experience as the legitimate source of knowledge and the focus of change. However, while critical theory argues that social conditions distort human experiences, so social structures and their effects are the primary sources of knowledge and foci of change (Clandinin & Rosiek, 2007; Bryman, 2012).

McCready (2010) argues that the plurality and fluidity of pragmatism offers a way of applying philosophical thinking to experiences which are complex and shifting. This is the case in palliative care intervention since it is a complex endeavour spanning physical, psychosocial and spiritual aspects of wellbeing (World Health Organisation, 2016). Arguably, some aspects of wellbeing are understood to be relatively fixed such as the impact of opioids on severe pain, but others are considered more changeable such as the meaning attributed by those with advanced disease to such pain. Palliative care has a plural ontology in the sense that the reality of it is complex and multifaceted (Dobrina, Tenze & Palese, 2014). Thus, it seems likely that pragmatism is well suited to research in palliative care and this will be explored in this research.

2.2.2 Key epistemological notions

Epistemology is the study of how knowledge is formed and comprehended. In adopting an epistemological position, a view is taken of the nature of truth, as opposed to belief, and how truth can be known. In the correspondence theory of truth, truth differs from belief through justification that it matches with the way the world is (Pritchard, 2006). However, what constitutes legitimate 'truth' can be understood in different ways.

Pragmatists have a particular comprehension of the nature of truth: it is a status, given to a belief through a process of verification and validation which is inherently subjective (James, 1907). In keeping with plural and fluid ontology, pragmatists construe fixed, certain and absolute truth as an unobtainable ideal. The everyday reality of truth is multiple, perspective bound and changing. Therefore, for pragmatists, truth simply represents best understanding at the time (McCready, 2010). Truth is fallible; it is always open to revision as a consequence of new understanding (McCready, 2010; Talisse & Aikin, 2008). Rescher (2003, p. 4) describes pragmatic truth as 'acceptance of commitment to the idea that something or other is so'.

The generation of knowledge of truth as espoused within pragmatism demands that researchers are constantly aware of the fallibility of existing truth and are open to the assimilation of new beliefs into truths. Furthermore, fallibility implies that new knowledge is not definitive; rather, it is a 'position that one comes to occupy' (Rescher, 2003, p. xvi). It merely represents current understanding and is fallible and mutable.

For pragmatists there are two conditions of belief becoming truth: instrumentalism, and coherence. These are discussed below.

Instrumentalism is the process of judging the truth of a belief through determining its practical use (McCready, 2010). In this sense truth is conceptualised as an instrument or cognitive tool which can be used to navigate and develop our understanding of the world (Schwartz, 2012). James advises, 'try to interpret each notion by tracing its respective practical consequences' (James, 1907, p. 24). Within pragmatic epistemology, the desire to know and therefore to find out is driven by practical imperative: to find knowledge that has positive, practical implications.

Critics of pragmatism are concerned that using practical effect to delineate truth is problematic, arguing that under this criterion, truths may be refuted simply because they serve no discernible practical effect at the time and falsehood may be legitimised simply because it is effective at the time (McCready, 2010; Pihlström, 2011). However, these arguments stem from an absolute understanding of truth: it is there to be found and remains constant over time. The notion of fallibilism determines that truth *becomes*; it happens to an idea. It is an instrument through which we can journey (James, 1907; McCready, 2010). If truth is judged through the lens of fallibilism, then arguably the risk of falsely verifying belief pales since truth is not a constant. The centrality of the practical imperative is coherent with palliative care research endeavour. Palliative care research is inherently concerned with the discovery of knowledge which enhances the care people and their families receive as they die

(Higginson et al., 2013). As such, the value of palliative care knowledge is its instrumental effect.

A second condition of the process of adopting belief as truth is its coherence or integration with existing truth (James, 1907). Pragmatists assert that in addition to its instrumental effect, truth is delineated from belief, at least in part, through its coherence with existing knowledge. This legitimacy comes from agreement within a critical community that something is true because of the positive impact that it has; of it being a solution to a problem at least for a time (Smith, 2020; Pihlström, 2011). The implication of epistemological coherence is then that truth must build on existing truth incrementally, particularly in the wake of an area of fallibility. These may be areas where the existing knowledge has become destabilised by contradiction or unease, and its fallibility is evident (McCready, 2010). The importance of coherence with existing knowledge is not unique to pragmatism and James (1907) recognises this. However, its emphasis differs from other traditions. For example, in the empiricist tradition truth is distinguished from belief on the basis of the weight of evidence (Avis & Freshwater, 2006).

The risk of building new knowledge on existing knowledge based on coherence is that untrue premises may be perpetuated (Avis & Freshwater, 2006). The need to consider this possibility is important, but Avis and Freshwater (2006) contend it should not be over emphasised since it is unlikely that the pre-existing knowledge will be false in its entirety and indeed, all new knowledge generated within any philosophical framework including pragmatism and empiricism has to be based on some degree of premise in

pre-existing knowledge. Palliative care is well poised to consider knowledge based on its coherence since there is an evolving evidence base and a critical community of researchers, practitioners and service users working within the field.

2.2.3 Key methodological implications

Research methodology is concerned with the study of how knowledge is, or might be, formed. In pragmatic thinking, all methodologies may be appropriate for finding out what the inquirer believes can be known. This is because knowledge is seen as plural, or in Jamesian terms, taking many forms (James, 1907); it is justified by its instrumentality and coherence not on whether it has been generated by a specific methodology. Therefore, pragmatic researchers must select the methodology that can most effectively generate the knowledge sought (Creswell, 2013).

Despite this endorsement, there are few examples of pragmatically engendered methodology (McCready, 2010; Morgan, 2007). Predominantly, pragmatism has been used as justification for the use of mixed methods approaches, particularly when used in action research (McCready, 2010; Johnson & Onwuegbuzie, 2004). Mixed methods combine different research methods for a specific purpose, often to increase the validity of the findings (Bowling, 2014), which is coherent with pragmatic pluralism. Action research focuses on positive change that addresses practical problems with those affected by them within a real-world situation (O'Leary, 2004); this is coherent with both pragmatic pluralism and instrumentalism (McCready, 2010). While these methodologies are well suited to pragmatism, other research methodologies may also be appropriate if they are coherent with pragmatic thinking.

Narrative research, specifically the approach of Jean Clandinin and her colleagues (Clandinin, 2006, 2013; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007), is the methodological approach of choice to address the puzzle within this research. I present, critically justify and explore the methodological consequences of this choice in the next section.

2.3 Narrative Research

Narrative research is a broad, qualitative research field comprising a group of methodological approaches rooted in diverse disciplines (Riessman, 2008; Creswell, 2013; Mishler, 1995). While there are differences within the group, narrative research centres on the exploration of, or through, narratives; be they the phenomenon being researched or the method used to analyse a phenomenon (Creswell, 2013; Riessman, 2008).

Riessman (2008) traces the narrative form to Aristotle's notion of tragedy in which action is re-imagined and dramatised to capture the associated emotions, events and experiences. There is a clear plot or storyline that moves through a beginning, middle and end, which usually involves an unexpected or difficult event and its resolution (Riessman, 2008; Bingley, Thomas, Brown, Reeve & Payne, 2008; Bingley, 2020; Elliott, 2005). Narrative forms have evolved, but they remain pervasive within human culture (Bingley et al., 2008). They are found in numerous forms including texts, images, drama and oral endeavour (Riessman, 2008).

I have chosen narrative inquiry for this research because it seeks to explore experience, ascribed meaning and causality of events through gathering and analysing stories (Haydon & van der Riet, 2014; Clandinin & Connelly, 2000; Riessman, 2008). This is particularly suited to the investigation of the research puzzle because it shares this focus. Narrative inquiry has a long and fruitful association with palliative care and bereavement research (Bingley et al., 2008; Gunaratnam & Oliviere, 2009; Molzahn et al., 2020; Sheilds et al., 2015). It has proved an important way to explore relationships between dying and bereaved individuals and their social context, and it has helped to shape collective meaning and shared understanding of dying and bereavement (Gunaratnam & Oliviere, 2009). Cecily Saunders, credited as the founder of the modern hospice movement, collected and analysed patient narratives. She used these to develop fundamental concepts such as 'total pain' which underpin clinical care (Saunders, 1978; Clark, 2018). In so doing, she developed generalisable theory from individual narratives with widespread clinical benefit.

I considered other methodological approaches. My initial research design was action research. It aimed to co-generate an intervention to support family members who were concerned about diminishing drinking with a group of clinical nurse specialists in palliative care. Action research would have been coherent with pragmatism and potentially may have led to a useful resource. However, examination of the literature showed insufficient understanding on which to confidently premise intervention.

I also considered phenomenology. While phenomenology encompasses several methodological and philosophical approaches, all of these emphasise exploration of

the meaning of a phenomenon as it is experienced (McWilliam, 2013; Creswell, 2013). Descriptive phenomenology attributed to Edmund Husserl focuses on the discovery of the common essence or core nature and structure of the phenomenon under investigation (McWilliam, 2013). The research methods are prescriptive: researchers are encouraged to 'bracket out' their own experience and move from the particular experience of a participant to explore the general phenomenon objectively. This ontological understanding is not consistent with pragmatism as it holds that a phenomenon is fixed and exists independently of those who experience it. Interpretive phenomenology is a collection of approaches developed by Heidegger, Sartre, Merleau-Ponty and others broadly from Husserl's ideas. They share the ontological understanding that phenomena cannot be separated from the interaction of people since they are inextricably intertwined (McWilliam, 2013). In particular, interpretive phenomenology has been fruitful in the exploration of people's experiences of health and illness, particularly in the discipline of nursing (Charalambous, Papadopoulos & Beadsmoore, 2009; Midtbust, Alnes, Gjengedal & Lykkeslet, 2018) and it may have been effective for developing understanding of family members' experiences of diminishing drinking. However, I rejected interpretive phenomenology in favour of narrative inquiry because of the latter's synergy with pragmatism and emphasis on instrumentalism or potential to go beyond exploration, and to be a tool for positive change.

2.3.1 The narrative inquiry of Clandinin

I decided to use the narrative inquiry approach devised by Clandinin and Connelly (2000) and developed further by Clandinin (2006, 2013). Clandinin's narrative inquiry

methodology is particularly suited to this research because, like the research puzzle, it is centred on experience. Hence, Clandinin (2013) defines it as, 'a way of understanding and inquiring into experience, it is nothing more and nothing less' (2013, p. 13).

Clandinin, intentionally, does not define the notion of a story or narrative in her writings or work. Instead she asserts that experience is fundamentally storied and can be studied; therefore, to study stories is to study experience. She illustrates this through reference to the Nigerian writer, Ben Okri who wrote:

In a fractured age, when cynicism is god, here is a possible heresy:

We live by stories, we also live in them.

One way or another we are living the stories planted in us early or along the way, or we are living the stories we planted – knowingly or unknowingly – in ourselves.

We live stories that either give our lives meaning or negate it with meaninglessness.

If we change the stories we live by, quite possibly we change our lives. (1997, p. 46)

Clandinin aligns her particular conceptualisation of experience to pragmatism arguing that narrative inquiry is a pragmatic methodology (Clandinin & Rosiek, 2007). Writing with Rosiek, Clandinin (2007) maps her narrative inquiry approach to James' (1909b) philosophy of experience and Dewey's (1938, 1976) criteria of experience written 25 years after James. Dewey regards experience as fundamental to the human condition, describing it as 'immediate, engrossing and matter of course' (Dewey, 1976, p. 325, footnote), cited by Clandinin and Rosiek (2007, p. 38).

Clandinin (2013) draws on James' ideas to emphasise that experience is relational in that it comprises interaction which takes place within a context and it does not exist independently of interaction. This is a different approach to the search for the 'essence' of an experience within descriptive phenomenology. Clandinin and Rosiek (2007) purport that pragmatic endeavour seeks to explore experience collaboratively alongside those within it rather than to 'discover' it from a distance. Clandinin and Connelly (2000, p. 20) explain the process: 'It is collaboration between researcher and participant, over time in a place or series of places, and in social interaction within milieus.'

Clandinin also draws on James' and Dewey's emphasis on experience as continual: it comes from previous experiences and leads to other experiences. Clandinin and Connelly (2000, p. 2) explain: 'Wherever one positions oneself in that continuum – the imagined now, some imagined past, or some imagined future – each point has a past experiential base and leads to an experiential future'. Consequently, human beings are changed by and through experience. To study experience from a pragmatic perspective is therefore to study one point within what James called a continuous 'stream of experience' (James, 1907, p. 28) and, in the process, generate new experiences either as part of the research or as a result of the research (Clandinin & Rosiek, 2007).

Finally, Clandinin draws on pragmatic understanding that experience has a social context. The stories people live and tell are 'the result of a confluence of social influences of a person's inner life, social influences on their environment, and their

unique personal history' (Clandinin, 2013, p. 17). Hence, narrative inquiry is a broader approach than just exploring the experiences of individuals; it is 'an exploration of the social, cultural and institutional narratives within which an individual's experiences are constituted, shaped, expressed and enacted – but in a way that begins and ends that inquiry in the storied lives of the people involved.' (Connelly & Clandinin, 1990, p. 42).

Clandinin has described the approach extensively across many years (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Clandinin, 2006, 2007, 2013) but predominantly writes conceptually with extensive nomenclature to describe her concepts (see Appendix 1 for a glossary of Clandinin's terms). She has published annotated exemplars illustrating the application of her methodology but with little emphasis on precise definition or method (Clandinin, 2013). Researchers have interpreted and adapted her approach. Clandinin's narrative inquiry has been used both within education (Gillan, van der Riet & Jeong, 2016; van der Riet, Jitsacorn, Junlapeeya & Thursby, 2017) and healthcare practice (van der Riet, Jitsacorn, Junlapeeya, Dedkhard, & Thursby, 2014; Haydon & van der Riet, 2014) mostly by a cluster of Australian researchers. Researchers have used the 'commonplaces' or parameters of temporality, sociality and spatiality within which stories occur as a tool for analysis. While Clandinin does suggest they are a useful starting place, she does not advocate them as the method of analysis; rather, she advocates 'thinking narratively' about data (Clandinin, 2013).

The broad scope of Clandinin's approach encourages researchers to apply expansive conceptual thinking to wide ranging human experiences in diverse ways. However, in

levering these possibilities there is a risk of losing cohesion as a distinct methodology, particularly if researchers rarely detail their understanding of the concepts in publications. This has echoes in Dewey's thinking since despite writing extensively about experience in his middle years, Bertman (2007) argues he refutes his own work in later years purporting that the term 'experience' was simply too vague to be helpful. In order to be transparent, researchers need to detail the way in which they have interpreted Clandinin's concepts and approach. Despite these issues, researchers using Clandinin's approach to narrative inquiry purport that it can engender deep and broad understanding of complex experience and can lead to new insight (Haydon, Browne & van der Riet, 2017; Haydon & van der Riet, 2017).

2.4 Summary

I have placed my prior commitment to the key principles of pragmatism at the heart of the conception, design and execution of this research. This is an unusual approach to research which is more commonly driven by the question, aim or hypothesis being considered, but I have argued that this is an authentic and coherent approach. I draw on key aspects of the ontological, epistemological and methodological insights of Peirce, James, Dewey and Clandinin in the design of this research and in interpreting and evaluating my findings. I have not set out to apply every aspects of pragmatism comprehensively because it is so diverse. Like all philosophies, pragmatism has its limitations, but palliative care may benefit greatly from pragmatic research endeavour because pragmatism recognises the plurality, fluidity and fallibility of knowledge, and the interactive, continual and contextual nature of human experience. Furthermore,

pragmatic research seeks to bring positive practical benefit to human experience
which is coherent with the goal of palliative care.

Chapter 3: Background

In this chapter I present the context of the diminishing drinking of dying people in the UK, and their family members' experience of it. I start by presenting how diminishing drinking has been conceptualised within palliative care by drawing on research and discursive literature. I will go on to explore the causes, consequences and therapeutics of diminishing drinking and consider some context and controversy in its clinical management. I will conclude by reflecting on the role of family members with regard to the diminishing drinking of their dying relatives, and the support which may be offered to them.

3.1 Terminology

The way in which people with chronic illness drink less and less in the last few days of their lives is described in the literature (Lokker et al., 2019; Hui, Dev and Bruera, 2015). However, there is no consistent and defined name for this process, instead there is a plethora of terms that describe related, but not synonymous, concepts. These terms are rarely defined, and each implies a slightly different meaning reflecting different foci. For example, 'declining intake' implies both declining eating and drinking. It may mean self-delivered oral intake but also intake through clinically assisted means whether intravenously into a vein, subcutaneously under the skin or directly into the stomach via a gastrostomy tube. Similarly, 'decreased' implies that the drinking has reduced but is stable. Terms can be delineated into those that describe the process, those that describe the clinical signs and symptoms, and terms that describe the clinical interventions but are otherwise random (Figure 5).

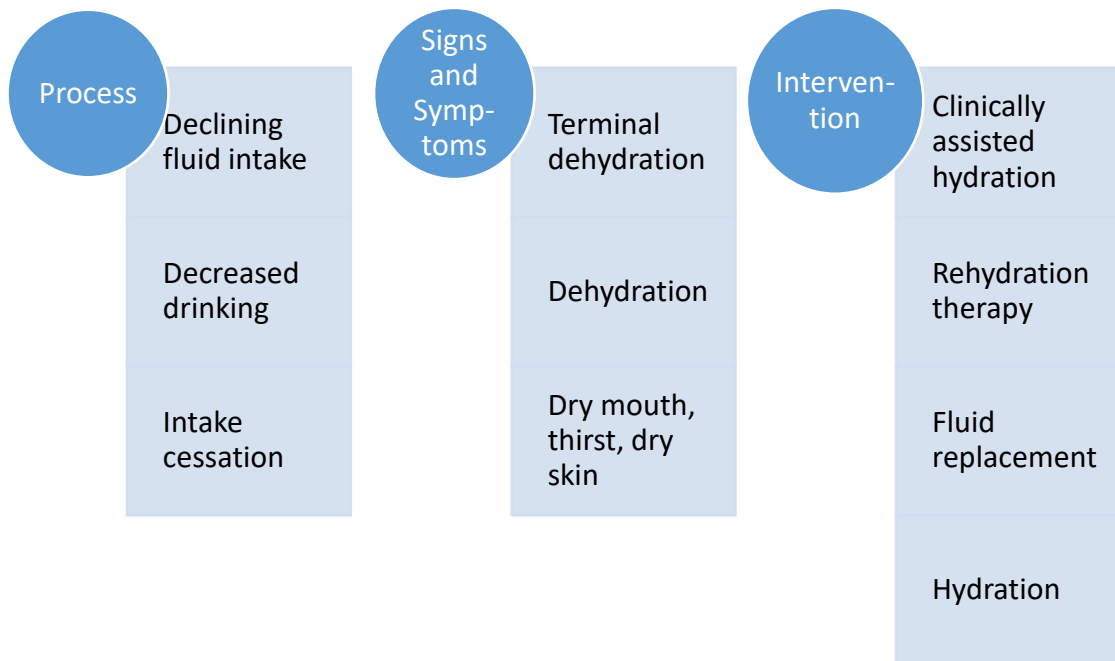


Figure 5: Typology of terms relating to diminishing drinking

The way in which family members and clinicians describe the process may differ, thus adding further complexity. Some terms have a technical hue such as ‘rehydration therapy’ in contrast to the more vernacular ‘a drip’. Other terms such as ‘dehydration’ describe a state that may or may not be readily apparent to the person and their family. Furthermore, the vernacular use of the word ‘drink’ also suggests alcohol consumption (Buxton, 2013). There is a risk that the plethora of imprecise terms may limit understanding or lead to misunderstanding between clinicians and family members. For example, clinical dialogue framed around ‘terminal dehydration’ may overlook family members’ concerns about ‘drinking’. Indeed, throughout the project’s duration I have needed to clarify to others that the research topic is not alcohol consumption.

The term 'diminishing drinking' is my own. I have deliberately used 'diminishing' in the present progressive tense to reflect its progressive nature. I have deliberately used 'drinking' because it is more familiar than clinical terms like 'intake'. It also specifies the consumption of any liquid intake through swallowing.

3.2 Causes

The causes of diminishing drinking of dying patients are many and varied. They include signs, symptoms and treatment of illness such as dysphagia (difficulty swallowing); nausea or vomiting; anorexia (loss of appetite); mouth and gum disease; generalised weakness; debility; delirium; and drowsiness (Lokker et al., 2019, Hui et al., 2015; Royal College of Physicians and British Society of Gastroenterology, 2010; van der Riet et al., 2006). People experiencing difficulty drinking may cough and choke, which further deters them from drinking, and if they are unable to cough effectively, there is a risk of aspiration (accidental ingestion into the lungs) which may cause pneumonia (Royal College of Physicians and British Society of Gastroenterology, 2010). The causes of diminishing drinking may include social and environmental factors such as inability to prepare drinks, appeal of drinks, and the social context and availability of carers (Royal College of Physicians and British Society of Gastroenterology, 2010). These are factors which family members may be able to influence directly.

Diminishing drinking has also been attributed as the choice of the person experiencing it. Voluntarily stopping eating and drinking (VSED) is a phenomenon recognised by a small but growing research literature (Ivanović, BÛche & Fringer, 2014; Saladin,

Schnepp & Fringer, 2018; Lowers, Hughes & Preston, 2021). In their systematic review of VSED, Ivanović et al. (2014) acknowledge that it has been defined in various, but synonymous, ways and encapsulate these as 'an action by a competent, capacitated person, who voluntarily and deliberately chooses to stop eating and drinking with the primary intention of hastening death because of the persistence of unacceptable suffering' (2014 p. 1). They characterise voluntarily stopping eating and drinking by considerable discipline and stamina rather than being a transient action (Ivanović, et al., 2014; Saladin et al., 2018).

3.3 Therapeutic Intervention

Guidance in the UK stipulates that the needs of those who are unable to drink should be assessed and intervention to meet their needs should be considered (General Medical Council, 2010). The literature reports a range of non-invasive and invasive palliative measures to support patients with diminished drinking. Non-invasive measures include mouth and lip care to palliate dryness and supporting fluid intake in the form of sipping small amounts of fluids from a beaker, syringe or sponge, or sucking ice chips. These are considered 'basic care' that should be universally offered unless they are detrimental to the patient (Royal College of Physicians and British Society of Gastroenterology, 2010). They are commonly delivered by nurses and carers, including family members (Department of Health, 2013).

Consideration of CAH is widely recommended, and it can be given subcutaneously, intravenously or via a gastrostomy tube (General Medical Council, 2010, NICE, 2015). However, its efficacy at the end of life has been contentious since at least 1983

(Zerwekh, 1983, Andrews & Levine, 1989, House, 1992). It will be discussed further in the next section.

Fasting and not drinking can be recommended to those who have unpleasant coughing and choking or who are clinically identified as being at risk of developing aspiration pneumonia. This is described as being designated 'nil by mouth' (Royal College of Physicians and British Society of Gastroenterology, 2010). The risk of coughing and choking unpleasantly may be small, particularly if assistance is provided and the risk may be preferable to not drinking. Therefore, withholding drinking should be a last resort particularly when people are at the end of their life, and should not be made without holistic assessment of the person's situation (Murray, Mulkerrin & O'Keeffe 2019; Royal College of Physicians and British Society of Gastroenterology, 2010; Department of Health, 2013).

3.4 Controversies and Context

The importance of non-invasive methods to support comfort is unquestioned. Beyond this, the palliative management of diminishing drinking and the ensuing dehydration has been a controversial matter, particularly in the UK. Whether CAH ameliorates or exacerbates discomfort from diminished drinking and dehydration is difficult to determine (Lokker et al., 2019, Davies et al., 2018; Valentini et al., 2014). In the absence of conclusive evidence, it is purported that CAH may worsen oedema, ascites and excess secretions and, more positively, that it may improve or prevent thirst, delirium and restlessness associated with dehydration (Dev, Dalal & Bruera, 2012; Davies et al., 2018; Lokker et al., 2019). The latest Cochrane review into this concluded

there was insufficient evidence concerning the benefits and harms of CAH to establish definitive guidance (Good, Richard, Syrmis, Jenkins-Marsh & Stephens, 2014). Similarly, evidence on whether or not CAH extends life is inconclusive (Lokker et al., 2019). A feasibility trial conducted by Davies et al. (2018) concluded it is possible to achieve sufficient recruitment, retention, adherence and safety of study interventions to undertake an adequately powered cluster randomised control trial to evaluate CAH in cancer patients at the end of life. The clinical outcomes of this feasibility trial data suggested that CAH delays, but does not reduce, the onset of delirium and excessive upper airway secretions. It may extend survival by a day or two. However, the feasibility trial was not sufficiently powered to draw conclusions from the outcome data.

Given this ambiguity, it is perhaps unsurprising that there is wide variation in views about, and use of, CAH. Raijmakers et al. (2013) found a variation of 12%–88% between rates of administration of CAH among cancer patients in the last week of life, with the higher rates being used in hospitals. Specialist palliative care clinicians have been found to hold cautious views about the value of CAH and are concerned about the discomfort administration may cause (del Rio et al., 2012).

The propensity towards withholding CAH was reflected in the implementation of the Liverpool Care Pathway (LCP). This clinical management tool was developed in the late 1990s by the Royal Liverpool University Trust and the Marie Curie Centre, Liverpool (Ellershaw, Foster, Murphy, Shea & Overill, 1997). As an example of an ‘integrated care pathway’, it was a formal and structured plan based on the end of life care delivered

in hospices, which could be disseminated and implemented by generalist staff and through which care could be audited. Having been endorsed in the End of Life Care Strategy (Department of Health, 2008), the LCP was disseminated to hospitals and later communities and care homes throughout the UK (Smith, Barrow, Ellershaw & Aldridge, 1999; Hockley, Dewar & Watson, 2005) and beyond (Di Leo, Beccaro, Finelli, Borreani & Costantini, 2011).

The LCP purported that dying people should be supported to take oral fluids for as long as they could, that aspiration should be monitored and that CAH should be considered if the person was symptomatic of dehydration (Marie Curie Palliative Care Institute, 2009). However, by 2012 families and some healthcare professionals expressed serious concern about the LCP which resulted in a media campaign against the tool (Neuberger, 2016). This led to the commissioning of an independent review of the LCP (Department of Health, 2013) which considered the experience of patients, families and professionals involved with the LCP and the associated research evidence base. The review concluded that advice regarding hydration was often not followed, particularly in hospitals where it was used to justify the withholding of fluids; the wording in the LCP documents did not sufficiently articulate the default position of support for hydration, and drinks were sometimes withheld even though there was no evidence of choking. The review recommended that the LCP be withdrawn (Department of Health, 2013).

Subsequent guidance for end of life care has advocated a more 'principles based' approach in which care should be tailored to each individual and their family.

Responding to the LCP review report, the Leadership Alliance for the Care of Dying People (2014) published *Five Priorities for Care of Dying People* in any setting which suggested that they should be supported to drink for as long as they wanted. NICE (2015) published guidance regarding the optimal end of life care of dying adults. It recommended supporting people to drink when they could and giving mouth and lip care. It also recommended that clinicians should review the need for CAH ideally daily, judging the risks and benefits on an individual basis. When making decisions, professionals should involve the dying patients if possible, and also those close to them. They should take into account their wishes and preferences including those documented in an advance statement or decision to refuse treatment and should acknowledge the uncertainty regarding whether CAH extends life (NICE, 2015).

This principle-based approach is buoyed by published quality standards for care of dying adults in their last days of life (NICE, 2017). Quality statement 4: Hydration mandates that 'Adults in the last days of life have their hydration status assessed daily and have a discussion about the risks and benefits of hydration options' (NICE, 2017, www.nice.org.uk). The structure of the quality statement suggests that the discussion should include 'the people important to them' (NICE, 2017).

Audit of this published standard shows that actual practice is variable. The auditable indicator which most closely aligns to family members' experiences of care of their relative with diminishing drinking states 'Bereaved family members feel satisfied that the person who has died was supported to drink or receive fluids if they wished' (NICE, 2017).

This indicator is measured within the annual National Survey of Bereaved People (VOICES). The latest survey was in 2015 involving 21,320 bereaved family members. This showed that 78% of bereaved relatives agreed or strongly agreed that support to drink or receive fluid was provided to their dying relative in the last two days of life (Office for National Statistics, 2016). However, this figure belies any difference in satisfaction rates across the various settings in which people die within the UK. This graph shows bereaved family members were less likely to agree that their relatives were supported to drink in hospitals compared with other places (Figure 6).

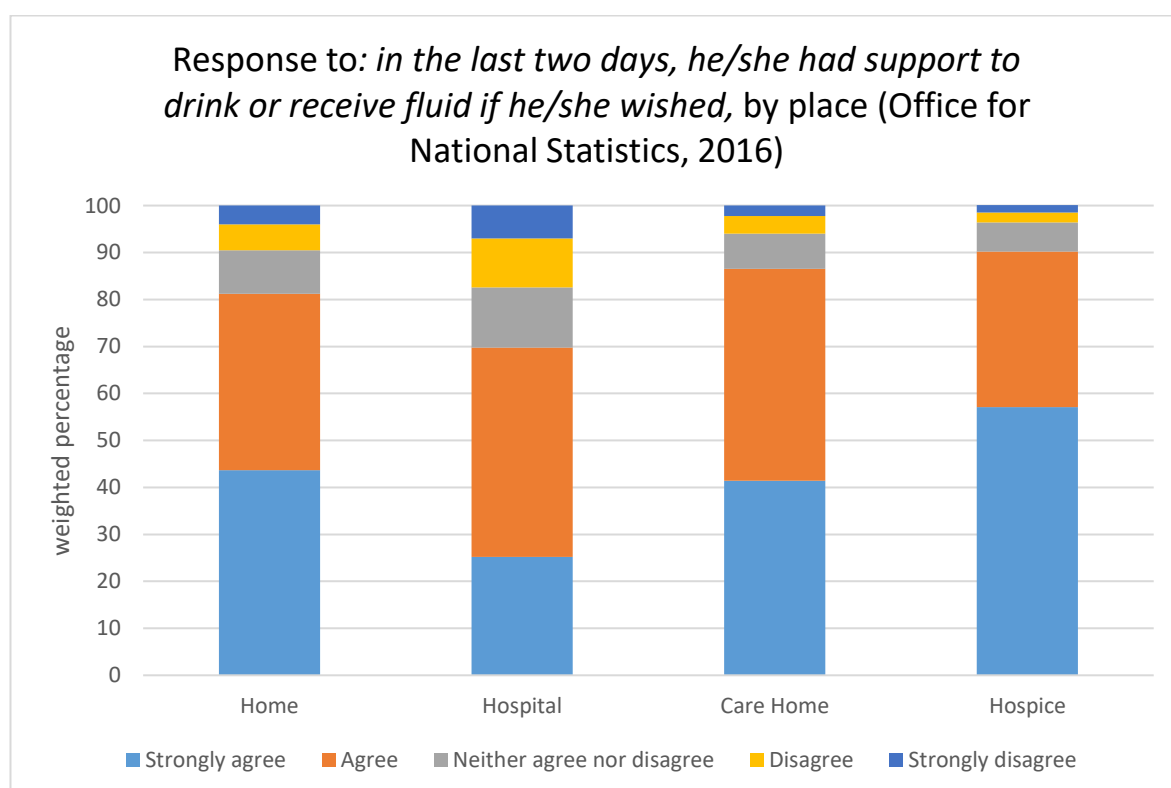


Figure 6: Weighted percentage response by place by bereaved family members to: ‘in the last few days, he/she has support to drink or receive fluid if he/she wished’

Figure 7 shows that hospital is the most common place of death in England (Public Health England, 2019; Broad et al., 2013).

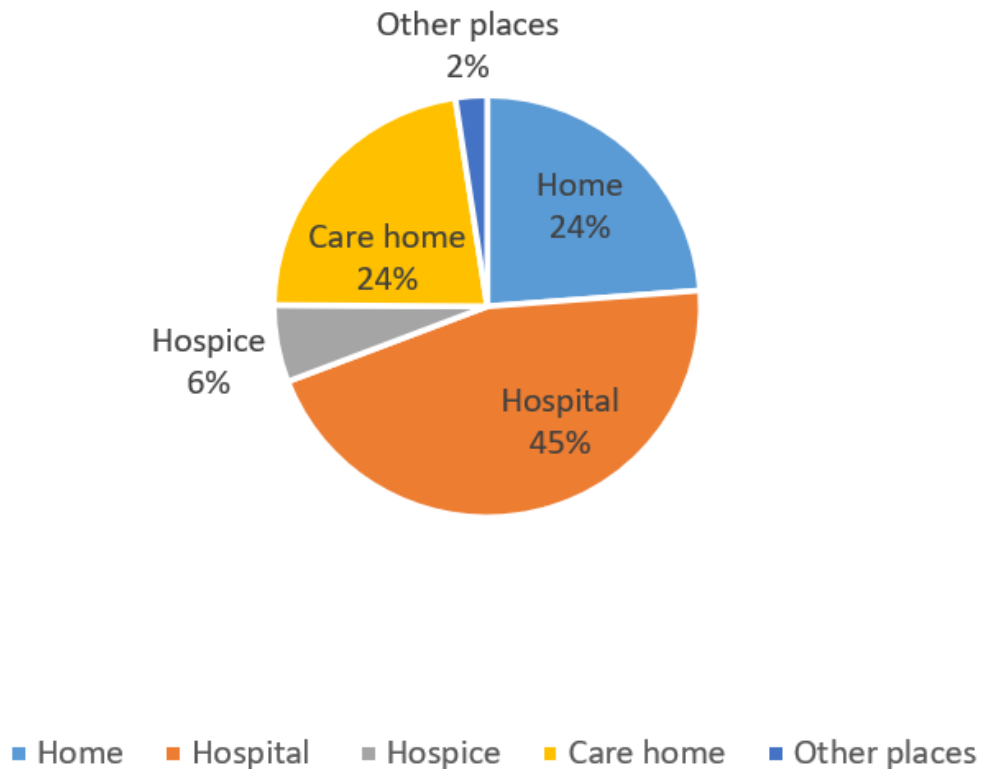


Figure 7: Place of death in England in 2018 (Public Health England, 2019)

Hospital can be a challenging environment in which to provide palliative care to patients and their family members. The quality of care in hospitals still falls short of optimal with no record of relatives not being asked about their own needs in 46% of cases (Royal College of Physicians and Marie Curie, 2016). Researchers have identified that the propensity of hospitals for cure and consultant-led decision-making; prioritising routine tasks; and limited emotional engagement with patients are limiting factors (Gott, Ingleton, Bennett & Gardiner, 2011; Chan, Macdonald, Carnevale & Cohen, 2018). Generalist teams should be supported by specialist palliative care services (NHS England, 2015), but most staff are unlikely to have received specialist

training in palliative care and are providing such care alongside other care demands (Gott et al., 2011). These limitations in palliative care of both patients and their family members in hospital indicate the need for development within this context.

3.5 Supporting Family Members

Supporting the family members of people who are dying is espoused as an integral part of palliative care philosophy and definition (General Medical Council, 2010; World Health Organization, 2016). Professionals acknowledge the distress of family members in the wake of diminishing drinking of dying relatives (van der Riet et al., 2008; van der Riet, Higgins, Good & Sneesby, 2009), but it is not clear how they might effectively support such relatives regarding diminishing drinking and its consequences at the end of life, particularly in a hospital setting (Pettifer et al., 2019).

The NICE (2015, 2017) guidelines emphasise a negotiated approach to decision-making through communication with family members, in which they are listened to and respected when the dying person wants, and the General Medical Council (2010) guidance encourages giving explanation of the likely risks and benefits of treatment while recognising uncertainty. The General Medical Council specifically comments that CAH is an area where the public may not be well informed. It also encourages the involvement of family members in assisting with non-invasive comfort measures such as supporting drinking and mouth and lip care (NICE, 2015). However, to my knowledge, the extent to which any of these approaches might support family members has not been formally evaluated.

3.6 Summary

The background to family members' experiences of diminishing drinking is complex in many ways. The terminology is not clearly defined and as a result the concept is open to interpretation. The consequences of diminishing drinking for the comfort of those approaching the end of their lives are also not clearly known, so it is perhaps inevitable that decision-making about some aspects of palliative care in this area is still open to debate. Family members are currently less satisfied with the way in which issues around hydration are managed in hospital than in other settings in the UK (Office for National Statistics, 2016). It is an area in which professionals and family members alike may have individual strongly held views. However, how best to support family members regarding diminishing drinking is not understood in any depth, despite NICE and the General Medical Council guidance emphasising communication, information giving, encouraging practical involvement and negotiation with families (NICE, 2015; 2017; General Medical Council, 2010).

Chapter 4: Existing Knowledge

In this chapter I report on a systematic review of research literature concerned with family members' experiences of diminishing drinking undertaken in 2017 and repeated in 2020. I have published much of this chapter as a meta-narrative review using the RAMESES publication standards for meta-narrative reviews (Pettifer et al., 2019) and presented it internationally (Pettifer et al., 2018).

4.1 Review Process

In pragmatic thinking, one way in which knowledge is legitimised is through its coherence with existing knowledge (James, 1907) (section 2.2.2, p. 29). Therefore, the aim of this review was to identify, map and analyse existing knowledge relating to the research puzzle, in order to recognising the existing foundation upon which new knowledge can develop. Additionally, the aim was to identify areas where future research might be fruitful. The following question was used to guide the review: **How have the experiences of family members witnessing the diminishing drinking of a dying relative been researched, and what is known about these experiences?**

The definitions of 'family members', 'witnessing', 'dying' and relative' were as given in section 1.1 (p. 13).

Meta-narrative review, developed by Greenhalgh et al. (2005), was selected as the most appropriate methodology. It draws on Thomas Kuhn's concept of scientific 'paradigms' as frameworks of agreed concepts and methodologies within which scientific endeavour proliferates. Kuhn argues that as scientific knowledge develops,

it will stretch the integrity of the framework in which it was formed to breaking point (Kuhn, 1962; Greenhalgh et al., 2009) so eventually a new paradigm will be needed (Bird, 2000). Meta-narrative review seeks to identify, map and analyse the paradigms or meta-narratives in which research has been developed and to consider their usefulness (Greenhalgh, Potts, Wong, Bark & Swinglehurst, 2005).

Meta-narrative review was most appropriate for several reasons. First, it shares a similar understanding of knowledge development to pragmatism. Kuhn's conceptualisation of knowledge sporadically breaking out of its framework is similar to James' notion of fallibility, albeit that James' conceptualisation has a more evolutionary hue. Second, it seeks to integrate and learn from diverse, heterogeneous evidence developed over time (Greenhalgh et al., 2009) and initial scoping of the topic found research was conceptually and methodologically diverse having developed over nearly 30 years. Third, meta-narrative review aims to open up new possibilities for understanding rather than answer a question definitively (Greenhalgh et al., 2005) and this is congruent with the stated aims of this review with regard to identifying future research.

The meta-narrative review process was adapted to take account of the resource constraints inherent in being a single reviewer. Normally, non-research papers such as influential discursive literature are included in meta-narrative reviews (Wong, Greenhalgh, Westhrop & Pawson, 2014) but this was not feasible within the resources available, so the scope of this review was limited to research only. However, the

fundamental focus on how an issue has been researched and understood within different narrative traditions over time (Greenhalgh et al., 2005) has remained intact.

4.1.2 Scoping process

The research traditions or narratives within which family members' experiences of diminishing drinking have been studied were scoped by browsing literature reviews and seminal texts. Three narratives were identified as shown in Figure 8 below:

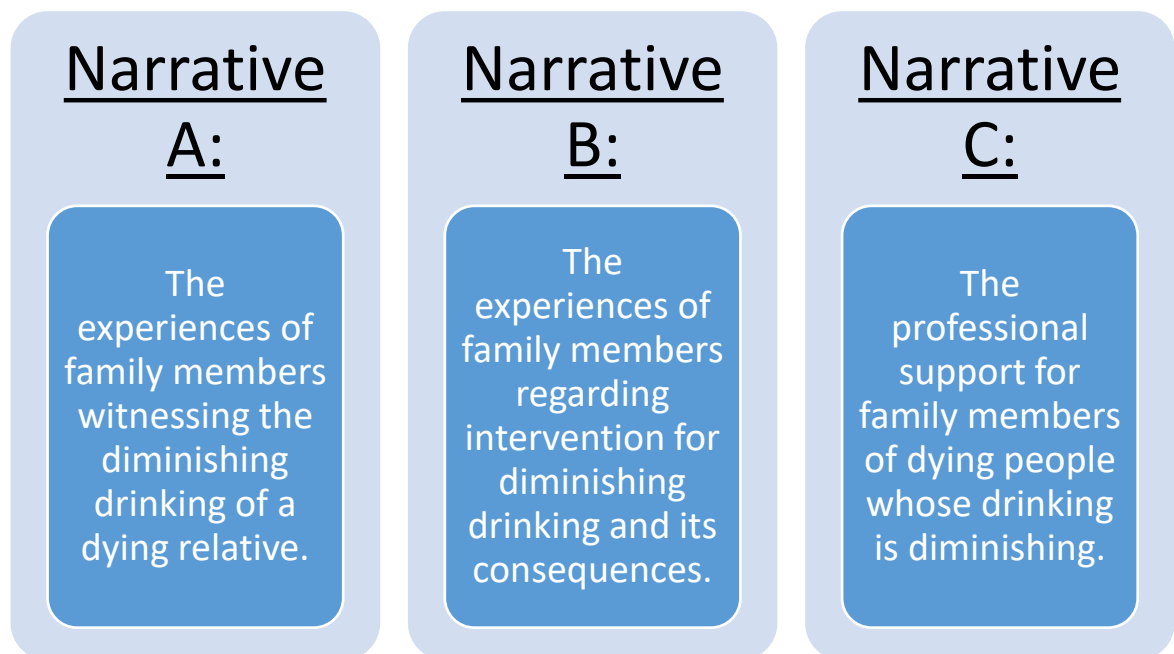


Figure 8: Narratives within research on family members' experience of diminishing drinking

4.1.3 Searching process

On the advice of a subject specialist librarian, I searched the Cumulative Index to Nursing and Allied Health (CINAHL), Medline, PsycINFO, PsycArticles, Scopus, EPPI-centre Database of Systematic Reviews and the Cochrane Collaborative Database of

Systematic Reviews. I searched from January 1982 to December 2017 in order to include the earliest published literature (Zerwekh, 1983) and extend to date. The search was first undertaken in 2017 and was updated in 2020 to add literature published between 2017 and 2020 (Amano et al., 2020).

With the support of the specialist librarian, three key search areas were identified using the acronym ProPheT, which denotes problem (Pro); phenomenon (Phe); and time (T). They listed free-text search terms in each area (Booth, Sutton & Papaioannou, 2016). Synonyms and additional relevant search terms were found from keywords in retrieved papers. The free-text terms and synonyms were truncated where possible and then searched in combination using the Boolean term OR as shown in Table 1 below.

Table 1: Free-text search terms of each question area

Element of ProPheT	Key area of the review question	Free-text search terms used
Problem	Diminishing drinking	drink* OR hydrat* OR dehydrat* OR 'oral intake' NOT sedat* NOT alcohol
Phenomenon	The experiences of family members	family OR families OR relative OR relatives* OR carer* OR caregiver*
Time	When a relative is dying	dying OR 'end of life' OR palliat* OR terminal* OR hospic* NOT 'vegetative state'

Titles and abstracts of the literature were searched for the identified free-text search terms. The literature retrieved in each of the three areas was then combined using the Boolean term AND to identify literature considering all three areas. Literature containing the free-text terms 'sedat*' AND 'vegetative state' in the title or abstract was excluded. In the context of palliative care, 'sedation' is a clinical intervention, and any associated diminishing drinking is a consequence of sedation not of dying (Cherny & Radbruch, 2009). Similarly, 'vegetative state' describes a neurological syndrome in which drinking ceases as a consequence but not necessary as part of dying (Noé et al., 2019). Literature containing the free-text term 'alcohol' was excluded as it relates to a

different meaning of the word 'drinking' from that in this review. Limiters were applied to reflect the inclusion and exclusion criteria.

Wherever possible, free-text terms were mapped to the relevant subject headings or MeSH terms of each database. Subject heading and MeSH terms were exploded to retrieve all relevant titles from the subject tree. Titles, abstracts and keywords of papers were searched for subject headings and MeSH terms using Boolean logic which mirrored the free-text searches.

Database searching alone is not considered optimal for meta-narrative reviews because of their broad, complex scope and their focus on understanding the paradigms or contexts in which research has been undertaken (Wong et al., 2014). Tracking the citations of seminal papers is recommended in order to find additional papers within the paradigms (Wong et al., 2014). The literature reviews identified through the database searches were chosen for tracking because they articulate the established knowledge in their chosen area. The prospective citations and references of the literature reviews were tracked wherever possible.

The scope of this meta-narrative review was broad in order to capture the multiple sources of knowledge relevant to the research question. The scope included studies which,

- included, as a substantial theme, any aspect of family members' experiences of diminishing drinking in the last few days of life;
- conceptualised and defined diminishing drinking in any way;

- were published between January 1982 and July 2020 (these dates were set to include the earliest discussion found within the field as undertaken in 1983 and to continue until the date the review was undertaken);
- were considered from any ontological or epistemological perspective;
- generated qualitative and/or quantitative data; and
- were conducted anywhere within the world but were available in English.

The scope excluded studies which,

- excluded consideration of the last few days of life;
- were position papers, literature reviews or policy guidelines;
- considered family members' experiences of diminishing drinking only as a finding; or
- considered voluntary refusal of drinking.

4.1.4 Analysis and synthesis processes

The papers that met the inclusion criteria were analysed and synthesised using the following process.

The quality of the papers was judged using the Quality Assessment and Review Instrument (QARI) critical appraisal tool (Joanna Briggs Institute, 2014). Although QARI has been designed for qualitative research appraisal, I judged its prompts flexible enough to facilitate appraisal across both qualitative and quantitative data. Poor quality papers were not excluded but the appraisals were used to inform the synthesis (Joanna Briggs Institute, 2014).

Relevant data were extracted from the retrieved papers using a modified version of the British Psychological Society data extraction tool (British Psychological Society, 2007). The modifications were made to categorise the research into the three narratives identified in the scoping phase (Figure 8), to place the data in chronological order and to highlight significant aspects of how the narrative had been conceptualised and studied. For example, to establish whether diminishing drinking was considered separately from diminishing oral intake of any kind.

The studies researched within each narrative were considered in detail and the following elements analysed:

- the chronological, conceptual and methodological development of each narrative;
- the knowledge generated within each narrative; and
- the limitations of each narrative.

The individual narratives were compared and contrasted. The limitations of the existing knowledge as a whole were appraised, and the potential for use of the knowledge for healthcare professionals supporting family members was considered.

4.2 Findings

The results of the search are shown in Figure 9 below.

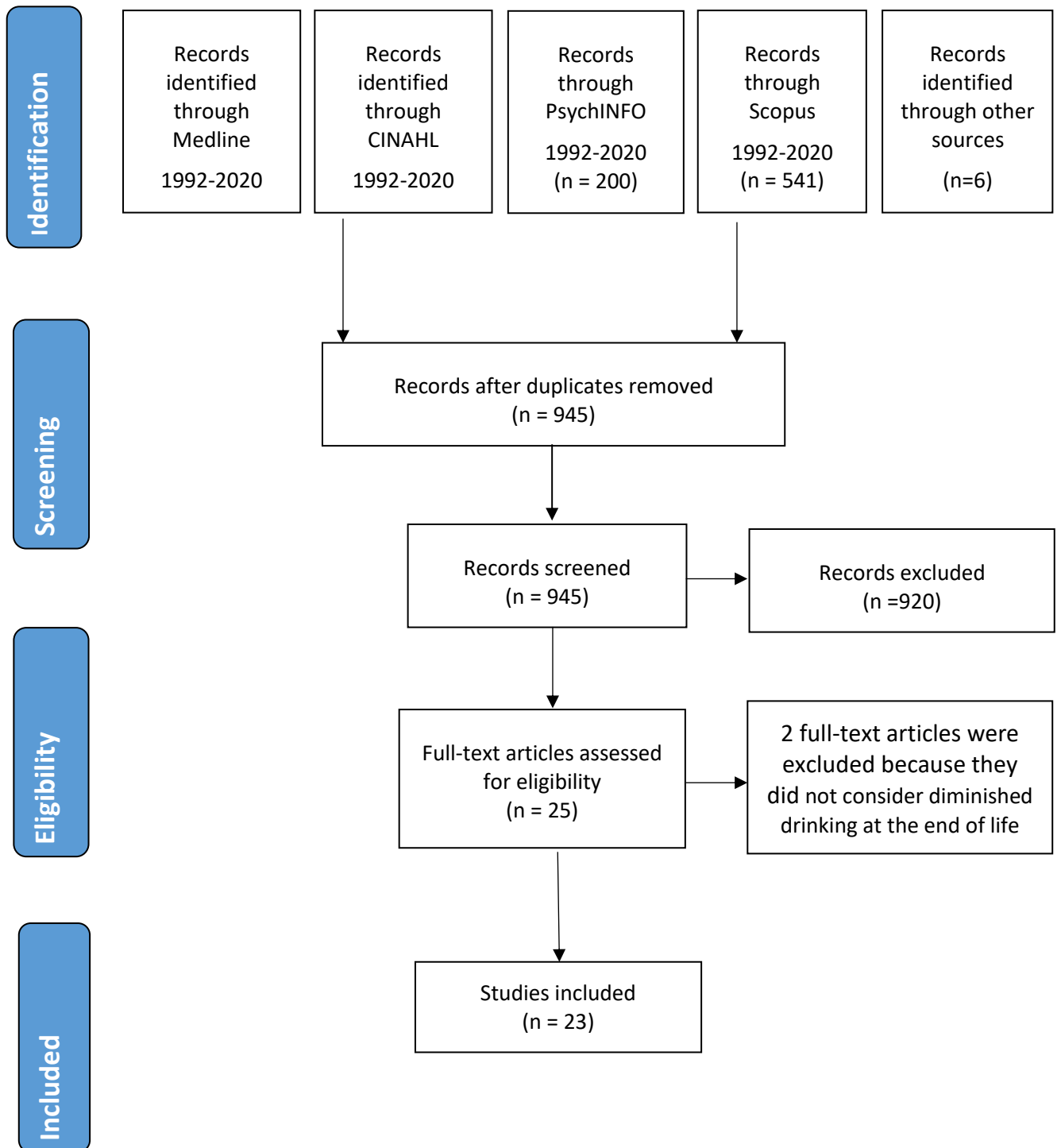


Figure 9: PRIMA diagram

4.2.1 Document characteristics

Twenty-three papers met the inclusion criteria. Two other papers were considered but were excluded after full text screening because they did not include consideration of diminishing drinking at the end of life.

The papers were grouped into the three narrative categories. The narrative categories, and key methodological features of included papers are presented in Table 2. Five of the included papers were concerned with the experiences of family members witnessing the diminishing drinking of their dying relatives (narrative A) (Mearns, 1997; Yamagishi et al., 2010; McClement, Degner & Harlos, 2004; McClement & Harlos, 2008; Raijmakers et al., 2013). Nine were concerned with the experiences, opinions or views of family members regarding intervention given to their dying relatives to address diminishing drinking (narrative B) (Musgrave, Bartal & Opstad, 1996; Parkash & Burge, 1997; Morita, Tsunoda, Inoue & Chihara, 1999; Morita et al., 2006; Rurup, Onwuteaka-Philipsen, Pasman, Ribbe & van de Wal, 2006; Cohen, Torres-Vigil, Burbach, de la Rosa & Bruera, 2012; Bükki, Unterpaul, Nübling, Jox & Lorenzi, 2014; Torres-Vigil et al., 2012; Amano et al., 2020). Two of these papers had collected data from both family members and professionals (Musgrave et al., 1996; Rurup et al., 2006). Eight papers reported research that had collected data from doctors, nurses or both regarding the concerns of family members about intervention for diminishing drinking at the end of life (narrative B, professionals) (Critchlow & Bauer-Wu, 2002; Ke, Chiu, Lo & Hu, 2008; van der Riet et al., 2008, 2009; Good, Sneesby, Higgins & van der Riet, 2011; Chambaere, Loodts, Deliens & Cohen, 2014; Higgins, van der Riet, Sneesby & Good, 2014; Cabañero-Martinez et al., 2016). A single paper focused on

supportive care (narrative C) (Clark, Raijmakers, Allan, van Xuylen & van der Heide, 2017).

Table 2: The narrative categories and key methodological features of included papers

Author(s) and Date	Narrative	Separate to eating?	Separate to clinically assisted hydration (CAH) or artificial nutrition and hydration (ANH)?	The reported point of dying trajectory on which the research was focused
Meares, 1997	A	No	Yes	Bereaved family members reflecting on period in which a dying patient's oral intake decreased 'below levels required to sustain life'.
McClement et al., 2004	A	No	Yes	Included family members of patients within 2-6 weeks of death at time of interview, and bereaved relatives who recalled declining oral intake.
McClement & Harlos, 2008	A	No	Yes	Patients within 2-6 weeks of death at time of interview and bereaved relatives recalling declining oral intake.
Yamagishi et al., 2010	A	No	Yes	Bereaved family members reflecting on experiences of cancer patients unable to eat or drink at 'end of life' (undefined).
Raijmakers et al., 2013	A	No	Yes	Bereaved family members recalling their perception of food and fluid intake during last month of life.
Musgrave et al., 1996	B (family)	Yes	No	All family of patients with prognosis of 10 days or less.

Parkash & Burge, 1997	B (family)	Yes	No	When patients were unable to drink orally.
Morita et al., 1999	B (family)	Yes	No	The family members of cancer patients with a prognosis of less than 6 months and unable to maintain 'satisfactory' oral intake.
Morita et al., 2006	B (family)	No	No	Bereaved family members recalling 'end of life'. This period included death but the point when it started was not defined.
Rurup et al., 2006	B (family)	Yes	No	Family members of advanced dementia patients assessed as unable to drink sufficient fluids to sustain life.
Cohen et al., 2012	B (family)	Yes	No	Family members of advanced cancer patients receiving hospice care focusing on prospective views of CAH in last weeks of life (undefined).
Torres-Vigil et al., 2012	B (family)	Yes	No	Family members of advanced cancer patients receiving hospice care in last weeks of life (undefined).
Bükki et al., 2014	B (family)	No	No	Family members of symptomatic advanced cancer patients focusing on prospective views and preferences at end of life (undefined).
Amano et al., 2020	B (family)	No	No	Bereaved family members of cancer patients considering the time when a patient 'could not eat enough' (enough was undefined).
Chambaere et al., 2014	B (professionals)	No	No	Retrospective consideration of decisions

				made at end of life (undefined).
Critchlow & Bauer-Wu, 2002	B (professionals)	Yes	No	Retrospective consideration of decisions when a long-term care patient was dying (undefined).
Ke et al., 2008	B (professionals)	No	No	Consideration of decisions that might be made about care of cancer patients with prognosis less than one month.
van der Riet et al., 2008	B (professionals)	No	No	When terminally ill patients were unable to eat and drink.
van der Riet et al., 2009	B (professionals)	No	No	Consideration of care at 'end of life' (undefined).
Good et al., 2011	B (professionals)	Yes	No	Doctors reflecting on dying patients (undefined).
Higgins et al., 2014	B (professionals)	No	No	Nurses' reflections about patients who were imminently dying.
Cabañero-Martínez et al., 2016	B (professionals)	Yes	No	Palliative care professionals' perceptions of hydration at end of life care (undefined).
Clark et al., 2017	C	No	Yes	Towards end of life (undefined).

4.2.2 Narrative A: The experiences of family members witnessing the diminishing drinking of a dying relative

Four studies, reported in five papers, consider the self-expressed experiences of family members witnessing the diminishing drinking of dying patients as part of reducing oral intake in patients with cancer (Meares, 1997; Yamagishi et al., 2010; McClement, et al., 2004; McClement & Harlos, 2008; Raijmakers et al., 2013). The key descriptive data

extracted from research in narrative A are presented in Table 3 at the end of this section (p.69). Two papers report different findings from the same piece of research (McClement et al., 2004; McClement & Harlos, 2008). The studies are from different countries in North America (Meares, 1997; McClement et al., 2004; McClement & Harlos, 2008) and Australia (Raijmakers et al., 2013). Three studies used different qualitative designs to generate in-depth data in specialist palliative care settings (Meares, 1997; McClement et al., 2004; McClement & Harlos, 2008; Raijmakers et al., 2013) and one analysed secondary data from a nationwide cross-sectional survey of the bereaved family members of cancer patients to quantify their distress and to shape care provision (Yamagishi et al., 2010). Studies within this narrative are largely positioned within wider research about cancer cachexia-anorexia, although one piece of research included a small number of patients with non-malignant disease (Raijmakers et al., 2013).

The findings of the studies demonstrate the significance of oral intake to family members (Yamagishi et al., 2010; Raijmakers et al., 2013). In Japan, most (80%) of the 452 bereaved family members of cancer patients who responded to their survey had witnessed dying relatives becoming unable to eat and drink and almost three quarters of these (71%) had been distressed by it (Yamagishi et al., 2010). The studies draw different conclusions about the source of this distress. Yamagishi et al. (2010), report family members felt helplessness and guilt because they believed their relative was distressed by this decline. The authors of the qualitative studies report that the responses of family members varied. Some family members accepted the reducing intake of food and drink as a normal part of the dying process (McClement et al., 2004;

Raijmakers et al., 2013) but others viewed it as part of a battle against the disease (Meares, 1997; McClement & Harlos, 2008; Raijmakers et al., 2013). The response of family members corresponded with their feelings about the decline and with their expectations of themselves as carers. Those who were accepting then found ways of showing care that did not involve eating or drinking, such as protecting their relative from pressure by others. However, others persevered in encouraging their relative to eat and drink and wanted healthcare professionals to do likewise.

The studies in this narrative discuss the potential of communication strategies to support family members and make recommendations for practice. Recommendations include anticipating the concerns of family members (Meares, 1997; McClement et al., 2004); giving guidance and information prior to family members becoming concerned (Meares, 1997; Yamagishi et al., 2010); initiating discussions (Meares, 1997); assessing expectations; and considering a range of different supportive approaches (Meares, 1997; Yamagishi et al., 2010; McClement et al., 2004; McClement & Harlos, 2008) and encouraging family involvement with practical care (Yamagishi et al., 2010; McClement & Harlos, 2008). However, these strategies may not be widely employed. Raijmakers (2013) found that relatives of patients referred to a specialist palliative care service in New Zealand recalled few detailed discussions about diminishing intake with professionals and those that occurred focused on information rather than on assessment or wider support.

In summary, knowledge generated within this narrative elucidates a plethora of emotions and responses by family members to the reduced oral intake of their

relatives; these predominantly had cancer. It also offers some supportive communication strategies. It is likely that family members have concerns about a dying relative's diminishing drinking, but within the current research these findings cannot be reliably disaggregated from their response to reduced oral intake as a whole. Furthermore, almost all of the studies involved family members of relatives who had cancer, which limits the utility of this narrative for wider understanding of family members' experiences.

Table 3: Key extracted data within narrative A

Key extracted data within narrative A: The experiences of family members witnessing the diminishing drinking of a dying relative								
Abbreviations used: Artificial nutrition and hydration (ANH), clinically assisted hydration (CAH), United States of America (USA)								
Citation and location	Aim	Care setting	Participants	Methodology	Data collection	Data analysis	Key relevant findings	Relevant recommendations
Meares 1997, USA	To explore the meaning of gradual cessation of eating and drinking described by women caregivers.	Adult in-home hospice patients	12 women, bereaved family members and primary caregivers of cancer patients who had died at home	Phenomenology	Interviews	Line-by-line coding and thematic analysis	Seven key themes were identified. These were the meaning of food, caregiver as sustainer, current losses, personal responses, ceasing to be-starved to death, being bereaved–the meaning now and paradox.	Each situation needs individual assessment and clarification of the values of family members. Nurses may need to open discussions proactively and initiate them early. Further research might include consideration of ethical decision-making and diverse cultural and disease contexts.

McClement et al., 2004, Canada	To report on a sub-theme of wider research entitled 'fighting back: It's best to eat.'	Specialist palliative care in-patient unit	13 adult in-patients, mostly with cancer, 13 family members, 10 bereaved family members, 11 professionals	Grounded theory	Participant observation and interviews	Grounded theory	The strategies family members used to encourage food and fluid intake were targeting the patient, food manipulation and the healthcare provider. Efforts to increase fluid intake comprised auditing care, blaming healthcare providers and petitioning for remedial intervention. These strategies can be emotionally difficult for professionals.	Healthcare providers need to anticipate, acknowledge and assess concerns and elicit the expectations of family members regarding care. More research needed for non-malignant groups.
McClement et al., 2008, Canada	To report on a sub-theme of wider research entitled 'letting nature take its course: it's best not to eat':	Specialist palliative care in-patient unit	13 in-patients, mostly with cancer, 13 family members, 10 bereaved family members, 11 professionals	Grounded theory	Participant observation and interviews	Grounded theory	The strategies family members who accepted declining intake as a 'normal' part of dying involved 'finding other ways to care'. These included participating in physical care, being present and protecting.	More research needed to test the findings, explore the issue in differing cultural contexts and investigate complexities of nutritional care.

Yamagishi et al., 2010, Japan	To clarify the levels and determinants of family members' distress about patients' cessation of oral nourishment.	Bereaved relatives of cancer patients who had died in palliative care units	452 bereaved family members	Nationwide cross-sectional survey	Piloted questionnaire	Univariate and logistic regression analysis using SPSS	71% found a relative becoming unable to drink very distressing or distressing; 60% felt a need for much, some or considerable improvement in professional practice; 69% reported helplessness and guilt; 60% had believed dehydration causes distress and 58% believed CAH is a minimum standard of care. 68% perceived professionals paid enough attention to their concerns.	Health professionals should relieve family members' helplessness and guilt, provide appropriate information, understand family concerns and provide emotional support.
Raijmakers et al., 2013, New Zealand	To understand family members' concerns about decreasing oral intake of dying patients.	Specialist palliative care service including in-patient, community and hospital team	Bereaved relatives of people who had died under specialist palliative care service	Qualitative (cit)	One-to-one semi-structured interviews	Thematic analysis	Oral intake at end of life was meaningful for relatives due to its nutritional value, enjoyment, social function, daily rhythm and expression of caring and love. It was distressing when the intake of patients	Healthcare professionals should be aware of broader meaning of declining intake to family members and that many aspects of the concerns of family members about decreasing intake

							<p>declined. Some viewed decreasing intake as a normal part of process of dying but others viewed it as the patient's choice to 'give up'. This left some family members feeling helpless and others relieved of the imperative to feed. Some felt caught in a vicious circle in which both patient and family did not want each other to worry. Participants recalled little communication with health professionals.</p>	<p>cannot be addressed by artificial nutrition and nutrition (ANH). Conversations with family members are needed.</p>
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4.2.3 Narrative B: The experiences of family members regarding intervention for diminishing drinking

The literature review found 17 studies about the experiences of family members regarding interventions given to their dying relatives to address diminishing drinking, and in some cases, eating and their consequences (Musgrave et al., 1996; Parkash & Burge, 1997; Morita et al., 1999; Critchlow & Bauer-Wu, 2002; Ke et al., 2008; Morita et al., 2006; Rurup et al., 2006; van der Riet et al., 2008, 2009; Good et al., 2011; Cohen et al., 2012; Torres-Vigil et al., 2012; Bükki et al., 2014; Chambaere et al., 2014; Higgins et al., 2014; Cabañero-Martinez et al., 2016; Amano et al., 2020). All 17 studies focused on the medical intervention of CAH and/or nutrition (Table 2). The studies did not explore any other supportive interventions, such as mouth care or sipping small amounts of fluid in depth, although these were present within the findings of one piece of research (van der Riet et al., 2008).

Nine of the studies presented data generated directly from family members (Musgrave et al., 1996; Parkash & Burge, 1997; Morita et al., 1999, 2006; Rurup et al., 2006; Cohen et al., 2012; Torres-Vigil et al., 2012; Bükki et al., 2014; Amano et al., 2020). The key descriptive data extracted from this research are presented in Table 4 at the end of this section (p.80). Two of these also collected data from professionals (Musgrave et al., 1996; Rurup et al., 2006) and four also collected data from patients (Musgrave et al., 1996; Morita et al., 1999; Cohen et al., 2012; Bükki et al., 2014). With the exception of Morita et al. (2006) and Amano et al. (2020) whose participants were bereaved family members, most studies included participants whose dying relatives'

life expectancy far exceeded a few days. Methodologically, they include both qualitative (Musgrave et al., 1996; Parkash & Burge, 1997; Cohen et al., 2012) and quantitative (Morita et al., 1999, 2006; Cohen et al., 2012; Torres-Vigil et al. 2012; Bükki et al., 2014; Amano et al., 2020) designs. They were undertaken within North America (Parkash & Burge, 1997; Cohen et al., 2012; Torres-Vigil et al., 2012); Europe (Musgrave et al., et al., 1996; Rurup et al., 2006; Bükki et al., 2014); and Asia (Morita et al., 1999; Morita et al., 2006; Amano et al., 2020).

Studies in narrative B can be largely positioned within wider research exploring the views of family members about CAH and/or nutrition at the end of life. Indeed, two pieces of research are sub-studies of randomised controlled trials about the efficacy of hydration (Cohen et al., 2012; Torres-Vigil et al., 2012). The research reflects the specific legal and cultural context of decision-making about CAH and /or nutrition at the end of life within the country in which the research was undertaken. For example, Morita et al. (2006) explored participants' understanding of legal options regarding end of life care in Japan.

The findings within this narrative demonstrate that family members hold a range of views about CAH stemming from their underpinning beliefs about the effects of hydration and dehydration, expectations of themselves as carers and their expectations of professionals. Most family members had positive views of CAH and one study found family members to be more positive towards CAH and nutrition than dying patients (Bükki et al., 2014). Reasons for these positive views included beliefs that it could reduce the symptom burden of dying patients (Parkash & Burge, 1997;

Morita et al., 1999, 2006; Cohen et al., 2012; Bükki et al., 2014; Amano et al., 2020); support food intake (Musgrave et al., 1996); increase energy levels (Cohen et al. 2012); and extend life (Cohen et al., 2012; Amano et al., 2020). However, a few family members viewed it negatively, considering that it might extend dying patients' suffering (Parkash & Burge, 1997; Morita et al., 1999; Cohen et al., 2012) and dependency by prolonging their lives (Morita et al., 1999).

There is some evidence that attitudes towards CAH are rooted in cultural and religious beliefs. Torres-Virgil et al. (2012) found family members from ethnic minority populations of 'Latinos' and 'Asians' in Texas were more likely to view fluids as having a nutritional role than European Americans. As a result, they may perceive fluid provision to be a basic human need and clinical assistance to receive fluids as fundamental to care. Similarly in Japan, Morita et al. (1999) found that half of family members of people in palliative care units held the view that CAH was fundamental to care, and Amano et al. (2000) reported 70.5% of their sample agreed that parenteral hydration and nutrition should follow when a patient was unable to eat, so arguably inferring that non-provision of CAH could be viewed as inhumane. CAH is similarly imperative within cultures that emphasise the preservation of life at all costs. This view is dominant in the Jewish culture (Musgrave et al., 1996) and was also identified in some participants within a 'white middle-class' Canadian culture (Parkash & Burge, 1997).

The research in Europe suggests that family members' attitudes to CAH are also influenced by the age and diagnosis of the dying person and their own expectations

of care (Rurup et al., 2006; Bükki et al., 2014). The reasons for the influence of age and diagnosis were not identified in the studies but may reflect societal notions of age-appropriate death. For example, Rurup et al. (2006) found that most family members in the Netherlands were supportive of CAH and nutrition being withheld from their older relatives with advanced dementia, particularly if they had increased pain and discomfort at the time. In these cases, most family members perceived not drinking as the patient's autonomous choice, which should be respected; however, those with religious beliefs were less likely to favour autonomous decision-making (Rurup et al., 2006). Family members' expectations of themselves and of professionals were also important in their attitudes. Some family members perceived that CAH was a sign of caring, but others did not, particularly if the withholding of fluids was medically justified (Parkash & Burge, 1997).

Eight of the studies reported on research that had collected data from doctors, nurses or a combination of both regarding the concerns of family members (Critchlow & Bauer-Wu, 2002; Ke et al., 2008; van der Riet et al., 2008, 2009; Good et al., 2011; Chambaere et al., 2014; Higgins et al., 2014; Cabañero-Martinez et al., 2016). The key descriptive data extracted from this research are presented in Table 5 at the end of this section (p.86). These studies were also methodically and geographically diverse and with qualitative and quantitative designs from across North America (Critchlow & Bauer-Wu, 2002); Europe (Chambaere et al., 2014; Cabañero-Martinez et al., 2016); Australasia (van der Riet et al., 2008, 2009; Good et al., 2011; Higgins et al., 2014); and Asia (Ke et al., 2008). This narrative of research with professionals about family members shows a shift in focus over time. It starts with the exploration of professional

attitudes towards the clinical state of terminal dehydration (Critchlow & Bauer-Wu, 2002), then shifts to the exploration of attitudes towards CAH and nutrition (Ke et al., 2008; Good et al., 2011; Higgins et al., 2014) and finally considers the withholding of CAH and nutrition (Chambaere et al., 2014).

In contrast to studies directly reporting family members' predominately positive views of intervention, most studies of professionals found they regarded CAH and/or nutrition as having a detrimental effect on the comfort of dying patients due to the potential for fluid overload and the possible discomfort of the cannulas (tubes) required to administer the fluids (Ke et al., 2008; van der Riet et al., 2008, 2009). However, this varied with the time of the research, with more professionals being supportive of it in earlier studies than in later ones (Musgrave et al., 1996; Critchlow & Bauer-Wu, 2002).

A cluster of Australian studies has explored the contrasts between family members' and professionals' views of CAH and/or nutrition in some depth (van der Riet et al., 2008, 2009; Higgins et al., 2014; Good et al., 2011) and some used the term 'contesting discourses' to describe the different stances of family members and professionals (van der Riet et al., 2008, 2009). Professionals postulate that dehydration decreases the suffering of patients but also recognise that family members may be distressed if clinical nutrition and hydration are not provided. These contesting discourses reflect wider struggles concerning the optimal care of dying patients and differences in the foci of acute care and palliative care settings (van der Riet et al., 2008, 2009; Higgins et al., 2014; Good et al., 2011).

Tensions about the management of dehydration also exist between different professionals (Higgins et al., 2014; Good et al., 2011). Good et al. (2011) found that doctors working in acute care settings had conflicting and confusing views about the effect of being dehydrated, with some believing it to be uncomfortable while others believing it is not. Some doctors associated CAH with cure, hope, life and caring and associated its discontinuation or withholding with hopelessness and abandonment. They recognised that their associations were culturally rooted in both themselves and the family members in their care. Two papers suggested that the tensions between different discourses were exacerbated by uncertainty about the dying trajectory (Higgins et al., 2014; Good et al., 2011).

Several studies in this narrative considered the potential of communication to support families as part of their research or in their discussion (Parkash & Burge, 1997; Torres-Vigil et al., 2012; Bükki et al., 2014; Chambaere et al., 2014; van der Riet et al., 2008; Good et al., 2011). Two studies found that relatives preferred verbal communication with doctors to written guidelines (Parkash & Burge, 1997; Bükki et al., 2014) and one found a correlation between family members' involvement in decision-making and satisfaction with communication about CAH (Bükki et al., 2014). However, it would appear that such communication can be limited in practice since Good et al. (2011) found doctors delayed or avoided discussing decision-making about CAH with family members in order to protect themselves from the difficult emotions associated with it.

In summary, knowledge generated about intervention for diminishing drinking and its consequences suggests that family members and professionals have a range of views about the effects of dehydration and potential benefits of CAH and /or nutrition. Their views reflect wider approaches to the care of dying people within the cultural contexts of individual studies. The views of family members and professionals are often culturally determined and can conflict. While direct perspectives of family members are present, much of the research in this narrative has come vicariously from healthcare professionals and the validity of professionals' knowledge of family members' perspectives can be questioned. Nevertheless, there is some commensurability in that professionals are aware of the divergence between the views of family members and their own. Returning to the puzzle posed in this research, while this narrative does give some insight into family members' experiences of CAH for dehydration there is minimal consideration of their experiences of any other interventions including more comfort-orientated measures such as mouth care or sipping low volumes of fluids. In some cases, it is impossible to disaggregate CAH from clinically assisted nutrition. It is also difficult to disaggregate family members' experiences of the last few days of their relative's life from their experiences earlier in their dying trajectory.

Table 4: Key extracted data within narrative B (Family members' perspectives)

Key extracted data within narrative B: The experiences of family members regarding intervention for diminishing drinking and its consequences (family members' perspective)								
Abbreviations used: Artificial nutrition and hydration (ANH), clinically assisted hydration (CAH), United States of America (USA)								
Citation and location	Aim	Care setting	Participants	Methodology	Data collection	Data analysis	Key relevant findings	Relevant recommendations
Musgrave et al., 1996, Israel	To identify the attitudes of patients, doctors, nurses and family members towards intravenous fluids in dying patients and their involvement in decision-making.	Adult oncology unit of a hospital	Convenience sample of 33 patients, 32 family members and 35 professionals	Pilot survey	Structured interviews	Responses categorised as positive, negative or neutral and statistically described	81% of families were positive towards intravenous fluids for administration of medication and symptom control. Doctors usually initiated decisions, with 13% involving family. Findings were considered contextual to Israeli community.	Wider research needed focusing on reasons for starting fluids.
Parkash & Burge 1997, Canada	To describe the issues of family caregivers when making	Home support and in-patient palliative care	7 family members: white, middle-class Canadian of	Qualitative (cit)	Semi-structured interviews	Categorised under a priori themes	The factors influencing caregivers were concerns about symptom distress	More timely discussions about hydration issues to consider patients' wishes, to increase

	decisions regarding CAH for dying patients.	programme with a medical centre	British or Irish origin				and positive and negative effects of rehydration on this, ethics, emotional considerations, information exchange, decision-making and culture. Caregivers' perceptions of the benefits of CAH are varied and are central to their decision-making.	provision of information and to elicit concerns of family.
Morita, et al., 1999, Japan	To clarify patients and family members' perceptions about CAH and identify factors in their decision-making about it.	In-patient hospice	62 hospice in-patients with cancer and 119 family members	Prospective survey	Structured interview Recording of potential contributing factors	Multiple logistic regression analysis	85% of family members believed patient could not get appropriate nutrition without CAH. 56% believed that dehydration hastens death.	More research including development of a tool to assess family members' concerns.
Morita, et al., 2006, Japan	'To clarify knowledge and beliefs of a general	General population	2,548 general population subjects and	Survey	Piloted questionnaire	Analysis of variance	33-50% of participants believed ANH should be continued as	Good practice in palliative care

	population regarding CAH' (and other aspects of end of life care).	and palliative care units	513 bereaved family members of people with cancer				minimum standard until death and 15%-31% agreed ANH relieved patient symptoms. No significant differences between those recruited from palliative care units and others.	should reduce inaccurate beliefs.
Rurup et al., 2006, Netherlands	To investigate the attitudes of physicians, nurses and relatives towards medical decisions about patients with dementia at the end of life.	39 nursing homes	190 patients with advanced dementia, 75 physicians, 136 family members, 178 nurses	Survey	Piloted questionnaire	Descriptive statistical analysis	65% of family members agreed more than disagreed or fully agreed that decisions of patients who refuse to drink should be respected. Family members agreed with this more than nurses or physicians, particularly if they thought relative had more pain and discomfort at time of decision. Physicians are more confident of peaceful death in the absence of CAH	More open discussion of likelihood of CAH influencing peaceful death. Greater cognisance of different perspectives.

							than either nurses or families.	
Cohen et al., 2012, USA	To describe the meaning of CAH for terminally ill cancer patients and their caregivers.	Hospice home care	85 cancer patients, 84 family caregivers	Hermeneutic phenomenology Part of larger randomised control trial	Interviews on day 1 and then 4 of the trial	Thematic hermeneutic analysis	Two themes emerged: hope – fluids were considered essential for survival, healing and staying healthy by family members; comfort – hydration was considered important for reducing pain, enhancing medication effectiveness, nourishing body, mind and spirit, and enhancing breathing and quality of life.	Need for individualised care. Recommends future research into meaning of dehydration and parenteral hydration and also consider cultural and gender preferences for it.
Torres-Vigil et al., 2012, Texas, USA	To identify whether patients with advanced cancer and their caregivers view CAH as	Hospice home care	54 cancer patients, 68 family caregivers	Optional and additional qualitative part of randomised control trial	Asked a single question during interview	Chi squared analysis for correlation using SPSS software	38% of participants felt fluid was more like food, 34% felt it was more like medicine and 14% as both. Ethnic minority participants more likely to view fluid as food (66%) compared	Professionals need to ask patients and caregivers about their perceptions to enhance communication and culturally appropriate care.

	food or medicine.						with white participants (42%) but no other significant differences.	
Bükki et al., 2014, Germany	To evaluate the needs, concerns, preferences and experiences of patients and caregivers regarding decisions about ANH at end of life.	Hospital wards providing cancer care	39 patients and 30 caregivers	Prospective, cross-sectional survey	Modified questionnaire	Descriptive statistics and correlation between ordinal variables assessed using SPSS software	Family members were more positive about assisted fluids and nutrition than patients when deciding on behalf of patients. No association with religiosity but advancing age was a factor in desire to forgo ANH in family and patients. Information did not change decision but did change confidence of relatives. Family concerned about pain, thirst and agitation. Family preferred detailed information from doctors; moderate	Early discussions focusing on addressing concerns. Research about cross-cultural differences. Assessments of level of knowledge of non-malignant groups.

							satisfaction with current communication.	
Amano et al., 2020 Japan	To clarify the beliefs and perceptions about parental nutrition and hydration of bereaved family members of patients with cancer.	Inpatient Hospice	610 bereaved family members	Cross-sectional nationwide survey	Questionnaire developed and tested by the researchers	Descriptive statistics and multiple logistic regression analysis using SPSS software	87.7% believed parental hydration required for patients who are unable to eat (87.7%). 81% believed parental hydration is a substitute for oral hydration.	

Table 5: Key extracted data within narrative B (Professional's perspective)

Key extracted data within narrative B: The experiences of family members regarding intervention for diminishing drinking and its consequences. (Professionals' perspective)								
Abbreviations used: Artificial nutrition and hydration (ANH), clinically assisted hydration (CAH), United States of America (USA)								
Citation and location	Aim	Care setting	Participants	Methodology	Data collection	Data analysis	Key relevant findings	Relevant recommendations
Critchlow & Bauer-Wu, 2002, USA	To explore how nurses working with elderly people view terminal dehydration.	Long-term care	64 registered nurses and licensed practical nurses	Survey	Modified questionnaire	Descriptive analysis, correlated to demographic variables	Age and experiences of nurses was associated with positive perceptions of terminal hydration; however, there was considerable diversity of views.	Recommendations for improvements in nurse education including how nurses can support decision-making with families.
Ke et al., 2008, Taiwan	To explore the knowledge, attitudes and behavioural intentions of nurses providing ANH for terminal cancer patients.	General hospital in Taiwan. Largely Buddhist or Taoist population	197 general and intensivist nurses	Survey	Self-developed structured questionnaire	Mean values and standard deviations calculated using SPSS	Nurses had reasonable general knowledge about palliative care but less knowledge of the effects of ANH. Difficulties of communicating about ANH with families and identified as one factor which	Greater education regarding ANH is needed to support nurses to communicate effectively.

							influenced its provision.	
van der Riet et al., 2008, Australia	To explore the issue of family members' desire to feed patients despite them being unable to eat and drink with healthcare professionals	2 palliative care units	15 nurses and doctors	Discourse analysis	2 focus groups and 4 interviews	Discourse analysis	Three discourses were identified: family members' distress at non-provision of CAH; professionals' belief that dehydration decreases suffering and polarisation between acute and palliative care settings.	Recommends communication, education and team approach. Staff need more information about pathophysiology of dying and clinical guidelines needs to be developed.
van der Riet et al., 2009, Australia	To report on the discourses of palliative care nurses and doctors regarding the management of nutrition and hydration at the end of life in patients with severe brain injury	2 palliative care units	15 nurses and 4 doctors	Discourse analysis	2 focus groups and 4 interviews	Discourse analysis	The main theme identified was 'blurring boundaries'. It refers to difficulties when decisions are complex because there is a tension between actions that promote quality of life before death but may also prolong suffering. This is particularly difficult	Recommends exploration of mixed management approach involving both curative and palliative focused care, including consideration of ethics and impact on professionals and families.

	and patients with cancer.						if dying is protracted and unpredictable.	
Good et al., 2011, Australia	To explore the perceptions of doctors regarding CAH for dying patients.	Medicine, haematology and oncology units	8 medical officers	Qualitative descriptive study	Face-to-face interviews	Discourse analysis	Professionals experience tensions surrounding uncertainty about the transition from curative to palliative care; communication with patient and family about dying; cultural expectations; conflicting views about effects of dehydration; technology and the media; hydration as being symbolic of hope; uncertainty as a battleground; and the futility of treatment. Negotiating transition from curative to palliative care is challenging for doctors, and decision-making re	More education of doctors regarding the effect of dehydration. Research regarding the impact of reducing intake of dying patients is needed.

							CAH is reflective of this.	
Higgins et al., 2014, Australia	To explore the perceptions of nurses regarding the provision and non-provision of ANH for dying patients.	Medical, oncology and haematology units	Acute care nurses	Qualitative, descriptive design	Focus groups	Thematic analysis	The main theme identified was the tensions of nursing dying patients. These tensions were nurses' limited involvement in decision-making, the balancing of treatment which could comfort or cause discomfort to patients and families, managing uncertainty and considering the potential advantages of withdrawing treatment.	Palliative approach to care is needed in acute care areas. Exploration of ethical issues nurses face in acute hospitals. Education for nurses on the effects of hydration and dehydration.
Chambaere, et al., 2014, Belgium	To explore decisions to withhold ANH.	All care settings	Doctors of deceased patients	Postal survey	Questionnaire	Descriptive analysis then multivariate logistic regression analysis	Family often involved in decision-making (76%). Decisions to forgo assisted fluids and nutrition vary with patient characteristics: more	Call for improved advance care planning. Need for early communication to promote autonomy.

							likely for females, when dying in care home or hospital and when suffering from cancer or neurological disease.	
Cabañero-Martínez, et al., 2016, Spain	To explore the perceptions, attitudes and opinions of health professionals regarding sub-cutaneous hydration of dying patents.	Specialist palliative care units registered in one of two regions of Spain.	Doctors and nurses working in specialist palliative care	Qualitative	2 with nurse focus groups and 2 focus groups with doctors	Content analysis	The relationship of the professional team and the family was important in addressing family members' emotional and informational needs. Early intentional communication focusing on emotional and informational needs is essential.	Authors recommend impact on protocols and guidelines for health management practices. A consistent approach is needed.

4.2.4 Narrative C: Professional support for family members of patients with diminishing drinking

The sole study within narrative C aimed to consider how healthcare professionals might support family members and address their needs (Clark et al., 2017). The key descriptive data extracted from this research are presented in Table 6 at the end of this section (p.96). This was a qualitative thematic analysis of interviews about declining oral intake with 10 experienced palliative care specialists working in a hospice. It describes professional support for family members delivered through communication between healthcare professionals, patients and family members working within specialist palliative care.

The findings of Clark et al. (2017) contrast with those of the earlier study by Critchlow and Bauer-Wu (2002) within narrative B, which was undertaken in a hospital setting and focused on nurses' perceptions of dehydration. Critchlow and Bauer-Wu (2002) found that nurses working in long-term care lacked the knowledge and skills to support family members. This contrast may reflect differences within the two care groups and raises questions about how the supportive strategies might be used beyond specialist palliative care.

Returning to the puzzle posed in this research, exploring professional support for family members of people with diminishing oral intake is an emerging and new narrative, thus far limited to a single study of specialist practice. No literature was found that focused on support for family members of people with diminishing drinking.

Table 6: Key extracted data within narrative C.

Key extracted data narrative C: Professional support for family members of patients with diminishing drinking								
Abbreviations used: Artificial nutrition and hydration (ANH), clinically assisted hydration (CAH)								
Citation and location	Aim	Care setting	Participants	Methodology	Data collection	Data Analysis	Key relevant findings	Relevant recommendations
Clark et al., 2017, New Zealand	To explore specialist palliative care practice regarding decreasing oral intake of dying patients.	Specialist palliative care including in-patient, community and hospital team	2 doctors, 8 nurses	Qualitative	One-to-one interviews	Thematic analysis	Three themes emerged. Palliative care professionals see declining intake as part of dying process. They recognise significance of this change and respond empathically, focusing on support, enjoyment and safety. Communication with family is important to professionals.	Future research into conversations of professionals and care recipients to develop care strategies and support communication.

4.2.5 Narratives A, B and C compared

The three narratives informing knowledge of the experiences of family members witnessing the diminishing drinking of a dying relative are summarised and presented alongside each other in Table 7. The table shows the findings, tradition and limitations in relation to addressing the research puzzle in each narrative. The commonalities and differences between them are discussed below.

Table 7: The tradition, key findings and limitations of each narrative

Narrative	Key findings	Narrative tradition	Key limitations
<p>Narrative A</p> <p>The experiences of family members witnessing the diminishing drinking of a dying relative</p>	<p>Most family members who experience diminishing oral intake of relatives are distressed by it. They may have feelings of helplessness, guilt and acceptance and may interpret the decline as a battle with disease. They respond in a range of ways from protecting patients from pressure to exerting pressure on them to eat and drink.</p>	<p>Narrative from cancer cachexia.</p>	<p>Knowledge about diminishing drinking cannot be disaggregated from diminishing eating.</p>
<p>Narrative B</p> <p>The experiences of family members regarding intervention for diminishing drinking and its consequences (family members)</p>	<p>Views of family members and professionals concerning use of CAH and/or nutrition may conflict. Attitudes towards CAH and/or nutrition are rooted in diverging cultural, philosophical and religious values and beliefs.</p>	<p>From research concerned with decision-making regarding CAH and nutrition of diminishing drinking.</p>	<p>Studies of family members' experiences of intervention have exclusively focused on CAH and nutrition without consideration of wider intervention.</p> <p>Much of the in-depth research has been undertaken in oncology and specialist palliative care settings; it may not transfer to more general contexts. Knowledge of family members' experiences cannot be disaggregated from nutrition. The last few days of life also cannot always be disaggregated.</p>

<p>Narrative B</p> <p>The experiences of family members regarding intervention for diminishing drinking and its consequences (professionals)</p>	<p>The research shows a chronological shift of professional concern from the clinical state of terminal dehydration to attitudes towards CAH and/or and, later, withholding CAH, consideration of its withholding. Professionals consider that dehydration decreases patient suffering and CAH has a detrimental effect but also recognise that some family members are distressed at its non-provision.</p>	<p>From research concerned with decision-making around CAH and nutrition.</p>	<p>As above but in addition, the knowledge has been gained though professionals. The research reflects the specific legal and cultural context of decision-making about CAH and/or nutrition at the end of life within the country in which the research has been undertaken and may not be generalisable beyond this.</p>
<p>Narrative C</p> <p>Professional support for family members of patients with diminishing drinking</p>	<p>Palliative care professionals see declining intake as part of the dying process. They recognise significance of this change to patients and relatives and focus on support, enjoyment and safety. Communication with relatives is important to professionals.</p>	<p>Emerging narrative about supporting family members.</p>	<p>The single study was undertaken with specialist palliative care professionals, not family members. Its findings may not be applicable to other contexts. Findings about diminishing drinking cannot be disaggregated from diminishing oral intake.</p>

Diminishing drinking has been researched from different perspectives which reflect the many ways it impacts palliative care endeavour. The findings of the three narratives are interrelated and augment each other. Arguably, the findings within narrative A are most directly relevant to the research puzzle since they explore family members' experiences, albeit of relatives dying from cancer; some knowledge of family members' beliefs about CAH dehydration at the end of life can also be inferred from narrative B, and narrative C points to potential areas for helpful interventions.

4.3 Discussion

Definitive conclusions regarding the experiences of family members of dying people with diminishing drinking cannot be drawn because the subject has not been explored discretely. Family members' experiences when witnessing diminishing drinking of dying patients has been researched only as part of a wider subject. While this does not preclude knowledge, it has meant that knowledge of the subject cannot be reliably differentiated. Definitions of 'end of life' have varied from consideration of the last few days of life to longer periods that are not always quantified. Many studies have researched the experiences of family members alongside those of professionals, presenting the findings collectively. This has meant that the perspective of each group is not always distinguishable (McClement & Harlos, 2008; Rurup et al., 2006). Research endeavour has focused predominantly on the experiences of CAH as an intervention addressing the diminishing drinking of dying patients and has responded to the imperative to involve family members in clinical decision-making about such interventions. Only five of the 23 included studies were concerned with understanding the experiences of family members regarding diminishing drinking and none of these

five disaggregate diminishing drinking from diminishing oral intake of any kind. The narrative exploring more support-orientated care is even smaller.

While the state of knowledge is limited, some understanding of the field can be tentatively inferred from it. All three narratives point to the significance of diminishing drinking for family members and the challenges for professionals seeking to support them. They imply that family members are likely to find the diminishing intake of dying patients distressing (Yamagishi et al., 2010; Raijmakers et al., 2013). Their experiences vary with their diverging cultural, religious and philosophical values and their beliefs. The experiences of family members are shaped by notions about the significance of liquids and drinking to life, what constitutes dying well and the concomitant nature of caring by both family members and professionals. These values and beliefs shape the experiences of both family members and professionals. They also shape the approach professionals take to caring for dying patients with diminishing drinking and to supporting their family members.

Discussion of communication strategies that may support family members is common to all narratives and there is some evidence that family members value consultation with healthcare professionals (Amano et al., 2020). Several studies recommend that professionals enhance their communication about CAH with family members (Parkash & Burge, 1997; Morita et al., 2006; Bükki et al., 2014; Amano et al., 2020). It would appear that professionals are well aware that this is a challenging area and are likely to find it useful to have more knowledge of family members' experiences. Although research into supportive intervention for family members with declining oral intake

has started, the single study discussed here was undertaken in a specialist palliative care setting so may not easily transfer to more general care contexts where uncertainty and conflicting demands are heightened (Al-Qurainy, Collis and Feuer, 2009).

4.3.1 Limitations

The strength of this review methodology lies in the capability of meta-narrative review to identify the way in which diminishing drinking has been studied, the current knowledge base and the fallibility inherent within it. However, the adaptations to the process used here to meet the resource constraints have limited the scope to empirical research only. The inclusion of discursive and policy literature may have provided further insight regarding how the experiences of family members witnessing diminishing drinking of a dying relative have been studied. The processes of searching and reviewing were undertaken by a single reviewer and involved judgements about the search process and suitability and synthesis of the identified research. The inherent subjectivity of this process was reduced by the involvement of expert supervision of the reviewer and advice from a subject specific librarian, although the use of multiple reviewers would have been preferable had resources allowed.

4.4 Summary

As stated, the purpose of meta-narrative review is to open up new possibilities for understanding (Greenhalgh et al., 2005) and in pragmatic terms this equates to identifying areas of fallibility. This review maps, analyses and synthesises what is known about the experiences of family members witnessing diminishing drinking of a

dying relative. It finds that the current knowledge of family members' experience of diminishing drinking is fallible simply in the sense that there is a paucity of research in the field; these experiences have not been discretely conceptualised and explored, and so the research puzzle remains. Some knowledge of these areas can be inferred from broader research undertaken within three distinct but related narratives: family members' experiences of witnessing diminishing drinking (narrative A); their experiences regarding intervention (narrative B); and professional support for family members in this situation (narrative C). Each narrative has been studied from a particular focus and consequently their relevance to the experiences of family members witnessing the diminishing drinking of a dying relative is limited.

Notwithstanding the limitations, this knowledge is important in two ways. Firstly it provides a foundation on which new research might build and be appraised. Secondly it points to areas where research is wanting. Researching family members' experiences in a different way to the three existing narratives identified in this review may develop knowledge. The research design focuses on family members' experience of diminishing drinking as a discrete concept, separate from diminishing nutrition and CAH. It focuses on the experiences of family members of those dying in a hospital setting from a range of diseases and circumstances, and it addresses the issues following the death so that experiences of diminishing drinking in the last few days can be explored.

Chapter 5: Research Design

In this chapter, I present the research design and practical method used to recruit and interview family members of recently deceased relatives as participants in the project, and then to analyse the data collected. I follow Clandinin's (2013) broad approach to research design interpreting it and adapting it to use in healthcare and within the resource constraints of the research. I also draw on examples of others who have used Clandinin's approach within healthcare settings (Haydon & van der Riet, 2014; van der Riet et al., 2017; Gillan et al., 2016). Towards the end of this chapter, I address ethical issues and consider rigour within the study.

5.1 Study Setting and Participant Population

Recruitment was undertaken in three hospitals within a large National Health Service (NHS) Trust within the UK. It serves a large urban population of some 1.2 million people with over 1,300 beds across three hospital sites. The population is socially deprived and culturally diverse with about 29% of children living in poverty (Care Quality Commission, 2017).

The target participant population was family members of dying patients who have witnessed the diminishing drinking of those being cared for in hospital. However, the family members of those who died suddenly and unexpectedly, for example from trauma, were excluded since their care would not have included diminishing drinking at the end of life. The family members of those who died within 48 hours of admission were also excluded since such a short period does not allow time for clinical

assessment, a clinical decision to manage care using a palliative approach and/or a significant period of diminishing drinking. Consideration was given to excluding family members who were not concerned or distressed by the process of diminishing drinking, but this was rejected since it could preclude exploring the experiences of those whose attitude may have been more positive or stoical. However, family members of relatives who died under the age of 18 were excluded as their experiences are outside the focus of this research. The inclusion and exclusion criteria are summarised in Table 8 below.

Table 8: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Having experienced the death of a relative. Having noticed this relative drinking less and less as they approach the end of their life. Being over 18 years old. Being willing and able to be interviewed in a practicable location for me to travel to, normally within 50 miles of work base. Ability to speak English.	The relative died suddenly and unexpectedly. The relative was in hospital less than 48 hours before their death. The relative was under 18 years old.

5.2 The Sample and Recruitment Process

The recruitment target was a purposive sample of between 10 and 20 individuals who had experience of the diminishing drinking in a dying relative. I used methodological

imperatives to guide the sample size (Baker & Edwards, 2012). The sample size of published studies that have used Clandinin's approach varies considerably from 62 (van der Riet et al., 2017) to four (Haydon & van der Riet, 2014). While no specific recommendation was identified within Clandinin's writing, the sample size relates to the amount of analysis of findings: studies with smaller sample sizes (under five) presented narrative accounts in which participants' stories were retold individually and studies with larger sample sizes presented finding which resonated across the whole collection. A sample size of 10 to 20 was considered large enough to address the research puzzle and enable some analysis across a range of participants in the group. The whole population was invited to self-select into the sample, if they had a story that they were able and willing to share. Two complementary recruitment strategies were used.

Family members of all patients who had died within hospitals visit the bereavement officers approximately three to 10 days after the death unless the death is referred to the coroner for investigation. At the meeting, the bereavement officers give the family members the death certificate and a small folder of information about bereavement.

For the purposes of this study, a research information pack was added to the information folder given to all relatives visiting the bereavement officers at the hospitals involved. The research pack contained:

- an invitation letter (Appendix 3)
- a participant information sheet (Appendix 4)
- two copies of the expression of interest form (Appendix 5)

- a pre-paid, pre-addressed envelope.

Family members interested in considering taking part in the study were asked to indicate this and provide their contact details on the 'expression of interest' form (Appendix 5) and then return it to me using the envelope provided. Up to two family members of a dying patient could express interest in participating in the study. The number of family members of each patient was restricted to two to prevent over emphasis on the context of one patient.

I contacted everyone who returned the expression of interest form by telephone. During this conversation, potential participants were encouraged to ask questions and clarify what was involved in participating in the study. In addition, I assessed whether they met the inclusion criteria required for the study. One respondent was excluded due to living outside the practicable travel area. At the end of this telephone discussion, verbal consent to interview was sought. If verbal consent was obtained, arrangements were be made for a meeting for an in-depth interview. Participants were offered the choice of location between the hospital, their home or a mutually convenient private meeting room.

Finding a successful recruitment strategy was challenging. I tried several options that proved unsuccessful. Initially, bereavement officers were asked to use the medical notes to assess whether family members met the criteria and only give information packs to those who did; but the officers were unable to do this in practice. Also, I tried to recruit in two separate NHS trusts but the bereavement officers at one trust did not distribute the packs I provided so the research continued with only one trust involved.

These challenges in setting up the research reflect wider difficulties of recruitment to palliative care research including recruiting in an unfamiliar organisation, gatekeeping and the demands of clinical workload (Stone et al., 2013). These challenges were overcome through adding research information packs to the bereavement folders given to every bereaved family member and then screening them for eligibility via a follow-up telephone call. This approach minimised demands on clinical staff.

5.3 Consent Procedure

Consent was sought in stages to allow for changes in potential participants' attitudes or level of distress, both leading up to, during and after the interviews (Gysels et al., 2013). Consent to be contacted was taken as implied by the return of the expression of interest form. Verbal consent to be interviewed was sought during the subsequent telephone conversation. Written informed consent to participate within the study was sought at the start of the meeting for in-depth interview (Appendix 6). Potential participants were advised that participation was entirely voluntary, they could cancel the meeting for interview without explanation and could withdraw consent without consequence at any time within the interview or up to two weeks following (General Medical Council, 2010). The possibility that the interview might be distressing was recognised and a distress protocol was devised to manage this (Appendix 9).

5.4 Telling Stories

Family members who agreed to take part in the study were asked to tell me about their experiences of diminishing drinking in a face-to-face interview in their home, or

other mutually agreed private meeting area. I conducted all the interviews and all except one took place at the participant's home.

I took a narrative approach to the interviews, aiming to collect participants' stories of their experience. I broadly followed the structure of narrative interviewing given by Anderson and Kirkpatrick (2016), which aims to let participants determine the content, pace and direction of the interview, albeit within the scope of the study (Anderson & Kirkpatrick, 2016).

I intentionally preceded the interviews with general conversation, showing interest in the home and personal objects or occupation. This was in order to foster a relationship in which participants could both compose and tell stories (Clandinin, 2013). I explained the process of the interview and set out the area of interest of the research. I started by asking participants to tell me a little about themselves, their family and the family member who had died. After this, I invited them to tell their story of witnessing the diminishing drinking of their dying relative, starting at the point that they first noticed the decline. Participants were invited to draw on artefacts such as photographs and notes if they were helpful in telling their stories. I used minimal prompts such as 'Oh, I see', body language such as leaning forward, and questions such as, 'What happened then?' to show interest and maintain flow. As the interview progressed, participants became more conversational in style as we talked about the story. I asked questions and used reflecting techniques to clarify areas and to invite participants to tell me about all areas in the scope of the study.

I developed an interview guide (Appendix 8) as a reference point for support with the interview process, and to remind me of the scope of the study. A pilot interview was undertaken with a person who had witnessed diminishing drinking of a dying relative some years ago in order to check the usability of the interview guide and to support me in using it. The interview guide was found to be suitable, and no changes were made to it following the pilot. However, it was not used verbatim as a list of questions or rigid structure. As the interviews progressed I used the interview guide less and less, allowing participants to determine relevant focus and scope.

5.5 Re-telling Stories

Clandinin does not offer a prescriptive formula or series of steps for undertaking narrative analysis (Clandinin & Connelly, 2000, p.132), rather she sets out principles and exemplars of what narrative inquiries 'do' and how they might 'think with narrative', 'to understand the lives being lived' (Clandinin, 2013, p. 39). In this way she takes a similar position to Frank (2010, p. 72) who advocates understanding method as a 'heuristic guide', not procedural guidance. Clandinin does suggest starting with happenings within each of three parameters or the three-dimensional space within which narrative unfolds (Clandinin & Connelly, 2000). She describes these parameters as 'commonplaces' drawing on the work of Schwab (1962) on the determinants of curricula. Figure 10 depicts the commonplaces as the dimensions of a three-dimensional cube within which a narrative occurs.

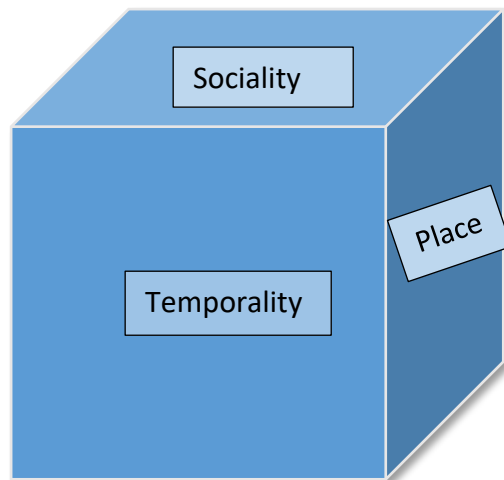


Figure 10: Commonplaces: The boundaries of narrative

The 'commonplace' of temporality attends to experience within a context of time and sequence. The 'commonplace' of sociality attends to the experience within both a personal and social context. The 'commonplace' of spatiality attends to the specific geography and environment of the experience. Clandinin also advocates that narrative researchers attend to what is happening 'backward and forward, inward and outward, with attention to place(s)' (2013, p. 39). She does not expand on what she means by these terms in detail, but infers consideration of the past, present and future of people and experiences. 'Inward' refers to consideration of their personal emotions and responses, and 'outward' to the institutional, cultural and social context.

I devised the process of analysis described below using the principles and exemplars offered by Clandinin (2013). The process is described sequentially. Although it was broadly undertaken in this way, it was also an iterative process in which I worked with each stage, engaging with the data and refining the analytical process as a result.

5.5.1 Field texts

Clandinin (2013) uses the term 'field texts' to denote records of interviews or other artefacts of narratives. Field texts were made by transcribing the interview recordings verbatim. I transcribed the pilot interview first and used it as an exemplar. The remaining interviews were transcribed professionally, using the exemplar as a template. The professional transcriber was subject to a confidentiality agreement (Appendix 7). The use of transcription software was considered but dismissed due to concerns about maintaining confidentiality. Transcription was detailed in order to capture as much nuance as possible including the relational aspects of the interview so both my and the participant's speech and utterances were included in transcription (Riessman, 2008). Words which were emphasised using tone were italicised by the transcriber to record the emphasis. I read each transcript alongside the audio recording for accuracy and familiarity. Any details which might identify the participants, their deceased relatives and/or their wider families were removed, and names replaced with pseudonyms. The anonymised transcripts were uploaded to Atlas.ti computer assisted qualitative data analysis software for storage. Atlas.ti was chosen over other software because of its versatility in labelling and linking lengthy quotations (Friese, 2019).

5.5.2 Interim texts

Clandinin (2013) uses the term 'interim texts' to denote records or working products of the analysis process. Downey and Clandinin (2010) refer to the

following metaphor of a person's life as shards of a shattered mirror to explain the process of analysis:

In narrative inquiry, we do not intend to reassemble the bits but rather to enter the strewn bits of a person's life in the midst and in relational ways, attending to what is possible in understanding the temporal, social and place dimensions within an ongoing life. Attending to the multiplicity of what becomes visible in the unfolding life, the narrative inquirer attends to the particularities of each "bit" or shard in order to compose multiple story retellings or ways to move forward in imaginative and narratively coherent ways. (Downey and Clandinin, 2010, p. 391, cited by Clandinin, 2013, p. 48)

In this explanation, Clandinin emphasises the ongoing and relational nature of narrative inquiry. In her exemplars of research, Clandinin (2013) co-constructs field texts within an ongoing relationship with participants. She does this by creating draft narrative accounts using the field texts from early interviews and then considering them with participants during later interviews.

I did not adopt this aspect of Clandinin's method for the following reasons. Clandinin's work is predominantly educational research with a developmental focus and can be undertaken with students with whom ongoing relationships might naturally occur over the course of an academic term or year. The re-telling of stories over time as the participants learn and change may be integral to the research. In contrast, my research focused on an issue occurring somewhat unpredictably and spontaneously. Entering

the unfolding stories of participants in an ongoing way as they occurred was not feasible and so I was reliant on recalled stories. Others have similarly adapted Clandinin's methodology when using it to study healthcare. For example, Crowfoot, van der Riet and Maguire (2016) undertook single, retrospective, interviews to explore people's experience of transient ischaemic attack, since it was not feasible to be present during the experience. It would have been feasible to return to participants and explore if and how their stories of diminishing drinking changed over the course of their bereavement, but the research was focused on experiences during the dying of their relative, not during the subsequent bereavement.

My process of analysis was interpretive. I sought to think narratively about family members' experience of diminishing drinking with these stories. In this way I focused on what the stories conveyed to me personally. My own experience and persona were part of the interpretation through sensitising me to notice, choose and interpret stories in particular ways. Clandinin (2013) describes this as thinking relationally, drawing on the work of Morris to explain that thinking with stories is a process in which we allow stories to 'work on us' (Morris, 2002, p. 1996). It echoes thinking by other narrative researchers like Frank, who argues that stories 'animate' human life by working with, for and on people (Frank, 2010). In this research, participants' threads of diminishing drinking are not conceptualised as a proxy account of what happened to the deceased; rather, they are the perception of family members which is in itself an important aspect of their experience of diminishing drinking. I created three types of interim texts from the transcript of each participant in turn: narrative accounts, narrative threads and chronicles. Each are described below.

Narrative accounts. I started to analyse the field texts by creating narrative accounts. Clandinin (2013, p. 132) explains the terms ‘narrative accounts’ or ‘narrative accounting’ as, ‘A representation of the unfolding of lives of both participants and researchers, at least as they became visible and were shared’.

Clandinin emphasises staying close to the participants by considering their stories as a whole, rather than by analysing fragmented short phrases (Clandinin, 2013; Riessman, 2008; Bingley, 2020). Each interview was considered as a whole, by repeatedly reading the transcript and listening to the audio recordings. The stories of diminishing drinking occurred at several levels: the whole interview was a story but there were also mini stories nesting within it. I highlighted mini stories, then reflected on the stories in light of the research puzzle.

I considered how Clandinin’s notions of temporality, sociality and spatiality were evident within the stories by asking myself:

- How does this story unfold over time?
- How do the people within this story relate to each other and the wider stories in society about diminishing drinking?
- How does the environmental setting influence the story?

Once I was familiar with what was occurring within these boundaries, I asked myself:

- What is this participant conveying about their experience of diminishing drinking?

I made reflexive notes about the whole story within Atlas.ti. I then created narrative accounts using the words of participants by selecting sections of the transcript in which participants conveyed their experience of diminishing drinking, removing my utterances unless they were essential to the meaning of the interview, and presenting it as a continuous story. An example of these narratives accounts is presented in Box 1 below. The participants were not involved in the writing of the narrative accounts, nor did they review them.

Box 1: Example of a narrative account: Jane

This narrative account was derived from the interview with Jane. It is given below as an example.

So how this occurred was: it was a really hot summer. My husband was in the Himalayas climbing, and I'd booked three weeks in Spain learning Spanish. He was fine when I left him. I think what happened was that it was just so hot. Whether he was drinking enough, I don't know, but he started having difficulties breathing so he went around the next door neighbour's, it's that kind of area, they called an ambulance, and the ambulance came and took him into hospital,

He was very poorly when he went in, all of his SATS were down, um, and then he was starting to have difficulties swallowing, so, um, he wasn't really eating, and, he wasn't drinking. And then the Wednesday, he just didn't look very well at all, and I said to him, "Do you want me to give you a bed bath Dad? You don't have to get up yet" and he said, "OK". And so I got a lukewarm bowl of water and two flannels. It's a privilege to do something like that for somebody at that time of life because it gave me the chance to have bodily contact with my Dad and to talk to him and for him to talk to me. And we were just talking and I was, you know, bathing his hands and just chatting to him, and saying, "Your hands are like mine Dad" and he was talking about his mother, and how proud she would have been of us. And then he just stopped, and he looked at me, and he said, "Jane" and he rarely called me by my name, because, you know, you don't as a family, you just talk to each other, and I said, "What Dad?" and he said, "I don't want to do this anymore" and I said, "OK, I understand what you're saying Dad, but you can't ask me for permission, it's your choice. You know, you're my Dad and I love you very much and you know, I'm not in your situation, I don't know what it feels like, but you can't ask me for the permission Dad, you need to do what you need to do". So, from my point of view, I think he'd stopped eating and drinking because he'd had enough. For a lot of old people it's the *last* thing that they've got control over I think. And, I think he had just decided that he'd had enough, and that was it, and I think that a lot of old people are like that, in my opinion.

They phoned me and said, "He's very, very sick". I went up on the Monday, and I

spent the week there. He was actually improving by then; they'd put him back on antibiotics. They'd got him on a drip and he improved from the Monday to the Tuesday. He wasn't eating a lot. He would drink if we were there literally forcing him, saying, "Come on Dad, you need to drink that". You want the best for your parents and to actually see him refusing food and drink, was really quite traumatic, because all we kept saying to him was "If you don't eat and drink Dad, you won't get strong, and you won't be able to fight this bug that you've got, and the sooner that you do that, the sooner you can get out of the hospital environment", which is what he wanted to do and we wanted that as well.

He was on a dementia ward you see, that's the only place they could fit him in. Dad didn't have dementia, all of the other nurses were always laughing, saying how alert he was, and he was, but it must have been awful for him because there was nobody to talk to other than me when I arrived there or my sister at the weekends. All the other patients had got dementia so they were either asleep or wandering around not knowing what their name was, so I wanted to get him out of there. I said, "Well, the first thing you've got to do is help yourself, and you can only do that. Unless you're eating and drinking, they won't let you go".

My criticism of the hospital would be, they didn't monitor or encourage him to eat or drink. Whether that was because he was in a dementia ward and they were doing one-to-one care with the patients, and my Dad appeared to be getting better, but I mentioned on a number of occasions, that I really did feel that they should be monitoring how much fluid he was drinking, um, because otherwise he'd end up back on a drip again.

He was sipping water through a straw, but not a huge amount. Because they weren't monitoring it, I couldn't tell how much, and he would have three of those Tetra Paks open on the table, on the go at any one time. You can't see into them and I couldn't tell how much he'd drunk, so I'd be picking them up, and he'd go, "Oh no, no" and he'd also lie: "Oh, I've got through one of those already". So I'd ask the nurses, and they'd say, "Oh yeah, I think he has actually" but they wouldn't *know* for certain because he's in a dementia ward and they were on one-to-ones with these other people. If there's a God in heaven, just let Dad pass peacefully, because he seems to be having a battle, it's awful watching him not eat or drink.

My husband had just climbed, like I said, the Himalayas, and he said to me, "Jane, we've had oxygen deprivation up there" and he said, "You start to get distorted. You don't want to eat or drink either" he said, "You really have to consciously think to drink, and your Dad wouldn't have been doing that" he said, "It may have been a conscious decision to start off with, but then, you know, he was gently going downhill".

I looked after my Dad, I made sure that he had the best that he could have. Um, the one overriding memory is that Wednesday, when I gave him a bed bath and we were talking and I knew that he was asking my permission to let go, and I knew that he would do that, because he didn't want to live like that. I didn't want him to be uncomfortable, but I also didn't want him to be in a state where he'd lost his dignity

and I could just see this being a circular event, that they would release him from hospital, not eating and drinking, the infection would come back again, and then he would be back in hospital. He was frightened and I didn't want my Dad being frightened, struggling for breath, like he was when he went in there. He passed away peacefully, you know, dozing off. That's the best that I could have hoped for really.

Narrative threads. While working with narrative accounts, it became evident that many participants had responded to the invitation to share their story because they wanted to convey a particular point or points about their experience of diminishing drinking. For example, Irene prefaced her story about her husband being denied food and drink with 'this is why you are here'. In addition, other points took on importance as participants reflected on their experience of diminishing drinking during the interview. Either way, these points were identified through emphasis of language, tone, emotion and repetition both immediately and by returning to the point later in the interview. These modes of emphasis are termed 'cues' in communication literature (De Souza & Pettifer, 2013) and are familiar to me from nursing and teaching. The sections of the transcript within a single interview were titled with a phrase that best exemplified the point of significance selected from the participant's words. Where points of significance were repeated, developed or referred back to in different sections of the interview they were linked together using the hyperlink facility in Atlas.ti to become a narrative thread. An example of this is given below in Box 2.

Box 2: Example of a narrative thread: Brenda

Example of a narrative thread from Brenda titled: *'This consultant is being really honest'*

It's..., it's..., it's very strange this, [rustling of papers], the consultant on the Assessment Ward said..., [rustling of papers], and my brother didn't understand it really, what he said..., he said, he said, um..., [rustling of papers], I've written it down, 'Mum will feel unwell for four weeks, more like..., more than likely, with the..., with the shingles but we're uncertain about how she will come through this, at the present time'. Now, that was on the Assessment Ward. So my brother said, "I think he's trying to frighten us Brenda, [pause] I said, "He's probably just telling you, this is where they are". You know, this is a very weakening, debilitating... thing, and the age is there, and you have to respect it... But I don't think he really understood how ill she was... my brother... Yeah, he..., emotionally, he couldn't process that... I was way down the line, once..., [pause], um, once I knew that. I was thinking... That's when my thoughts changed, most definitely, because I thought... This consultant is being really honest.

Linked with:

Actually that day, the consultant had seen me, and said, "Brenda, you know, there's still, you know, two or three treatments that we can do, to keep your Mum comfortable, and when it's appropriate to do so" so she went, "there's under the skin", and, you know.

Linked with:

I'm so grateful [pause], to the hospital [pause], but especially to her doctor and consultant... Because they explained it so well... And they were positive all the way through, about what they were doing, and why they were doing..., and what did we think, and what would we be feeling, seeking our views, and explaining it further, but, staging it as well... um, so, that made the journey more gentle really, for us,

Linked with:

Um, but it..., everything was so in-line with what the doctor and the consultant had told me all the way along.

Chronicles. I also created chronicles from fragments of the field texts assembled chronologically in order to represent participants' stories of their relative's diminishing drinking over time. Clandinin and Connelly describe chronicles as 'the sequence of events in and around a particular topic or narrative thread of interest' (2000, p. 122). One chronicle is presented in the thesis: that of Colin.

5.5.3 Final texts

I am using 'final texts' here to denote the report of findings, distinguishing it from the working analysis of 'field texts'. Clandinin and co-authors, and those researchers who have used Clandinin's methods for their own studies, adopt a variety of mechanisms to present findings, sometimes presenting the whole narrative accounts of a small number of participants (Haydon & van der Riet, 2014). I have chosen to analyse and present findings which resonated across the participants as a group in order to show the range of narratives. I created these texts through the following process.

Firstly, the narrative threads and chronicles identified within each interview transcript were sorted into the three strands or categories within the scope of the research puzzle. These strands were a priori so, in the main, differ to the narratives identified in the literature review, albeit that strand A and narrative A largely concur.

Strand A: Experiences of the diminishing drinking of dying relatives

Strand B: Responses to diminishing drinking

Strand C: Experiences of healthcare and support

Secondly, 'resonant threads' were identified within each strand. Clandinin (2013) uses the concept of 'borderlands' to look across narrative threads and identify which threads resonate in some way. She defines the borderlands as spaces where there is 'the possibility for multiplicity of experience' (Clandinin, 2013, p. 137) and there is a need to see these experiences in relation to each other. This is not the same as identifying commonalities and clustering them as themes as in narrative thematic

analysis (Bingley, 2020); rather, it is a process of exploring relations between the experiences of participants. These strands and the resonant threads within them are presented in Chapter 6 and are illustrated with a chronicle and excerpts from the transcripts. My presence within the interview is included in excerpts when it is integral to the participant's story. My minimal prompts and utterances that serve simply to show interest and encourage the participant have been removed to avoid disrupting the flow.

5.6 Rigour in Narrative Research

Notions of validity, generalisability and reliability are traditional criteria for judging the rigour of research (Mason, 2018), although their applicability to qualitative research is much debated (Seale, 1999; Bowling, 2014; Bryman, 2012). Some qualitative researchers have developed alternative schema, which they argue are more suited to judging research whose premise is broader than a notion of a single, absolute, truth regardless of context (Bryman, 2012). For example, Guba and Lincoln (1995) propose criterion based on hallmarks of trustworthiness and authenticity, which can be seen as a reinterpretation of validity, generalisability and reliability more suited to qualitative research (Bryman, 2012). Mason (2018, p. 236) contends that these broad concepts are useful for qualitative research since they are to do with ensuring and demonstrating to others that the research is 'appropriate... thorough, careful, honest and accurate', rendering their arguments convincing. She suggests that validity, generalisability and reliability can be applied to qualitative research if they are interpreted conceptually, rather than technically, and in the light of the epistemology guiding the research.

Validity is the notion that something is as accurate as it claims to be. Mason (2018) describes it in ways that closely parallel internal validity in qualitative research: 'judgements about whether you are 'measuring' or explaining what you claim (p. 236). In order to consider this, she recommends first reflecting on the quality of the chosen methods in relation to the aim of the research and how effective they have been in generating authentic data. Second, she recommends reflecting on the quality of interpretation of the data, its justification and transparency.

The choice of narrative inquiry has been advantageous because it is well suited to exploration of ill-defined experience (Clandinin, 2013). The recruitment being open to any family members who had experienced diminishing drinking offers some confidence that the data genuinely reflects the experience of those who wished to share their story, rather than those who may have been selected by recruiters. My intention in choosing narrative interviewing was to foster an environment in which participants could share their stories with me candidly and I might hear them authentically. Narrative inquiry has engendered interpretative data analysis in which I have attributed meaning to these stories. The authenticity of my interpretation can, arguably, be justified by my in-depth engagement with them in the light of knowledge of wider literature and my own stories about diminishing drinking; a process Clandinin terms 'thinking narratively' (2013). I have sought to interpret the stories authentically, seeking to convey what the participants wished to share and to be transparent about the process of interpretation.

Generalisability, or external validity, is the extent to which wider claims about a topic can be made beyond what is evident from the particular inquiry undertaken. Narrative inquiry, like much of qualitative research, is situational and unique to its context; therefore, its findings are not empirically generalisable to the general population (Riessman, 2008) although they may be generalisable to theory (Bryman, 2012; Mason, 2018). Furthermore, the findings are not intended as a definitive statement that is reliable in the sense of being replicable and consistent over time and in other contexts. Instead, the aim within this research is to generate insight into the research puzzle. This insight may be generalisable and provide a basis for further exploration. (Mason, 2008; Riessman, 2008; Elliott, 2005).

5.7 Ethical Considerations

The nature of healthcare research with and about people means that it will have an impact on both participants and the researcher (Elliott, 2005; Clandinin, 2013) so the study was designed to identify the impact and mitigate any negative consequences. Family members might have found it burdensome to be approached to participate in research shortly after bereavement. Feedback about this was sought from a lay research advisory group who felt that that approaching newly bereaved family members was reasonable but suggested that the invitation letter should be as brief as possible to minimise this burden and enable those who did not wish to consider participating in the study to dismiss it quickly and without reading the participant information sheet. The recruitment process was designed so that I had no direct contact with participants without their consent.

Once recruited, participants may have found talking about their experiences of witnessing the diminishing drinking of a dying relative upsetting. This may be the case particularly in narrative interviewing since it involves sharing stories of a person's inner emotional experience (Clandinin, 2013; Elliott, 2005). However, such distress is not inevitably harmful, it may be cathartic and valued (Crowther & Lloyd-Williams, 2012; Butler, Hall & Copnell, 2017). As an experienced palliative care nurse, I felt confident to listen sensitively to upsetting experiences concerning dying and bereavement and be able to recognise this and mitigate distress should it become overwhelming or harmful. I developed a distress protocol to clarify and assist in this (Draucker, Martsolf & Poole, 2009) (Appendix 9).

Engaging with stories about dying may have been distressing to me as a researcher. As an experienced palliative care nurse, I felt prepared to do this. I was also supported by a skilled supervisory team and had access to confidential counselling and support services in the universities in which I studied and worked.

Although the study was designed to minimise and address risks as far as possible, it was not possible to prevent them entirely. Therefore, they were highlighted in the participant information sheet (Appendix 4) and in discussions with prospective participants in order to ensure they were fully informed prior to consenting to take part. Bereavement research has been recognised as sensitive since it is potentially intrusive, personal and emotional (Sque, Walker & Long-Sutehall, 2014). While this study was not about bereavement per se, it was closely related to it. There is debate surrounding whether bereaved people should be protected from potentially

distressing research or included in the opportunity to shape future care through research, but evidence suggests given full information, newly bereaved people are willing to balance the risk of distress and the potential value of participating themselves (Crowther & Lloyd-Williams, 2012).

The proposal for this research was scrutinised and approved by North West Greater Manchester research ethics committee (Appendix 2). An amendment to the approval was granted when it was found necessary to allow research information packs to be included in the bereavement folder given to every bereaved family member.

5.8 Summary

Chapter 5 has described the research design including the recruitment process and method of analysis. It has also explained how I used and adapted Clandinin's (2013) narrative inquiry to guide the method. The chapter appraised the rigour of the research and described how ethical considerations were addressed. The findings will be presented in the next chapter.

Chapter 6: Findings

The research findings are presented in this chapter. It starts with a description of the results of the recruitment process and describes key details of the participants and their deceased relatives as the participants described them. The findings are presented with illustrative excerpts and short quotations. Although each excerpt is presented discretely, they are frequently intertwined within and across stories, and so some could illustrate more than one resonant thread.

6.1 Recruitment

Over 1,000 information packs were distributed to bereaved people. 14 people responded, which is around 1.4 % (Pettifer et al., 2020). Thirteen of these were recruited and one was excluded since they lived outside the recruitment area.

6.1.1 The participants

The selected characteristics of the participating family members together with key features they offered about their deceased relatives are compiled in Table 6. Most participants described themselves in terms of their occupation; some also told me their religion and cultural heritage. They described their relatives in terms of their age, former occupation, and illness.

The participants are not representative in any statistical sense of family members of those who have died in hospital. However, the age, diagnosis and reasons for admission of their relatives are in common with many people who die in the UK (Office

for National Statistics, 2020), and both participants and their deceased relatives have a range of occupations and cultural backgrounds.

Table 9: Key characteristics of participants and key features they offered about their deceased relatives

Participants			Deceased relatives				
Pseudonym	Description	Relationship to deceased	Age	Occupation and religion	Illness	Cause and length of admission	Specialist care
1 Mark	Lawyer	Son	69	Retired school support worker,	Lung cancer, pneumonia	'Recalled' to oncology, 2 weeks	None
2 Jane	Wife	Daughter	88	Company director	Heart failure, suspected renal cancer	Chest infection, 5 days	None
3 Colin	Newly retired	Son-in-law	95	Widower	Dementia, stroke	Chest infection, 2-3 weeks	Speech and language therapy, dementia specialist
4 Irene	Wife, Christian	Wife	90	Ex-military, Catholic	Chronic obstructive pulmonary disease,	Pneumonia, 7 days	Speech and language therapy
5 Ajinder	Former police-woman, carer, Sikh	Daughter	90	Carpenter and joiner, Sikh	Dementia, epilepsy	Constipation, developed pneumonia, 'weeks'	Speech and language therapy
6 Derek	Retired implant designer	Husband	67	Wife	Motor neurone disease	Breathing difficulties, a week	Community palliative care, speech and language therapy

7 Susan	Civil servant, Christian (not practising)	Daughter	93	Retired publican	Chronic obstructive pulmonary disease,	Fall at home, chest infection, 12 days	None
8 Frank	Retired chef	Son	96	Wife	Dementia	Deterioration, 6 weeks	None
9 Brenda	Educationalist, Catholic	Daughter	97	Nurse, Catholic	Shingles	Collapse, 2 weeks	None
10 Rhoda	Former nursing assistant	Daughter	86	School cook, cleaner	Leukaemia, rheumatoid arthritis	Deranged bloods, around 2 weeks	Palliative day care
11 Bernard	Teacher	Husband	70s	Teacher	Lung cancer	'To be built up', 11 days	Palliative care
12 Martina	Teacher, Catholic, from South America	Daughter	91	Wife, Catholic, South American,	Osteoarthritis,	Fall, developed pneumonia, 2-3 weeks	None
13 Estelle	Teacher, photographer, French	Friend					

The participants comprised four men and nine women and were family members of 12 deceased people. Two women were associated with one deceased person since one was her daughter and the other was a family friend who had shared the caring. These two participants were interviewed separately and, in line with the methodology, the field texts were analysed as distinct but related experiences. All participants have been given a pseudonym for this project. As shown in Figure 11, three participants were spouses of their deceased relative, eight were adult children, one was a son-in-law and one was a friend of the deceased.

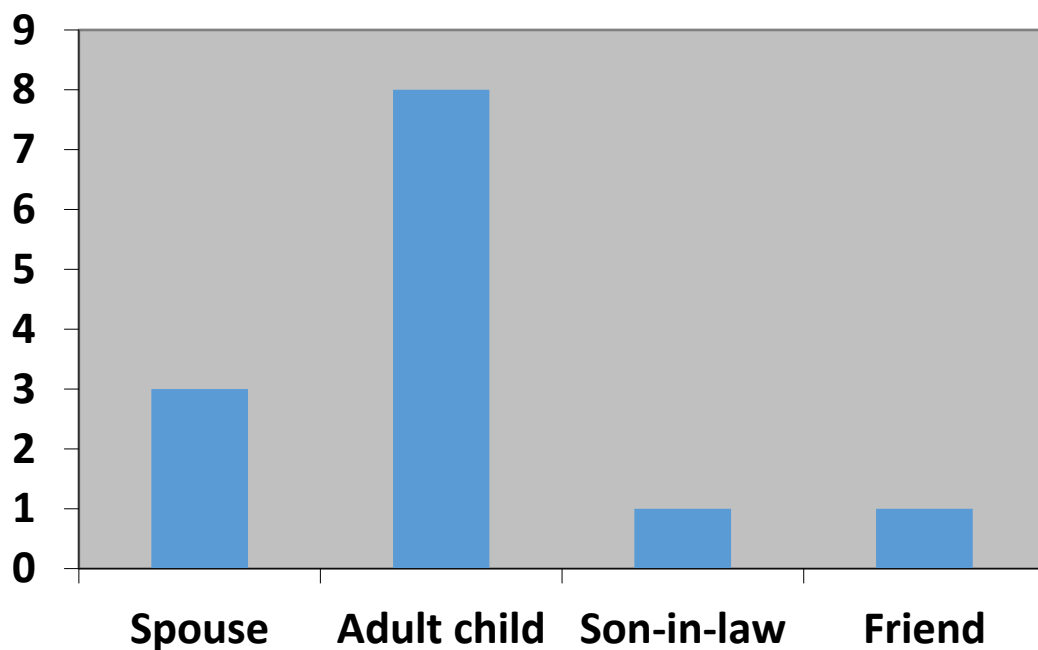


Figure 11: Relationship of participating family members to their deceased relative

Short vignettes of each of the participants are given below in Box 3:

Box 3: Vignettes of participants

Vignettes of participants

Mark was interviewed first. The interview took place in a meeting room round the corner from his office during Mark's lunch hour. Mark grew up with his parents and elder brother in the north of the city. Mark seemed to be a natural storyteller, who gave a lengthy account of the death of his brother at the age of eight and its impact on his family relationships. When his mother was diagnosed with lung cancer, Mark took an analytical approach to monitoring her drinking. He noticed how initially she built relationships with healthcare assistants and hospital 'hostesses' over food and drink ensuring they looked after her well, but her drinking declined as her condition deteriorated. He described how his father was affected by the loss of his habitual tea making for his wife.

Jane was the elder daughter in the family. She grew up in a small, tight-knit community where her widowed father had lived all of his life. Now married and living on the south coast, she travelled back to stay with her father during weekdays while his health was declining. Her sister, who worked during the week, supported their father at the weekend. Jane wanted to convey her experience that people stop drinking because they '*have had enough*' i.e. they do not wish to continue living and see stopping drinking as a means to exert control over the process of dying. She describes being torn between encouraging her father to drink to get strong enough to leave hospital and not wanting him to prolong a period of poor quality of life.

Colin and his wife had cared for Colin's mother-in-law and father-in-law when they moved close by some six years earlier, often visiting on a daily basis. Initially, Colin's mother-in-law was their main concern but when she died the needs of his father-in-law became apparent. In his account, Colin tracked his father-in-law's diminishing drinking over '*about a year*': something which he found difficult to watch. The telling of this process of '*going down to nothing*' was the central thread of his account. He peppered this thread with stories of events which occurred along the way often linking them to the effects of his father-in-law's dementia on his taste, memory, appetite and sensitivity to heat.

Irene is a widow, living alone in a terraced house on the outskirts of a city. Her husband's mobility had been decreasing over some years. Irene cared for him as long as she could but three years earlier he had moved to a nursing home for former military personnel. Irene had found the enforced parting very sad, but felt he was well cared for and they enjoyed trips out together when they could. His ability to swallow also declined and he frequently struggled with choking and aspirating. Irene's husband was reluctantly admitted to hospital with pneumonia about a week before he died where he was designated '*nil by mouth*' due to his risk of aspiration. Irene shares her experience of this in her interview.

Ajinder is the younger daughter in a devout Sikh family living together in a large Victorian family home in the city. Her interview took place in the living room of this home, which was adorned with Sikh iconography, and Ajinder was proud to show me the decorative woodwork on the doors which her father had made. Her mother

came in and slept quietly on the sofa at one point. Ajinder had been in the local police force but had given up work to care for her elderly parents. Her father died in hospital at the age of 90 following a lengthy illness of dementia and epilepsy.

Derek married his wife some 50 years ago and had lived in the same house most of that time. They had two daughters, one of which lived locally. They had been substantial carers of their grandchildren now aged 11 and 9. The interview took place in their home, a few weeks after her death from motor neurone disease, aged 67. Derek gave a chronological account of her nine-month illness, her deteriorating drinking and the care he gave, mostly at their home. His wife was under Marie Curie home care. Her illness started with speech difficulties. The diagnosis was difficult, but his wife had a strong sense of living for today, which he attributed to her family background. Derek was positive about being her carer, describing it as 'a blessing' in his retirement, particularly since his grandchildren were now less needy. Derek continued this attentive care when his wife was admitted to hospital with breathing difficulties; checking when fluids ran out, spooning water and regularly cleaning his wife's teeth with a damp toothbrush. He noticed that she was sucking on the toothbrush so continued to offer this regularly. He felt that he was intuitively doing what his wife wanted and '*doing the right thing*'. He believed this understanding came from their long marriage and the lengthy period of caring. Derek was aware that his wife was dying.

Susan is a civil servant, married with adult children and stepchildren. The interview took place in the dining room of her small flat. She had cared for her mother, a retired publican who lived '*a couple of miles down the road*', by regularly shopping and taking her prepared meals. When her mother was admitted to hospital, Susan visited regularly. She took the view that it was not for her to question her mother's dwindling desire to drink. She recognised that this would lead to her mother's death but accepted this.

Frank was married and a newly retired chef. I interviewed him in his home. In the main, Frank talked of his mother's dying; however, he also told stories about the death of his father which had occurred in another hospital three days before his mother's death. Following a short, unsuccessful discharge to a nursing home, Frank's mother was re-admitted to hospital with a chest infection and treated with antibiotics and intravenous fluids. Frank discovered that she had been diagnosed with dementia some months earlier by looking in the hospital notes. He reflected on whether it was right to want his mother to live for himself, or better for her to allow her to die. Drinking and liquids were key to his dilemma.

Brenda was interviewed in her semi-rural home on the outskirts of a market town. She told a story of how she encouraged her mother to drink and reflected on the value of fluids for wakefulness, the kidneys and '*everything*', which exposed her positive beliefs about drinking. Brenda is semi-retired retaining her interest and involvement in health and vulnerable young people not in school. Brenda is the eldest of three children, one of whom lives more locally to her mother than her, but Brenda portrayed herself as the sibling who was the most proactive carer: visiting her mother in hospital most days, being most aware that her mother was dying and wanting to make this process as comfortable as possible.

Rhoda was married with two adult children living locally and living in a large Victorian house. Rhoda had worked as a healthcare assistant. Rhoda's mother, a school cook, had lived some 10 miles from her. She had been diagnosed with leukaemia for the six years prior to her death at the age of 86 and was admitted to hospital from the oncology day centre because of deranged bloods. Rhoda was aware her mother was dying and had hoped she could go to the local hospice, but unfortunately this had not been possible as she had deteriorated in hospital.

Bernard, recently widowed, was living alone in a small, terraced house. He was a keen gardener and was keen to show me his colourful annuals before the interview. He and his wife had two adult daughters and several grandchildren. Bernard's wife complained of a hoarse voice and then taste changes. She died in hospital shortly after being diagnosed with cancer of the lung while waiting for a biopsy to ascertain the histology. Bernard visited frequently.

Martina was the only child of wealthy South American parents. She came to the UK to study, training as a language teacher, and settled. Her widowed mother moved to the UK when she needed care and lived in a flat opposite Martina and her friend Estelle. Martina visited her mother when she was admitted to hospital following a fall where she noticed her diminishing drinking. When Martina stopped visiting due to her own illness, Estelle took over.

Estelle was French and taught languages in schools. She and Martina were close friends of over 20 years, and shared Martina's maisonette. Estelle had visited Martina's mother in South America. When Martina's mother moved to the UK she lived almost opposite so Estelle got to know her better, visiting regularly particularly when Martina was unable to do so because she was unwell. I interviewed Estelle in Martina's mother's flat, directly after interviewing Martina. Estelle was an amateur photographer and had taken photographs of Martina's mother; she showed these to me and drew on them during the interview.

6.1.2 The relatives

Participants described their deceased relatives by their diagnoses, age, former occupation, religion and cultural background, and personal qualities. Ages ranged from 57 to 95 years and they came from a variety of occupational backgrounds. Four participants described the religion of their relatives: one being Sikh and three being Catholic. They had had a range of long-term illnesses and co-morbidity: motor neurone disease, chronic obstructive airways disease, heart failure, stroke, dementia and cancers; and one shorter-term illness which was shingles. Most were admitted to

hospital due to acute infections although two had fallen or collapsed, one had constipation and one was recalled due to poor blood counts. In the view of the participants, none was admitted intentionally for terminal care. They were cared for in generalist care hospital settings. Three were also supported by specialist palliative care nurses either in or beyond the hospital setting. Three were under the care of speech and language therapists. Their reported length of stay in hospital from admission to death ranged from five days to 'several weeks'.

6.1.3 The interviews

All participants gave their consent prior to the interview and there were no subsequent withdrawals. All interviews took place in the home of the participant, except for one that took place in a church meeting room. Several participants showed me photographs and other artefacts of their family including photographs of the deceased relatives. Irene gave me a notebook containing written reflections on her experience which she wanted to be included in the research, so it was treated as a field text along with her interview transcript. Most interviews took between an hour and an hour and a half although two, those with Bernard and Estelle, were under an hour. The interviews took place between three and 24 weeks after the death had occurred. Several participants became emotionally upset during the interview but wanted to continue. Irene and Susan told me they found the interview cathartic.

6.2 Strands

The research findings are presented below within the three strands. Table 10 names the strands and depicts the resonant and selected narrative threads presented to illustrate each strand.

Table 10: Table of strands, resonant threads and narrative threads

Strands	Resonant threads	Selected, illustrative narrative threads and chronicles
Strand A: Experiences of diminishing drinking	Thread 1: The nature of diminishing drinking	Colin's chronicle: <i>Going down to nothing</i> Colin: <i>a narrowing down</i>
	Thread 2: Beliefs about drinking and drinks, not drinking and being dehydrated	Brenda: <i>This will help you</i> Colin: <i>Dehydration is a horrible thing</i> Colin: <i>Fluid is a building block of life</i>
	Thread 3: Consequences	Mark: <i>She wanted, she needed the water</i>
Strand B: Responses to diminishing drinking	Thread 1: Monitoring and interpreting	Colin: <i>That sort of funnel shape</i> Mark: <i>I was checking</i> Brenda: <i>Is she drinking?</i> Estelle: <i>A big change</i>
	Thread 2: Promoting	Ajinder: <i>Making sure that it happened</i> Ajinder: <i>Get a PEG feeding tube</i> Ajinder: <i>Get that done for Dad</i>
	Thread 3: Accepting	Susan: <i>Fair enough</i> Susan: <i>I don't see it as sad</i> Martina: <i>In one way she wanted to go</i>

		<p>Jane: <i>Doing it to make me happy</i></p> <p>Jane: <i>I didn't want him... hooked up to tubes</i></p> <p>Jane: <i>I don't want to do this anymore</i></p> <p>Jane: <i>Getting what he wanted</i></p>
	Thread 4: Comforting	<p>Derek: <i>it kept her mouth moist</i></p> <p>Rhoda: <i>at least I can do something</i></p>
Strand C: Experiences of healthcare and support	1. Professional healthcare	<p>Brenda: <i>trying different ways</i></p> <p>Martina: <i>the nurses can't do that because there is another one who is falling</i></p> <p>Jane: <i>they weren't monitoring it</i></p> <p>Brenda: <i>I always went at lunchtimes...it would help the staff</i></p> <p>Mark: <i>a disconnect</i></p>
	2. Risk of aspiration	<p>Colin: <i>There was a risk in it</i></p> <p>Frank: <i>It just wasn't going down</i></p> <p>Frank: <i>I like this</i></p>
	3. Clinically assisted hydration (CAH)	<p>Frank: <i>When she was on the drip she was a lot better</i></p> <p>Rhoda: <i>The state of her arms</i></p>
	4. Professional support	<p>Bernard: <i>The nurses gave us... gauze</i></p> <p>Frank: <i>It's what needed to be said</i></p> <p>Mark: <i>Nobody would say</i></p> <p>Colin: <i>They (family) can connect</i></p>
	5. Tension and conundrum	<p>Rhoda: <i>Really, at this point in her... journey?</i></p> <p>Ajinder: <i>Dad's not at end of life</i></p> <p>Irene: <i>Why put him through all that agony?</i></p> <p>Irene: <i>she didn't know my husband I knew my husband</i></p> <p>Irene: <i>I'm upset</i></p> <p>Rhoda: <i>That's what they think we want to hear</i></p>

6.2.1 Strand A: Experiences of diminishing drinking

The resonant threads concerned with the experience of diminishing drinking as perceived by participants is presented in strand A below.

Strand A Thread 1: The nature of diminishing drinking. I started each interview by asking the participants when they first noticed a change in the drinking of their family members. In response, all described how their dying relative's drinking diminished gradually within a context of general deterioration culminating in death. The length of this process varied. For some it was over months and years prior to death, for others it was much less. Participants linked the process to other problems associated with the deceased's diagnosis such as forgetfulness caused by dementia and narrowing of the oesophagus caused by advancing lung cancer. The decline was usually punctuated with memorable events in which drinking habits changed. Some participants cited changes to long-established and treasured habits, including drinking wine before bed (Martina) and drinking a preponderance of tea (Mark), as significant staging posts in their relative's decline. The chronology of Colin's experience was particularly illustrative of the process of diminishing drinking.

Chronicle from Colin: 'going down to nothing'

ME: So when did you notice that his drinking was changing?

COLIN: *That goes back probably about a year now. It started with..., he was spitting out bits of food but he was drinking quite well.*

His sense of taste changed massively. I don't know if that was through his medication or the Alzheimer's effect. He'd be a bit selective about when he'd drink and when he wouldn't, but the carers used to encourage him to take sips. They'd (visiting carers) make him a drink, and he would just forget about it. They would just come in and do the lunch, leave him a cup of tea, and then go back, and then we would come in later and it hadn't been touched... He would not remember to drink.

Probably three months ago, his appetite for drinking changed. It turned out it was a throat or a mouth infection, so it was probably proving difficult for him to drink and was painful. They cleared it up, but he never recovered his appetite to drink. He became more sensitive to, um, to the heat of a substance as well. He was in hospital for two or three weeks [before he died], and in that time his eating and drinking went down to nothing.

You know, it's quite disturbing to observe. By the time he died, he probably hadn't had a..., a proper drink for a month. I don't think anyone could have done anything more than they did, and it was part of the decline that had started way back with spitting out bits of his food.

In recounting an ongoing process of decline, Colin situates diminishing drinking as occurring across time, in several places and involving several groups of people who were caring for his father-in-law. While there were memorable markers in this process, diminishing drinking was not a discrete phenomenon occurring within the last few days of life but one aspect of a process of general deterioration occurring gradually over several months.

Colin, like most other participants, linked diminishing drinking with diminishing eating, viewing the former as a latter part of the decline rather than a separate issue. The following excerpt illustrates this connection.

Colin: 'a narrowing down'

So the swallowing and the, um, you know, those..., what you call those intake appetite issues. They go back quite a while... um, and so it only affected his..., his, um, his liquid intake, um, much later down the line. But it was that... So there was a narrowing down of what we could feed him.

Strand A Thread 2. Beliefs about drinking and drinks, not drinking and being dehydrated. The second resonate thread concerned with the nature of diminishing drinking was beliefs about drinking, drinks, not drinking and dehydration in the body. I have used the term 'drink' to mean a liquid drunk by mouth and 'fluids' to mean liquids given through intravenous or subcutaneous routes. However, some participants used 'fluids' to mean liquids consumed via any route, and their words have not been altered. For all participants, drinking and drinks were strongly associated with either quality or quantity of life, or both. Drinks were enjoyable and drinking was a social activity. The belief that drinking and drinks had a positive impact on health and wellbeing was predominant. They positively impacted on strength, level of alertness, ability to recover and skin integrity, and as a consequence, on the likelihood of discharge home from hospital. The preparing and giving of drinks was

seen as a caring, loving activity that is fundamental to human relationships. Drinks and the giving of drinks was associated with giving and receiving comfort while dying.

Participants talked fondly of drinks their relatives particularly enjoyed, often with others. Irene's story included her husband's enjoyment of both cappuccino coffee and occasionally lager: He *'liked a cappuccino... And sometimes he had a lager, not all the time, but he had a lager'*. Mark's parents were avid tea drinkers: *'Her drink of choice is tea... and would drink gallons of tea...It's just that generation'*.

Drinking was more than simply pleasurable: it was also relational and social. Brenda especially wanted to be with her mother at mealtimes to encourage her mother with eating and drinking and also felt that it was good for her mother.

Brenda: 'This will help you'

BRENDA: I..., I tell her to drink, and she drinks. It's how you do it, isn't it...? You've got to have a way, "This will help you Mum". That's how I do it, I always say, "This will help you Mum....Keep going, if you drink that, then I'll drink this" [chuckles]. And we chat in between, do you know what I mean? We make it not... "You've got to drink"; if you..., my Mum is a sort of person, if you tell her, "You've got to do this" she won't, she'll only do it if she decides that she's going to do it, you've got to know her inside out and upside down... And she's very good at putting you off, [chuckles] so I always say, "This is gonna help you Mum, it will help me as well". So, I will drink... And we have a drink.

ME: How did you think it would help her?

BRENDA: *I..., I was... I thought she would be less sleepy, I just thought..., [pause] I just thought she was dehydrated, if she hadn't had much to drink for the whole 24 hours... Before I was there, I was..., I was assuming, that she was going to be dehydrated, and..., and I'd seen that pinch..., a piece of research about the pinch?*

ME: Right, where you can tell how the...? Where you can tell how dehydrated someone is?

BRENDA: *Yeah, I just had a little go at that [pinches skin], with the... without her even knowing it... And I..., I just, I suppose in my heart of hearts, I thought, you can't go all that time and not be drinking. It just..., you know, my mum needs fluids... To be going through her system, it's good for her kidneys, it's good for everything.*

This excerpt also shows both what Brenda believes about drinking and how these beliefs influence her action. Brenda draws on her enduring knowledge of her mother and their relationship to encourage her to drink because she believes the liquids will enhance her health. This belief is rooted in her professional knowledge of health.

In addition to stories about the positives of drinking, participants also told stories which expressed belief that not drinking and consequently being dehydrated was detrimental to health. It would be uncomfortable, painful and would hasten death. Colin put this most poignantly in the excerpt below:

Colin: 'Dehydration is a horrible thing'

COLIN: *The hydration, um, dehydration is a horrible, horrible thing... So, he'd want them..., you..., you'd want their hydration levels raised... And that's just part of human comfort, isn't it, um, I'd hate to see someone pass away through, um, [pause] the pain of a dehydration issue.*

ME: OK. So, dehydration..., dehydration is painful do you think?

COLIN: *From what I've ever seen or...That..., well I've got no first-hand experience... um, but I would expect it to be, you know, I know that whenever I've been thirsty, it..., it's been very..., you know, it..., it's quite uncomfortable.*

Colin returned to his beliefs about the importance of fluids later in the interview:

Collin: 'Fluid is a building block of life'

COLIN: *Sorry, I just..., actually, going on back..., I think also, it's probably something that's pre-programmed in us, that, you know, um, access to..., to fluids is a building block of life...Um, so it's just a pre-programmed thing... So, if someone is thirsty, you give them...*

ME: You give them a drink.

COLIN: *A drink, yeah.*

In describing fluids as '*a building block of life*', Colin alludes to beliefs that fluids are foundational and essential to life so supporting others with drinking is imperative.

Indeed other participants including Susan alluded to this in different ways, with the predominant belief being that dehydration caused or signals death. Mark links not

drinking to deterioration: *'So then she'd then been thirsty, but hadn't then drunk it, because it had, it had gone warm. And then she deteriorated quite sharply after that'.*

Strand A Thread 3. Consequences. The participants' stories have resonant threads about the effects of not drinking and being dehydrated as a result: predominantly they believed that the patients would be thirsty but also that they would have dry or sore mouths. Many participants recalled their dying relatives telling them that they were thirsty. Others deduced it from observing other effects of dry mouths and tongues or actions such as sucking on moist mouth swabs, or they simply inferred that relatives were thirsty because they had not drunk recently. Others related it to the warm hospital environment and to the particularly hot summer.

Mark told a story that illustrates how the actions of his mother made him realise she was thirsty.

Mark: *'she wanted, she needed the water'*

I took her mask off, because I knew that the oxygen that she was on was making her very dry... Because you could see, her teeth. Um, it was..., um, they wasn't black, but it..., the pure oxygen... Yeah, very much so. So, I was trying to think, well, she needs something to drink, um, and she wasn't conscious, so when we took the mask off, within 20, 30 seconds, she couldn't breathe, and obviously that was what was keeping her alive at that..., you know, it was so close to any..., 36 hours before she died, so it was like, that's... So I..., I..., I gave her a sip of water, and it made her cough... So I put the water up to her mouth,

and she..., she obviously took a bit of it, I could see her physical reaction was, she wanted..., she needed the water, and you could see... Her tongue come out... And then she just coughed, and obviously it must have caught her..., she was like..., and she..., I winced for her. So..., so I put the mask back on, um, and it was like physically there for..., she was having great difficulty with that, and she must be dehydrated, so, I know, I know that she's very near the end, that..., but I didn't tell my dad that.

His mother's thirst was important for Mark: *'that was a big concern for me, that's why I tried to give her some water... Because I was worried that she was thirsty'.*

In summary, the participants' stories described diminishing drinking as a process of declining intake, which usually started with declining eating and continued to drinking by degrees. Diminishing eating and drinking were not always distinct. Family members recalled particular events along this trajectory such as changes in eating and drinking habits. They viewed diminishing drinking as part of their relative's overall decline and not specifically the last few days of life. Drinking and drinks were valued as positive for physical health and family relationships. Conversely, not drinking and being dehydrated was associated with discomfort. It was perceived as a cause of decline and an effect of illness.

6.2.2 Strand B: Responses to diminishing drinking

This section on Strand B presents and discusses the resonant threads concerned with the response of participants to the diminishing drinking of their relatives. All of the

participants monitored the diminishing drinking of their relatives and told stories of their own response. These stories contain complex, interwoven and shifting narrative threads with each participant offering a unique perspective. They promoted drinking through a combination of practical, verbal and attitudinal means: sourcing favourite drinks, acquiring adapted cups, straws and beakers, supporting with holding and tipping vessels, giving water from soaked gauze or sponge, moistening and cleaning mouths and/or asking healthcare staff for drinks for their relative. Some participants also intentionally accepted diminishing or ceasing drinking at times and some actively sought and engaged in comfort orientated care.

The participants explored their reasons for their actions in the interviews; seeming to re-live and re-tell the stories by looking backwards at events with new insight gained since the death occurred. Each participant's motivations and reasoning was influenced by their perceptions of their relative's experience of diminishing drinking and its consequences, the approach of the deceased towards both their drinking and their death, the participants' enduring relationship with their dying relatives and their previous experiences and attitudes towards dying. Understanding the experiences of diminishing drinking of dying persons is beyond the scope of this research, but family members' perceptions of it are pivotal to their own experience.

Strand B Thread 1. Monitoring and interpreting. Participants monitored their relative's diminishing drinking both before and during their final hospital admission. Often this was by noticing changes to long-established habits, but also by noticing clinical records and the availability of drinks within the hospital environment. For

some, monitoring happened inadvertently; they simply noticed what was happening but for most it was intentional proactive observation that was recorded in some form, be it physically or mindfully. Whether the monitoring was active or inadvertent, participants usually interpreted the diminishing drinking as a signal of decline. Colin explained how he noticed the changes occurring at home through the online shopping order he did for his father.

Colin: 'that sort of funnel shape'

Well, um, I..., I mean, I do the um, the on-line shopping ordering... And um, so I..., there was probably five or six..., probably six varieties... Of these little pots that we'd get in for..., um, and his memory was so..., you could have got him just one thing, um, and he wouldn't remember day-on-day... That that's what he'd had... But we gave him a variety of stuff... And, you know, I can remember sort of starting with a sort of a six..., you know, a rotation of six different things, and then it sort of went down, and that's..., that's why I'm doing this...Um, because it's sort of... It was the..., it was the following it down... So um... In the end, there were only two different types that he'd..., he'd eat... Um, and after that, it was..., it was Fortisip... and that, you know, that was sort of..., [sighs] when I said the last couple of months were particularly stressful... um, and painful for him, um, that's about the time that he was on the Fortisip, and it's, you know, and then it became about liquid intake, and... and um, he..., he only took the Fortisip for quite a small time, and his..., his appetite for that was always..., always, willingness, or ability to..., to take that diminished, and, you know, again, in that sort of funnel shape.

While telling this story, Colin made a funnel shape with his hands visually shaping what he noticed happening. His words: *'his appetite for that or his willingness or his ability to take that'* illustrates how Colin's mind held multiple possibilities as to the cause of diminishing drinking.

Mark was more actively monitoring his mother's fluid intake while visiting in hospital. He was checking what his mother was drinking, checking it was recorded and drawing conclusions from it. He explained this in the excerpt below:

Mark: 'I was checking'

What was interesting was, then there were the notes, the clinical notes, and I..., and I was checking... and every time that they'd made her a cup of tea, they'd obviously noted it down, and so I was checking how much she was drinking, because it's part..., I'm analytical, and it's part of my job... and I was making sure... That's why I was keeping on top of it. I don't think they were noting how many jugs of water she was having, there was always one there... Um, but on one of the particular hot days, I..., I remember she was saying, "The water's gone warm, can you ask them to give me some more cold water?" Which suggested to me, she'd asked for it, she'd not drunk it, it had gone..., brought to room temperature... So when she did want to drink..., so, how long does water take...? So then she'd then been thirsty, but hadn't then drunk it, because it had, um... it had gone warm, and she'd probably had a cup of tea in the interim.

Mark's story raises factors which relate to the environment, in that it was a particularly hot summer. There were issues in the hospital environment about the desirability and availability of drinks and whether drinking was effectively monitored and recorded. Later in the interview he explained how he interpreted his findings: *'I'm trained to be analytical, so I was looking for clues, and..., and..., and that's what..., I knew what was coming, because of that, said to me, that that was one of the markers straightaway, it was, yeah, once that stops, her body's going to stop, just shutting down basically'*.

As well as monitoring her mother's drinking, Brenda was monitoring the availability of suitable drinks:

Brenda: 'Is she drinking'

BRENDA: *On this occasion, I couldn't access her records because they were kept away from the patient, and as I say, normally, I would be able to look at them and see, you know, well, is she eating, is she drinking?*

ME: So that would be in her chart somewhere and you'd have had a look at it?

BRENDA: *If I was there during the daytime, she was hardly drinking when I was there, and I'm thinking to myself, "Well I wonder how much she is drinking and if she's not drinking, how often is the water getting changed?" Visually, there didn't seem to me, to be much evidence, one that she was drinking very much, but, two, even that the drinking water was being replenished that often to be fair.*

Participants interpreted their own findings about the diminishing drinking alongside their observations. Mark concluded that the decline would cause death. To Estelle, diminishing drinking was an early signal of her mother's decline.

Estelle: 'a big change'

ESTELLE: *I was getting quite worried... "She's not herself, you know, can you believe your Mum...?" [said to Martina]. "She doesn't want to drink a glass of wine" [chuckles]. And I say, "It's unusual" [chuckles]. Yeah.*

ME: Yeah, so, you noticed, and...?

ESTELLE: *Yes, she loved to have a glass of wine, oh yeah. But you should have seen the quantity, the bottles of wine we were bringing here for her...So yeah, there was a big change.*

This process of monitoring and interpreting their relative's drinking foreshadowed a plethora of approaches in response.

Strand B Thread 2. Promoting. Ajinder had the most proactive approach to ensuring her father drank and, when unable to drink, received fluid through assisted means. She took this approach early on in her father's declining drinking caused by advanced dementia and continued it resolutely until his death. She described her strategy to ensure her father drank when he was at home in the excerpt below.

Ajinder: 'Making sure that it happened'

AJINDER: *When he got to like the advanced stage of dementia...Um, [pause] um, Dad didn't really, um, start conversations... and talking or anything, he would just sit there quietly... Um, and like, you know, we would always be the ones... Um, initiating conversations with him, or asking him, or probing him... You know, "How are you Dad, are you fine, are you in... any pain...? Do you want anything to eat...? Do you want anything to drink?" And um, and then like, um..., um, and I mean sometimes, Dad, like when we'd ask Dad, "Do you want something to drink?" Dad would say, "No" and I think it's because, when Dad got to the advanced stage, Dad had forgotten how to say yes... So, every time my Dad..., whenever we'd ask him, Dad would always say, "No" and I would like, look at the clock, and like, um, because what we did is, we started keeping a chart... of when his..., um, when was the last time we gave Dad fluids and...always think, "Well hang on, Dad's not had any fluids now, so I'm going to give him some fluids" and then Dad would take the fluids. Even though he said no, he would..., he would take the fluids... He would take..., and um... You know, we would put, um, things like Ribena or...orange juice, or water, or ...tea, you know... You do, and you just, um...*

ME: Have it there, yeah.

AJINDER: *Yeah, and what we would do, um, sometimes we would have, um, like a one litre jug of water... So that at least he was getting, um, plain water... And then, any other drinks in between, you'd like, um, you know, you'd like..., um, Ribena, tea or a juice. So to..., to make sure he ended up in getting the two litres, you know... Um... Um, so..., and so that's what we would do.*

AJINDER: *So we were making sure that it happened. Dad..., Dad would just sit there, you know.*

Ajinder's response to her father's diminishing drinking was highly proactive throughout the course of his decline and dying. She remained resolute in making sure her father continued to have fluids when his ability to swallow deteriorated, insisting that he had a percutaneous endoscopic gastrostomy (PEG) tube inserted. She explained:

Ajinder: 'get a PEG feeding tube'

Personally, what I would recommend, is that when someone starts suffering from..., from dysphasia, to get um..., um, a PEG feeding tube inserted in them... before they get to the late stage of dyspha..., dysphasia, so that um, [pause] that it would make it easier for the carers... for one thing... so at least..., because when the person's sleeping... at least you can give them the fluids... without having to wake them up.

Ajinder's account was peppered with explanations of why she had taken such a proactive approach to her father's diminishing drinking. Her approach was motivated by her determination to ensure that her father's life ended in a timely way. Timeliness was linked to having exhausted treatment which might extend life, not to age. This approach was central to her father's orthodox Sikh faith which she shared, though not as devoutly as he.

Ajinder: 'get that done for Dad'

Dad was a devout Sikh, and Dad did not want to go before his time, because we believe that the soul remains on earth... Until your time, [pause] is up, and then you move on to wherever you've got to go... and um, and so Dad wanted us to fight for him, and to make sure that Dad did not go before his time, so whatever..., and he said, "Whatever there is available medically possible..." To get that done for Dad.

It seemed Ajinder felt responsible for her father and saw her role as making sure her father drank in order to preserve his life and ensure he did not die prematurely. This was in keeping with her and her family's faith. She described her father's personality as 'old school', engendered from serving in the Indian Army during World War 2, meaning stoically getting on with work, not letting others know your weaknesses and avoiding being a burden to others: 'I remember my dad was also the type of not to cause anybody any stress, or be a burden upon them'. Ajinder saw herself and her family as his carers and advocates since he would not articulate his needs to others and their familiarity with him meant they were best placed to know his needs. She stressed that she had Lasting Power of Attorney for health and advised that in the context of advanced dementia, the carer's role was parental saying:

He's like a six month old baby, you know, he might say no, but like what you'll have to do, is you have to be the... the parent now, and you have to..., because like a baby, like it could be sleeping... When a baby's poorly, you know... they're

not going to wake up, they're going to be sleeping, so you have to wake them up and... and give them their fluids.

Strand B Thread 3. Accepting. While most participants encouraged their relatives to drink at times, they moved towards acceptance of diminishing drinking as their relative became less well. For Susan, Jane and Martina this was, at least in part, because they believed their relatives were intentionally refusing to drink to varying degrees in order not to extend their lives.

Susan found her mother's appetite diminished over three years. Initially she tried to encourage her to drink, but as time passed she took a different approach, feeling that her mother would make her own choices about drinking and she should respect them. Earlier in the interview, she describes her mother: *I'd say yeah, she was... very, very independent.*

Susan: 'Fair enough'

I suppose, as I say, it was a case of, I don't feel she'd been a particularly good drinker, in terms of keeping herself hydrated, because it's one of the things I used to say to her, she'd say, you know, "Oh, I feel thirsty" or this, that and the other, and so I'd say, "Well, you know, if you're not having much to drink Mum, you know, you're not gonna, you know, um, sort of feel properly well or anything like this, um, you know, you need to be drinking more", "Oh, I have what I need" or "I have what I want" or whatever else. "Fair enough" you know... Sort of leave it at that, as I say, it got to the point where you didn't...

You know, you didn't bother because Mum's gonna do what Mum's gonna do
[chuckles].

In contrast to Ajinder's determination to ensure her father had drinks and fluids, Susan was much less interventional. Susan did not feel responsible for her mother's drinking or that she could alter it. Susan referred to her mother's strong personality as fiercely independent and did not indicate that this should have been overruled. Like all participants, Susan implied a causal link between not drinking and dying but accepted this as her mother's choice which she considered to be appropriate at her age (93).

Susan: 'I don't see it as sad'

You get to a point as well, where you don't want to be constantly saying... "Have a drink... I'll get you... sort of forcing it... And you think..., and I..., I did get to a point, probably with Mum the last couple of years, where I thought, do you know what, at her age, she can do what she likes. You know, you know, it's not up to me to force feed her or... You know, force drink down her or whatever, um, if she doesn't want it, she doesn't want it... You know, that's it... You know, at her age, she's had..., she's had a good innings, you know, um, I don't see it as sad that she went at the age that she went.

While Susan implies a link between diminishing drinking and desire to die, Martina links it explicitly, surmising that her mother's diminishing drinking may have been partially because she wanted to die having lost the glamorous persona she once had:

Martina: 'in one way she wanted to go'

It was an impossible situation, yes, her body, her brain, and I think it's worse a lot worse in her case, because she knew, she used to be a very glamorous woman...very, very, very elegant...and beautiful, and um, she hated herself, because of what she looked like, she hated herself because she couldn't do anything, um, and um, so whether, in a sense, um, she wasn't desperate for drink, you know, it was..., she..., she would just..., and she wasn't desperately hungry either...and she probably, in one way she wanted to go.

Jane's response to her father's declining drinking was to encourage him to drink and also to respect his wishes not to. Her story illustrates how family members' approaches change over time and how they justify this change of heart. Jane conjoined these two apparently disparate approaches by surpassing them with the imperative of 'wanting the best'. She explained: 'you want the best for your parents, and to actually see him refusing food and drink, was really quite traumatic'. When her father was first in hospital Jane was proactively encouraging him to drink because she believed it would improve his health and enable him to leave hospital, though she recognised her father was only acquiescing to her demands:

Jane: 'doing it just to make me happy'

You know, "Would you like orange juice, what would you like?" and he wanted some of those Fruit Shoots... So I got him a couple of those, um, but a lot of the time he'd go..., I think he was doing it just to make me happy, so I'd go

and get them... and then they would just be on his tray... And I'd say, "Have you tried these yet Dad?" "Um, no".

However, later on, Jane changed her approach explaining: 'If he's not going to drink, if he's going to take that choice, then you have to respect that'. In her story Jane reflects on conflicting aims and consequently which approach was best from the vantage point of some months after the death occurred.

Jane: 'I didn't want him... hooked up to tubes'

Yes, I encouraged him to drink, I did my best, I did not, you know, want..., I didn't want him to be uncomfortable, but I also didn't want him to be in a state where he'd lost his dignity... I mean, he was getting to the point of being incontinent, he wasn't enjoying food, there was no TV there, he wasn't doing his puzzles, and because his oxygen levels were depleting, obviously because he..., he..., you know, he was dehydrated again, I didn't want him to be on this constant round of being hooked up to tubes, and taken off, and I could just see this being a..., you know, a circular event.

Jane's encouragement was driven by a belief that eating and drinking would improve her father's health so that he could leave hospital and the trauma she felt watching her father's drinking diminish. Her hesitancy was driven by desire to respect her father's approach. Jane told the story of a salient conversation with her father while she was washing him at home. He expressed his weariness with living. She returned to this thread several times indicating it was fundamental to her experience.

Jane: 'I don't want to do this anymore'

And then the Wednesday, he just didn't look very well at all, and I said to him, "Do you want me to give you a bed bath Dad? you don't have to get up yet" and he said, "OK". And so I went and I got a lukewarm bowl of water and two flannels, and actually, it's a privilege to do something like that for somebody at that time of life, because it gave me the chance to have bodily contact with my Dad... And to talk to him, and for him to talk to me. And we were just talking, and I mean, he must have found it difficult to breathe again, he was coughing, and obviously the pneumonia had come back, and I was, you know, bathing his hands and just chatting to him, and saying, "Your hands are like mine Dad" and he was talking about his mother, and how proud she would have been of us. And then he just stopped, and he looked at me, and he said, "Jane..." and he rarely called me by my name, because, you know, you don't as a family, you just talk to each other, and I said, "What Dad?" and he said, "I don't want to do this anymore" and I said, "OK, I understand what you're saying Dad, but you can't ask me for permission, it's your choice...You know, you're my Dad and I love you very much, but..., and you know, I'm not in your situation, I don't know what it feels like, but you can't ask me for the permission Dad, you need to do what you need to do". So, from my point of view, I think he'd stopped eating and drinking because he'd had enough. For a lot of old people..., and I looked after, you know, old people, um, for my church as well, it's the last thing that they've got control over I think.

Jane interpreted his diminishing oral intake as him exercising control within his life and choosing not to sustain it because he wanted to die: *'So, I think he'd stopped eating and drinking because he'd had enough. It's the last thing that they've got control over I think. He was frightened. And, people of my Dad's era, don't want to be a bother'.*

Jane felt that being in control was vitally important to her father and she returns to this point several times throughout the interview with words such as: *'I go back to my original comment, this [eating and drinking] was where my Dad had got control and he didn't want to be doing this'.* Being in control to get what he wanted was part of her father's personality and a feature of the familial dynamics between her father, sister and herself. Jane told another story, from earlier in her father's illness to illustrate this:

Jane: 'to get what he wanted'

JANE: *Until me and my sister..., um, we didn't speak for two years, because when my Dad came out of hospital, he played one of us off against the other, because he wanted to go home, my sister wanted him to be moved down to her in warden assisted, I didn't mind where he went as long as he was safe... Um, and he played one of us off against the other...*

ME: To get what he wanted.

JANE: *To get what he wanted which was to go home.*

Jane's perception that her father voluntarily and intentionally stopped drinking because he wished to reduce his remaining life was not unusual, but she was very clear

about it. Most participants were more tentative in this aspect of their story, surmising that diminishing drinking might have been partly intentional to reduce their life.

Participants faced a dilemma: whether to encourage drinking or accept its diminishing with their beliefs for its consequences, which they tried to navigate as best they could against a shifting landscape. For some, this was a dilemma between what was best for them and what was best for their relative. As Jane put it, *'It's not about me or my sister, it's about him'*. They drew on their long relationships with their relatives to try and negotiate this dilemma.

Strand B Thread 4. Comforting. While some participants came to accept and respect their relative's diminishing drinking, Derek, Bernard and Rhoda both accepted it and focused on ameliorating its effects by maintaining oral comfort. Mark also did this in his efforts to ameliorate thirst (Strand A, Thread 3) and Irene indicated she would have liked to have adopted a more comfort-orientated approach (Strand C, Thread 5). Derek, who had worked as a designer of dental implants, was very concerned about his wife's oral comfort in the face of her diminishing drinking and motor neurone disease. He responded very practically, investing in beakers, spoons and finally a toothbrush to support her to keep her mouth moist. He describes his endeavour:

Derek: *'It kept her mouth moist'*

So, we were spooning water in, then I noticed..., and..., and it happened here earlier on, that [name removed] was having her teeth cleaned, and she was

really sucking on the water, out of the toothbrush hairs... So we were doing that, because, um, it was observed [chuckles] by other patients and nurses, that I was cleaning my wife's teeth on a very frequent basis, and of course, um, chit-chat and conversations, they knew I was connected with the dental industry, and they said, "Are we supposed to be cleaning teeth that often? And I just said [chuckles], 'No, but my wife does like to have a damp toothbrush in her mouth'". And I think, you know, the..., that was my way of thinking, it kept um, her mouth moist, and she was taking the..., the water from the toothbrush hairs, by capillary action or whatever. And um yes, so she was having odd spoonful of water, I can't say it was in quantities, I mean the whole day's water intake by spoon, might have been a glass full.

Derek was aware that his wife was dying at this time but saw his endeavour as helpful: *'I mean... I thought I was doing the right thing'.*

Rhoda, a former nursing assistant, undertook 'mouth care' using tools given to her by the nursing staff. Rhoda found the activity personally comforting to undertake, as well benefitting her mother.

Rhoda: 'at least I can do something'

RHODA: Well, I suppose that was a comfort in a sense, because of dry mouth, and all of that sort of stuff, um, [pause] [Rhoda's sister, named removed] had stopped by then, asking her [chuckles] if she wanted to drink basically,

[chuckles] *but yes, so that, for me, that [offering mouth care] was more of a comfort thing than it was...*

ME: A comfort for her or for you?

RHODA: *For both really... because I was thinking, "At least I can do something".*

The comfort Rhoda takes from offering mouth care is similar to the comfort Brenda takes from offering drinking (Strand A, Thread 2) despite their actions and intentions being different.

At the time they undertook mouth care, Rhoda, Derek, Bernard and Mark unequivocally understood that their relatives were dying, it was happening as a result of disease and could not be changed through drinking or any other means. Irene was close to this understanding and regretted her hesitancy about it. Rather than trying to maintain drinking and fluids or accept their relative's diminishing drinking, they proactively focused on comfort. Rhoda alluded to choosing this approach, but unfortunately I interpreted, so that her alternative remained unsaid. If I had not, she may have indicated that she was not expecting the care to impact on her medical condition or life expectancy.

In summary, in Strand B the participants' responses to diminishing drinking, actions and reasoning, is complex. Every participant was monitoring their relative's diminishing drinking, interpreting it as a sign, but sometimes also a cause of decline. Each responded with a unique approach based on their reasoning about what would be best but, for most, this shifted through the course of their relative's dying

trajectory. These approaches can be sorted into three categories: proactively promoting drinking, accepting the effects of diminishing drinking and ameliorating the effects of diminishing drinking. All were motivated by their perceptions of what their dying relative wanted and the nature of the relationship between them.

6.2.3 Strand C: Experiences of healthcare and support

This Strand C section presents resonant threads about participants' experiences of diminishing drinking in the hospital setting. It includes relations with hospital staff, experience of accessing drinks and intervention to address the consequences of diminishing drinking, whether actual or anticipated. While the focus of this section is the hospital environment, participants also told stories set in the home and nursing homes, which became a point of reference during their hospital admission or when imagining how a different environment may have changed the experience. This was particularly true of participants such as Irene, Derek and Jane who had hoped that death would occur at home or in a hospice rather than in hospital.

Strand C Thread 1. Professional healthcare. Participants told stories about their experiences of healthcare for their relatives with diminishing drinking dying in hospital. Nurses and healthcare assistants took practical action to assist drinking such as offering water on a teaspoon, in a beaker or through a straw, and providing fresh tea and cold water. There were also stories about practical actions to ameliorate dry mouth including moistening and offering small sips of drink. Families valued healthcare staff monitoring their relative's drinking. Brenda, in particular, recalled the practical actions of nurses which supported her mother to drink.

Brenda: 'trying different ways'

they were looking at different ways in which to give her..., um, trying with a bit of..., not a long straw, but, you know, different length straws, I think they tried the beaker... different length straws... The teaspoon proved to be the best for her.

However, other participants including Jane and Martina described times when ward environments were busy and nurses were unable to support patients to drink due to greater priorities.

Martina: 'the nurses can't do that because there is another one who is falling'

So, they will explain to me, some of them are wanderers, and they have to look after them, so they wouldn't..., I mean, they prepare her breakfast, but leave it on the table... and um, and if, you know, the patient..., the patient, well she could hardly hold the cup, but you got..., you know, even if the nurse came to hold it, um, it would take..., for something that we drink in two seconds... it will take half an hour, you can't do that in a hospital, you know, the nurses can't do that, because there is another one who is falling.

Some family members worried that drinking was not being monitored by healthcare staff in contexts where staff were busy. This was especially the case for those who were particularly focused on monitoring but were unable to visit during the day or frequently. Jane was one.

Jane: 'they weren't monitoring it'

He was sipping water, but through a straw, but not a huge amount, because they weren't monitoring it, I couldn't tell how much, and he would have three of those Tetra Paks open on... the table, on the go at any one time, so I couldn't... you can't see into them, um, and I couldn't tell how much he'd drunk, so I'd be picking them up, and he'd go, "Oh no, no" and he'd also lie: "Oh, I've got through one of those already". So I'd ask the nurses, and they'd say, "Oh yeah, I think he has actually" but they wouldn't know for certain... because he's in a dementia ward... He's a patient without dementia in a dementia ward, and they were on one-to-ones with these other people.

Where only limited nursing care to support drinking was available, family members took on the role themselves, often choosing to visit over lunchtime to support eating and drinking. Brenda and Derek were particularly proactive about this.

Brenda: 'I always went at lunchtimes... it would help the staff'

Um, they were holding the drink for her... When I um..., when..., more when we were on the Ward [ward name removed], um, she would..., you..., you..., you just hold it and she would..., she would take control of it. But then of course, I always went at lunchtimes, we agreed that feeding would be a good time to go, it would help the staff as well.

Participants interpreted the approach of healthcare professionals caring for their relative's diminishing drinking from their actions, often linking it to whether or not the relative was expected to live. Several participants found that the actions of healthcare shifted and could be inconsistent between groups of healthcare staff, described by Jane as 'a disjunct'. Mark gave the following example of this. A healthcare worker asked his father to complete a menu card indicating his mother's preferences for the following day. His father took this as a sign that she was expected to recover and eat but Mark recognised it was simply disjointed care with the hostess being unaware that his mother was expected to die.

Mark: 'a disconnect'

So a nurse had come around, and said, "Oh, is..., is..., is your mum going to have anything to eat?" and I'm..., I'm like, "I think she's about to die, so like whether she should have chicken chasseur..., what..., what..." And I thought that was quite insensitive, but it was almost like the auxiliary nurses... who were doing..., the catering staff, there was a disconnect between them and the clinical information.

Strand C Thread 2. Risk of Aspiration. Colin, Irene, Ajinder, Derek and Frank all had stories about the risk of their relative's aspirating on drinks and the way this risk was managed. Mark told me how his mother coughed when given a drink. Colin and his wife Frank were told about the risk by nurses on the ward and consequently became reticent about giving drinks:

Colin: 'there was a risk in [it]'

My wife would still try and get him to take a..., take a sip...um..., but um, it just wasn't happening, and..., and the..., the particularly good nurse had also, um, had been very clear with us about the risk of, um, that aspiration...um, so, you know, we knew there was actually..., it was..., there was a risk in, [pause] trying to drink, and getting him to drink, and um, yes, so in fact my wife probably at that point, just gone to moistening the mouth.

In some cases, thickener was used by healthcare staff with the intention of supporting drinking and preventing aspiration, though participants were not sure that it made drinking any easier. In addition, thickened drinks were unappetising, removing the pleasure that drinks once had. Frank explains:

Frank: 'it just wasn't going down'

She'd have tea or water or squash, and they'd put a thickener in it... Um, "why is the thickener in there?", "Um, it helps her swallow", "Right, OK", "But it doesn't feel as if she's drinking it", "Do you know when you're drinking it? It doesn't feel as if it's going down", "Yeah, but if we don't put it in, she drinks too much at once, and it starts her choking". So um, basically, we had to put the thickener in everything she had, and it just wasn't going down for her, so it was very, very hard.

Later, Frank explained how he circumvented the advice, and how much his mother enjoyed the drink:

Frank: 'I like this'

But then the day she passed away, she had half a cup of tea on her own, literally picking it up, the nurse didn't notice, but we gave it to her without the thickener... Um, she had two spoonful's of sugar in it, and she only ever had one [chuckles] and she said, "This is really nice, I like this" and she had a meal as well.

Strand C Thread 3. Clinically Assisted Hydration (CAH). The relatives of all the participants, except Mark's, had had CAH during their hospital admission which most described as 'drips'. No relatives were reported to have received subcutaneous fluids. Ajinder's father received fluids both intravenously and via gastrostomy. Most participants understood the primary purpose of the drip was rehydration, but some understood it to be giving protein, minerals, nutrition or antibiotics. Ajinder proactively demanded fluids, but others like Bernard and Mark felt that the presence or absence of CAH was a medical decision and trusted that doctors would give their relative the most appropriate care.

In keeping with participants' beliefs about drink and drinking, drips were usually seen as improving health and extending life. Frank described a circle of improvement and decline predicated on the CAH.

Frank: 'when she was on the drip, she was a lot better'

FRANK: *The drip was helping... In our eyes, because when she was on the drip and she was, um, should I say, um, what's the word? Hydrated, hydrated. When she was hydrated, she seemed to be more alert, and more able to help and look after herself, um, when she was on the drip, she was eating slightly more, not a lot... but she'd be able to eat a bit more breakfast, um, that's more of her favourite meal of the day, if you know what I mean? Um, so when she was on the drip she seemed a little bit, [pause] better in herself, but then slowly, they would take the drip off, because she was hydrated, to see how she how she would drink on her own, but because she was dehydrated, she didn't drink anything.*

ME: So, it was a circle?

FRANK: *It was a circle, when she was on the drip, she was a lot better... And when she came off the drip, she went downhill, then they'd put her back on the drip again, and she'd get better again.*

Later in the interview, Frank reflected on the effects of the intravenous fluids linking them with extending her life: 'Um, I think if she wasn't on the drips, she'd have gone before Christmas... Simple as... I think it just extended her life'.

Derek was the exception to this. Derek's wife deteriorated and died rapidly following a diagnosis of motor neurone disease. Derek understood the hydration his wife was receiving would improve her comfort but not increase her life expectancy: 'It [intravenous fluids] was something that was aiding her to be comfortable'.

Despite the advantages, participants also raised negative effects of intravenous fluids. Frank, Rhoda and Martina told me that CAH had caused considerable bruising. Rhoda understood that her mother was having intravenous fluids as a matter of routine in hospital. She noticed that this was detrimental to her arms:

Rhoda: 'the state of her arms'

RHODA: *She was getting dehydrated... and even though she'd got a Do Not Resuscitate, you know, all those..., and everybody knew she was going, they did give her fluids... and we..., because obviously, it was more needles... Well it wasn't, obviously it was that one [biopsy needle], but if you'd have seen the state of her arms when, you know.*

ME: Was it into her veins or into her..., top of her arm?

Rhoda: *No, into her vein Annie... Yeah.*

ME: So it's intravenous?

Rhoda: *Yeah, and so they'd give her that, probably, [pause] because she was probably in hospital.*

In summary, participants experienced a range of responses from professional healthcare towards diminishing drinking of people in hospital. Their care ranged from assistance to drink, to giving intravenous fluids, to withholding drinking and comfort measures to mitigate the effects of diminishing drinking.

Strand C Thread 4. Professional support. There were few stories of healthcare staff supporting participating family members directly. However, there were positive examples of nurses and healthcare assistants facilitating families to care for their relatives by providing them with equipment and encouraging family members to offer drinks and moisten lips and mouths. It was not clear whether the intention was to support families by doing this, but this was the result. Bernard was one of those who benefitted:

Bernard: 'the nurses gave us... gauze'

The first week, she would drink a little bit... um, and then..., then..., then the second week, when [name removed], quite obviously..., going..., going downhill very quickly, um, the nurses gave us, I think it was gauze, that we dipped in the water and moistened her mouth, and she liked... that, but she couldn't really do much more than just whisper.

Although some family members recalled helpful conversations about decision-making around intravenous fluids and end of life care in general with doctors and nurses, others reported that clinicians had not discussed diminishing drinking with them. Frank discussed how healthcare staff were helpful.

Frank: 'that needed to be said'

FRANK: The doctor at first said he didn't want to put her on the drips just to prolong her life basically, which was a hard conversation, but looking back now, it's what..., that needed to be said... Um, if that had been said a fortnight or so

before, it might have been easier... because then we'd have realised how bad she was, because when you're talking to her, she was fine, she'd be there, but when she was fast asleep, and she wasn't on the drip, she could have been anywhere, if you know what I mean? Um, she..., we said she'd be asleep, but it's more like unconscious... Um, her body was feeding off itself, and, she just wasn't there, um, the one nurse with the syringes was very, very helpful... Um, let's say I can see her in my head, but I couldn't tell you what her name was... Um, there was another staff nurse, possibly Chinese, Thai, something like that, and she was beautiful, and...

ME: What did she do or say...?

FRANK: *Just being there.*

Frank's story indicates the value of communication but also the value of care. Mark explained how lack of information about his mother's prognosis left him unsure about the right approach to his mothers' diminishing drinking:

Mark: 'nobody would say'

They told us to come in, because she's passing away, a..., um, and what we didn't know, was if we're looking at days, hours, weeks. So, in the midst of that was, if she's not having anything to drink now, is it because she only has got two hours left, so it wouldn't matter? But, if we'd have asked the question, they would have said, quite guardedly, but rightly, "We don't know". "So, but if you don't know, it doesn't hurt to have a drink then does it, or does it?" I don't... But nobody would say, um, maybe because there's so many unknowns, I guess.

Similarly, Colin emphasised the importance of family members sharing their knowledge of the whole trajectory of their relatives decline with healthcare professionals so it might influence decisions about future care:

Colin: 'they [family] can connect'

Um, but you know, through all three experiences of my father, my mother-in-law and my father-in-law, um, there had been points at which I thought, "My God, if..." you know, you think of older people who don't have family around them... no one actually to... take an oversight of their care and... an oversight of what people are proposing, an oversight of if they're being treated, and it's the right treatment, um, I..., I, you know, some..., some... in every occasion... I thought, "God..." you know, "That..., that's awful..." That could happen or not to happen I should say. And also, they can connect the..., um, connect the context of the patient's, um, life and health and activities, to the medical staff, you know, so, in my dad's case, that context, background information helped him form how they treated him, but the mother-in-law, there were occasions where again, um, the context that we gave, informed some of her treatment, and also, um, with..., with my father-in-law.

Stories about professional care of family members were infrequent. However, the stories about care that were told suggest that offering of practical equipment, simply being present, communicating about expectations of the dying trajectory and what

professionals hoped to achieve through their care of the dying person was what participants found helpful.

Strand C Thread 5. Tension and conundrum. Participants told stories of different approaches to the way that diminishing drinking and its consequences were managed and the competing reasons for adopting them. These different positions caused tension to various degrees between different family members and between family members and hospital staff. Rhoda recalled a conversation with her sister which illustrates their different approaches at the time: promoting and accepting.

Rhoda: 'really, at this point in her... journey?'

And I..., I did speak to her once about it, and I..., and that's what I just said, "You should..., she'll have it if she wants it, if she wants a drink [name removed] she'll have it" and she was like, "But she needs to drink, she needs to drink" and I said, "Well yeah, she does" and then [name removed] goes into, "But it will affect her... this and it will affect her that," and I said, "Yeah, it probably will, but, you know, really, at this point in her... journey shall we say?"

Related conundrums lie at the heart of these differences: firstly whether to try to extend life or to intentionally allow death, and secondly whether, on balance, drinking liquids or CAH will improve or reduce the comfort of dying relatives. The conundrums require judgements about what is 'right' in the face of an uncertain and shifting trajectory.

Tension between participants and professionals occurred when their approaches were mismatched. The mismatch occurred in both directions: Ajinder's approach was strongly promoting, but healthcare workers wanted a more ameliorating approach. This was inappropriate to Ajinder since, in her view, her father was not dying.

Ajinder: 'Dad's not at end of life'

They said: "Your dad's at end of life" and we were like, "No, dad's not at end of life, he's at advanced stage, he's not at end of life, um, he still needs to be fed, you still need to give him liquids, fluids" and they were going, "No, no, he's at end of life, you can't feed him" etcetera, and they, um, kept my dad hungry... Didn't give him any water for three whole days, and three whole nights, um, and we had to..., we said, "Look, you have to, you've got to put dad on a drip" etcetera, and the reply was, "Well, he's going to be dead in a few days".

Later in the interview, Ajinder described feeling vindicated in her view because her father lived some further six months: *'Dad passed away on the [date removed] of November, so clearly, Dad was not at end of life, back in May, June time last year... Because otherwise he wouldn't have survived this long.'* Ajinder's story shows tension occurring as a result of different conceptual understanding of diminishing drinking and different views of prognosis. Healthcare staff perceived it as an inherent part of imminent dying and Ajinder perceived it to be part of a much longer disease process with which her father was living.

Conversely, Irene would have liked a more ameliorating approach but felt unsupported in this by healthcare staff. She cared for her husband for many years at home and then visited him daily in a local nursing home. When he contracted a chest infection and was admitted to hospital, she was expecting he would die. She told me, with considerable emotion, of her frustration that her husband's immediate comfort and pleasure was not the overriding priority in his healthcare despite him being at the end of his life.

Irene: 'Why put him through all that agony?'

He was dying... [name removed], so why did they bother? What..., why put him through all that agony, moving him off the ward, going to the X-ray, back again, having the tube down? Why didn't they just take him off the antibiotics completely, and let him..., and then if he wanted to drink, give him a drink... Why not? You know, I..., I can't see it, he was dying anyway, so why not let him have...? If you're a prisoner, and you're being hung, you're allowed a last meal, my husband was allowed nothing.

Later Irene told me of the importance her long-term relational knowledge of her husband which led her to different perspectives to hospital staff. She echoed Colin's reflections about the importance of family as overseers (Strand C, Thread 3) and Ajinder's of family as advocates (Strand B, Thread 2).

Irene: 'she didn't know my husband, I knew my husband'

And I just felt, why, why couldn't they just leave him, let him have a bit of soup or something? Just let him..., just forget the tube, and I know that the tube came, because of what this language lady was saying...and she didn't know my husband, I knew my husband...and I knew that he'd have relished in something to eat, [chuckles]...and I know..., and I also know, um, she was doing her job...but it doesn't help though.

Irene did recognise and share fears about the consequence of drinking and that it might cause choking. She told me this held her back from asserting her views with healthcare staff and advocating for her husband. This left her with some distress.

Irene: 'I'm upset'

I'm upset, because I didn't react and say to her, "Leave him alone, I'm going to take over" and say, "If he wants a drink he can have one" and I didn't, and I didn't because I was more frightened of, if I'd have said this and gone down that road...Um, and anything and he would have coughed and..., he was always..., because he was always coughing, always.

Rhoda was concerned about whether having intravenous fluids was the right thing for her mother. She was perhaps influenced by her background as a healthcare assistant as she recognises that this is also difficult for healthcare staff whom she assumes know that people are dying. She questions whether drinking is helpful to dying people, or

whether professionals encourage hydration because they perceive it is what family members want.

Rhoda: 'that's what they think we want to hear'

RHODA: *I think again, it was hard for the medical..., you know, for the nurses, because obviously..., again, it's a hard one for them, because they ultimately know that, [pause] the outcome for Mum... So, I suppose like you said, you're there to help them, aren't you... and you think that... not making them drink, but encouraging them to drink... Is going to help them... But...*

ME: It's a conundrum.

RHODA: *It is, it is... It is a hard one, and are they doing it because, [pause] that's what they think we need to hear.*

The response of healthcare workers towards family members of people within diminishing drinking was marked by conundrums which were inherent in the situation and necessitated judgements about how they should be navigated. Tensions between healthcare staff and family members manifested themselves where approaches differed; with family members adopting an advocacy role drawing on their relational knowledge of their relative over time. In the stories of Ajinder and Irene, the tension had caused some conflict. Communication is the primary means through which such tensions might be negotiated.

6.3 Summary

The experiences of participants regarding the diminishing drinking of their relatives are complex, multiple, inter-woven and reach beyond concerns about dehydration. Their experiences are integral to family lives and personal histories of illness. As such they differed, reflecting the unique beliefs, values and circumstances of each family. For some, responding to the diminishing drinking of their family members involved profound dilemmas about how best to care for a dying relative. Their views conflicted with the predominate approach of healthcare professionals, particularly over the management of aspiration risk and CAH. Participants' experiences of support from healthcare professionals regarding diminishing drinking were mixed but generally limited. They point to greater information and communication as being desirable to enhance support.

Chapter 7: Discussion

I started this study with a commitment to the pragmatism of William James and John Dewey. I have applied their perspectives of knowledge to research a contemporary issue in palliative care using Clandinin's narrative inquiry (Clandinin & Connelly, 2000; Clandinin, 2013), which is rooted in pragmatism (Clandinin & Rosiek, 2007). I chose to explore family members' experiences of diminishing drinking because the student nurses, whom I taught, found supporting such family members challenging; and their concerns reflected national controversy about the palliation of diminishing drinking within hospitals at the time (Department of Health, 2013; Seymour & Clark, 2018). On review, I found a paucity of research on which clinicians might draw to inform their practice, although wider research literature concerned with CAH for dehydration and professional support offered some insight.

I framed my exploration around the research puzzle given in section 1.1 (p. 13) The purpose of this inquiry was to gain deep and broad understanding of family members' experiences in order to develop new insight which might lead to future practical benefit (Haydon et al., 2017; Haydon & van der Riet, 2017). This purpose is in line with pragmatic thinking: knowledge is fallible, plural and distinguished by instrumentalism (or practical use) and coherence (or integration with existing understanding) (section 2.2.2, p.29). The puzzle was deliberately open-ended since understanding the scope of the experiences was part of the exploration.

In Chapter 7 I return to the research puzzle and address my research findings in the light of James', Dewey's and Clandinin's thinking. I start by discussing family members' experiences of the diminishing drinking of relatives within Clandinin's commonplaces: temporality, sociality and place (Clandinin & Connelly, 2000; Clandinin, 2013). These parameters give a particular narrative lens through which to think about family members' experiences of diminishing drinking. Taking each parameter in turn, I consider the coherence of these experiences with understanding in the existing research and in relation to wider relevant literature. I also identify their implications. I then proffer an insight about participants' responses to the diminishing drinking of their dying relatives in hospital. I conclude by arguing that family members' experiences of diminishing drinking are rooted in their notions of personal and social identity which they endeavour to assert in the face of diminishing drinking and advancing illness. I discuss the instrumental potential and implications of these notions within Chapter 8.

7.1 Temporality: Experiences over Time and in Sequence

The 'commonplace' of temporality points to understanding experiences within time and sequence. It comes with the premise that experience is constantly in transition (Clandinin, 2013). James, Dewey and Clandinin all conceptualise experience as something that evolves continually over time, from and into itself. James refers to experience as 'a stream' (James, 1907) with preceding experiences influencing or determining present and future ones. The findings of this study concur with James' conceptualisation in that the participants' situated diminishing drinking as a continual process which unfolded within declining illness: starting with diminishing eating, but

then burgeoning to encompass drinking, signalling and culminating in death. In this way, their experience was that diminishing drinking is the later stage of an unfolding process, occurring within overall decline and not specifically in the last few days of life. All the participants in this study shared this experience although the duration of process varied with the disease of their relative. When reflecting on this process during interviews, participants identified significant events which marked change to another stage along the way, admission to hospital being one.

Thinking narratively about the temporal dimension of family members' experiences of diminishing drinking encourages consideration of its history. Riessman (2008) cautions that this is not straightforward since storytellers revisit and edit the past in order to make sense of it and to present it to a particular audience with a consistent plot. In retrospectively tracing preceding events, storytellers create links, making choices about what to privilege in their stories and what not to. Frank (1995; 2009) argues that illness 'calls for stories' (Frank, 2009, p. 162) for several reasons, one of which is the narrative work of creating flow and coherence to life stories disrupted by the unexpected and traumatic. In restoring the flow of disruption in their lives, storytellers make sense of such disruption from illness in their lives by making consequential links thus forming a narrative plot. Other people may have made different connections. However, this distancing effect gives storytellers' choice about how to be within their experience of illness, and it is through the choosing and telling, that these choices are shared (Frank, 2009).

The significance of conceptualising diminishing drinking at the end of life as the culmination of an unfolding process over time inherently connected to eating and disease progression could be easily dismissed as irrelevant to the clinical scenario. This is because it is retrospectively constructed and subjective. However, it is these revisited experiences that family members bring to their encounters with healthcare staff, not objective observations; therefore, the question of how best to attend to this revisited experience is relevant (Frank, 2009). The situation of experience of a particular issue within the context of life-threatening illness has been identified in other illness narratives too. For example, when exploring the experience of pain of people with cystic fibrosis, Goggin (2019) found that participants shared their stories of pain within their wider experience of living with the disease, rather than in isolation.

Diminishing drinking as an ongoing process of decline runs counter to the way in which it is presented within the UK guidance on care in the last few days of life care. Both the LCP (Department of Health, 2013) and the NICE guidelines which succeeded it (NICE, 2015) focus on diminishing drinking and the palliation of its consequences within the last few days of life, albeit using differing terminology. Given this emphasis, healthcare staff may not be routinely cognisant of these wider influences on approaches to diminishing drinking of family members or take them into account in their care.

In the reviewed research literature, drinking has been considered alongside eating and often earlier in the dying trajectory than in the last few days (Meares, 1997; Yamagishi et al., 2010; McClement et al., 2004; McClement & Harlos, 2008). Since this approach

is consistent with family members' perception of it, their recommendations may be more relevant than the literature review purports (Pettifer, et al., 2019). For example, McClement and Harlos (2008) recommend research into nutritional care at the end of life within diverse cultural contexts. Such research would be highly pertinent to diminishing drinking within a conceptualisation of it unfolding from diminishing eating.

This temporal conceptualisation of diminishing drinking also has implications for the way in which clinicians perceive and assess diminishing drinking. It demands a broad consideration of diminishing drinking including the history of how it has occurred and progressed. This has ramifications for including family members in assessment since they are likely to hold such knowledge. Such inclusion may reassure family members that the issue is important and understood.

7.2 Sociality: Experiences within Social and Personal Contexts

The 'commonplace' of sociality attends to the experience within both a personal and social context. It comprises the personal emotions, beliefs and thinking of individuals, often nested within the wider social, cultural and institutional narratives of the groups and communities in which experience occurs (Clandinin, 2013). Each participant's experience of diminishing drinking was situated within their unique personal and social contexts; however, some commonality was evident. I will discuss these in two sections: participant's personal beliefs and perceptions about diminishing drinking and the social context within which they occurred. Although presented here in separate sections, these aspects are interconnected rather than distinctive.

7.2.1 Personal beliefs and perceptions

The overriding personal belief of every participant in this study was that diminishing drinking and dehydration had detrimental consequences for their dying relatives, including further deterioration, a shortened life and thirst. No participant saw diminishing drinking as positive. Some family members believed their relatives had made an intentional choice to reduce or stop drinking in order to hasten their deaths because they had had enough of living. In these cases, participants perceived the diminishing drinking was about their relatives asserting personal control over their life in a situation over which control was increasingly limited and the desire to be in control was a strong personal characteristic.

Participants' perception of the point their relatives had reached in the dying trajectory influenced their beliefs about causation and reversibility. Some family members believed the diminishing drinking was reversible, and its remedy could reverse overall decline. For example, Ajinder and Jane (initially) perceived their fathers' diminishing drinking to be the effect of increasing weakness and loss of desire to drink. They thought their fathers' health could be restored with sufficient liquid intake, either through drinking or through CAH. Others linked diminishing drinking to inevitable terminal decline. Participants changed their views or expressed multiple views about causation and reversibility as their relative's condition deteriorated over time.

Participants' beliefs about the nature of diminishing drinking, its causation and reversibility echo the research literature on family members' experiences of declining oral intake. In their qualitative interviews of bereaved relatives, Raijmakers et al.

(2013) found family members thought oral intake increased strength and energy and contributed to preserving life. Participants' beliefs were also consistent with views about the benefits of CAH (Parkash & Burge, 1987; Morita et al., 1999; Cohen et al., 2012; Bükki et al., 2014). However, they run counter to the dominant professional view that diminishing drinking is part of the natural process of dying (Clark et al., 2017); and the view that dehydration might positively enhance the comfort of those near to the end of life (Higgins et al., 2014, Good et al., 2011).

Raijmakers (2013) also found that some family members thought decreasing oral intake was an intentional choice, although she did not report any link to personal control. The small literature about voluntarily stopping of eating and drinking (VSED), for example the study by Lowers et al. (2021), and Ganzini et al.'s (2003) study in Oregon, also affirms the views of the participants in this study suggesting that people choose VSED because they feel ready to die; such dying people feel living is pointless and desire to control the circumstances of their death. However, the experience of my participants does not meet the VSED definition since the participants report that relatives' intent to stop drinking was transient. Although, there is a paucity of literature pertaining to family members' experiences of VSED (Ivanović et al., 2014), Saladin et al. (2018) acknowledge the challenge they face between respecting their relative's wish to hasten death and their feelings about losing their relative. A recent study found that family members considered VSED to be a positive choice since it avoided worse ways to die from advancing disease, and hence were supportive of it (Lowers et al., 2021).

7.2.2 Social and familial context

Participants' personal beliefs about diminishing drinking nestle within a social and familial context. Drinks and drinking were a much-valued part of the family relationships of the participants in this study: a source of pleasure and family cohesion and identity. Drinks and drinking were a mechanism through which familial relationships were built and sustained. For example, Derek and his wife kept favourite drinks for their grandchildren, Mark's parents made each other tea every 20 minutes or so and Jane affectionately recalled trips to local restaurants. These behaviours were associated with fond memories about pleasurable family times. There were also makers of the individual identity of participants' relatives: Martina's mother drank a glass of red wine in bed, Irene's husband liked a lager.

These findings echo wider literature about the role of eating in connecting spousal relationships and the consequences of disruptions of it through cancer. In her study of interdependency in the experience of involuntary changes to weight and eating in patients with advanced cancer and their families, Hopkinson (2016) found that offering and sharing food is a meaningful, social activity through which families come together on a physical, social and emotional level and demonstrated care of each other. Similarly, in her qualitative phenomenological inquiry into primary caregivers' perceptions of intake cessation of dying relatives, Meares (1997) found food and eating to be significant for most caregivers. The significance of food and drink beyond physiological nourishment has been documented from different perspectives (Ratcliffe, Baxter & Martin, 2019; Lupton, 1996; Thompson & Hassenkamp, 2008).

Rituals surrounding food and drink can develop bonds, and establish culture (Thompson & Hassenkamp, 2008) and identity (Lupton, 1996).

Familiar characteristics and activities changed as diminishing drinking evoked loss of familiar habits, markers of identity and family connection. Some family members encouraged their relatives to drink in order to avoid such actual and anticipated losses. Frank, Irene and Jane, for example, wrestled with whether their approach to diminishing drinking was motivated by their desire to avoid loss rather than for the benefit of their relative. Frank put it starkly: *'we realised that it was time to sort of say, well, what's going to be the best thing for Mom, rather than the best thing for us'*.

Both Hopkinson (2016) and Meares (1997) had similar findings in their studies of the impact of eating changes on family members of those with cancer. Meares (1997) also found women caregivers experienced spiralling losses including loss of connection in the relationship as their relative's intakes declined. Similarly, Hopkinson (2016) found that when eating is disrupted by illness it can also disrupt these connections within family relationships.

Despite changes in drinking and its subsequent loss, this study also found potential for drinking to remain an enduring connective within family relationships long into the course of terminal decline; it also remained within the hospital setting, albeit in a different way. Examples were taking favoured drinks into hospital and supporting relatives to drink. Paradoxically, ameliorating the effects of diminishing drinking by, for example, moistening mouths can also offer this connective function; indeed

offering comfort performs something of the same function in a different way. As further examples, Rhoda found comfort in being able to do something for her mother, and Bernard was particularly appreciative that nurses facilitated his caring for his wife by giving him gauze to moisten her mouth. Drinking endures longer in dying people than eating and most other familial activities and therefore can be a source of enduring connection despite decline (Meares, 1997).

7.3 Place: Experiences within Hospital

The commonplace of 'place' attends to the physical space in which the events of the story take place and their interplay with the story. Clandinin asserts that experience and place are connected so that people and their experiences are shaped by place(s), and conversely place(s) is shaped by people and their experiences (Clandinin, 2013). This study focused on family members' experiences of diminishing drinking in hospital since it is the most challenging setting in which to support family members with this issue (Office for National Statistics, 2016) (section 3.4, p. 49). Frank (2009) details the disruption and disorientation that hospitalisation can confer to narratives and argues that creating narratives can re-orientate people across time and space, writing, 'To emplot actions is to situate them in a temporality that narrative creates, as plots unfold in spaces, the unit of the plot gives those spaces coherence' (Frank, 2009, p. 164).

All the participants in this study started their stories at a point prior to their relative's admission and continued it into their hospitalisation, so it straddled at least two places and attended to diminishing drinking in both.

Participants told stories of ways in which the hospital environment affected their experience of their relative's diminishing drinking. These included positive experiences of hospital staff supporting them in practical and emotional ways, and also experiences where the hospital environment was less favourable, particularly about monitoring of drinking and liquid intake, management of the risk of aspiration and use or otherwise of CAH.

The concern of some participants regarding the effective monitoring and support of drinking of dying patients raises issues about the effectiveness of such care in hospitals. Monitoring signs and symptoms that suggest a person may be in the last days of life, including reduced desire for food and fluids, is a quality standard for end of life care in the UK (NICE, 2017). Furthermore, national guidelines in the UK imply that supporting people to drink is a professional responsibility (NICE, 2015). Most participants did not recognise these imperatives or at least did not convey criticism to me. Instead they were usually sympathetic when staff were unable to offer practical support of dying relatives with diminishing drinking, surmising that staff were busy and supporting drinking took lower priority than other activities. An ethnography of the impact of the hospital environment on the care of dying patients supports the participants' supposition (Chan et al., 2018). Chan et al. (2018) found the staff of medial wards prioritise life prolonging over palliative care and biomedical tasks over basic tasks when workloads are overwhelming, sometimes to the extent that basic tasks were not undertaken.

Most participants in my study readily took up aspects of supporting relatives' drinking to varying degrees because they valued the connection with their dying relative. However, it did leave some participants feeling staff were uncaring, echoing the findings of Robinson, Gott and Ingleton's (2014) integrative review of patient and family experiences of palliative care in hospital. Notwithstanding their desire to help, participants' ability to monitor and support drinking was constrained by the hospital environment and their role within it. For example, without access to kitchens they were unable to prepare hot drinks or store cold ones. When they were unable to visit, participants wondered about the quality of monitoring and provision of care in their absence. While the impact of restricted visiting hours and shared rooms in hospitals on care of the dying and their families is well documented (Robinson et al., 2014; Robinson, Gott, Gardiner & Ingleton, 2018), to my knowledge the impact of lack of kitchen facilities is a new finding.

It is notable that participants felt little involvement in both the delivery and decision-making about technical aspects of care. While most understood the risk of aspiration, they found management strategies impracticable in a variety of ways. For example, Colin's wife became reticent to offer her mother drinks, Frank and Mark found thickened fluids to be unpalatable and Irene found the withholding of drinks traumatic. Most were positive about CAH but were not directly involved in decisions about it. The few participants who could recall conversations with staff about aspiration risk or CAH reported them to be informative not discursive. National guidance on clinical decision-making in the UK promotes discussion with family members about such care (NICE, 2017). However, the wider literature concurs with

the findings here and suggests reasons why discussions may not occur (Robinson et al., 2014; Robinson et al., 2018). Good et al. (2011) found that moving towards a palliative approach was emotionally difficult for both family members and doctors alike, and consequently doctors found discussions about withdrawing CAH could feel confrontational, particularly if family members had not yet 'come to terms' with the inevitability of death. Similarly, Higgins et al. (2014) found nurses experienced 'unease and unrest' in the face of uncertainty about whether or not hydration improved or reduced the comfort of dying patients; this caused reluctance to engage with family members.

The dearth of participants' experiences of professional support for themselves is notable. Hudson and Payne (2011) assert that despite the clear intention of palliative care to improve the quality of life of families it may not be the reality for all. There is a lack of appropriate assessment tools, and research-based intervention and policy initiatives to support family members in a systematic and comprehensive manner (Hudson & Payne, 2011; Aoun & Ewing, 2018). Where assessment tools exist, most are generic and focused on the needs of family members caring in the home (Ewing & Grande, 2013; Ewing, Brundle, Payne & Grande, 2013). However, participants pointed to areas where healthcare staff did support or could have supported family members. These were facilitating their practical involvement in care and having open communication about their relative's dying trajectory and care management. These findings concur with existing research in which unmet carers' needs have been identified as knowing what to expect in the future and supporting to manage symptoms (Aoun & Ewing, 2018).

7.4 Responses to Diminishing Drinking in Hospital

Clandinin's framework of commonplaces, the boundaries within which experience unfolds, coupled with her emphasis on thinking narratively about these experiences is a route to insight into the experience of the participants in this study. However, such insight alone does not address the demand for instrumental potential inherent in the pragmatic thinking of William James. Clandinin and Rosiek (2007) allude to this by citing Dewey:

The regulative ideal for inquiry is to generate a new relation between a human being and her environment – her life, community, world - one which “makes possible a new way of dealing with them, and thus eventually creates a new kind of experienced objects, not more real than those which preceded but more significant, and less overwhelming and oppressive.” (Dewey, 1981, p. 175, cited by Clandinin & Rosiek, 2007, p. 39)

Despite this acknowledgment, Clandinin and Rosiek offer scant guidance or exemplars about how such a new relation may be developed in a healthcare context. In this next section I discuss participants' responses to the diminishing drinking of their dying relatives in the hospital environment. In doing so, I represent how participants made sense of the unfolding changes in their relatives, interpreting them in the light of their experiences and responding in the way they felt best. I end this section by discussing the potential of this insight to engender 'new ways of dealing' with such situations (Dewey, 1981, p. 175, cited by Clandinin & Rosiek, 2007, p. 39).

I have depicted the responses of participating family members to the diminishing drinking of their dying relatives within Figure 12 below. The behaviour of family members can be grouped into three approaches: promoting drinking, accepting diminishing drinking and actively ameliorating the effects of diminishing drinking. In turn, these approaches arise from each individual's reasoning about diminishing drinking drawing on their unique context described within the commonplaces above: their conceptual understanding of diminishing drinking, beliefs about diminishing drinking, perception of their relative's point within the dying trajectory and family relationships, and their experience of the hospital environment. I have called this reasoning. The figure depicts reasoning, approach and behaviours flowing with each other. This reflects James' (1907) metaphor of experience as 'a stream'.

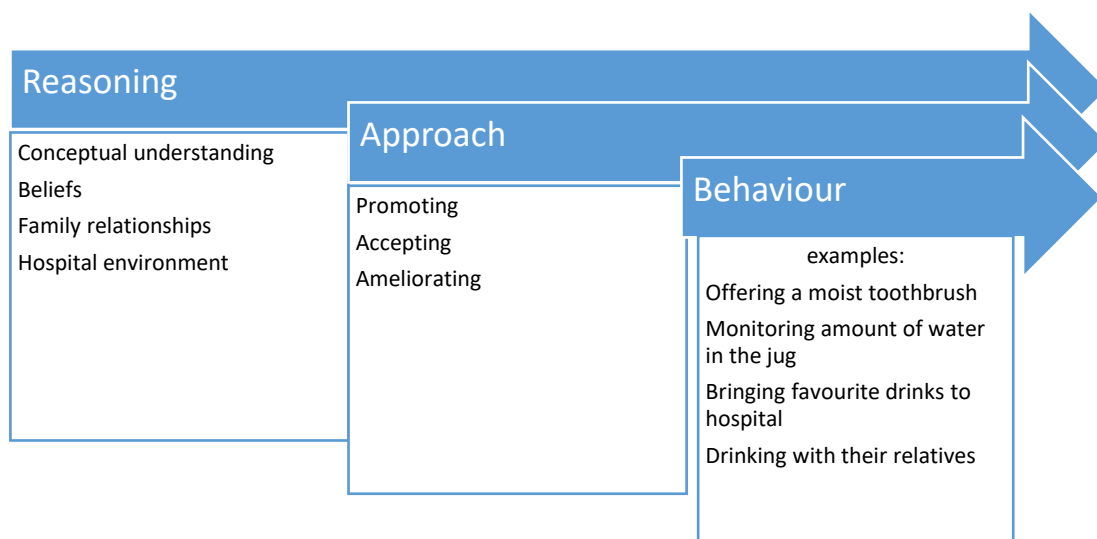


Figure 12: The responses of family members' experiences of diminishing drinking in hospital

7.4.1 Behaviour

Participant family members described practical actions or behaviours which they took in response to the diminishing drinking. On the face of it, many of these are simple, everyday tasks such as asking healthcare staff for a cup of tea or bringing favourite drinks into the hospital. These behaviours will be readily evident to healthcare staff and family members may require their involvement to undertake them.

7.4.2 Approach

The demonstrable behaviour of the participants was indicative of their overall approach to diminishing drinking at the end of life in hospital. Participants' approaches can be grouped into broadly 'promoting', 'accepting' and 'ameliorating'. Figure 13 shows the three approaches to diminishing drinking illustrated with quotations.

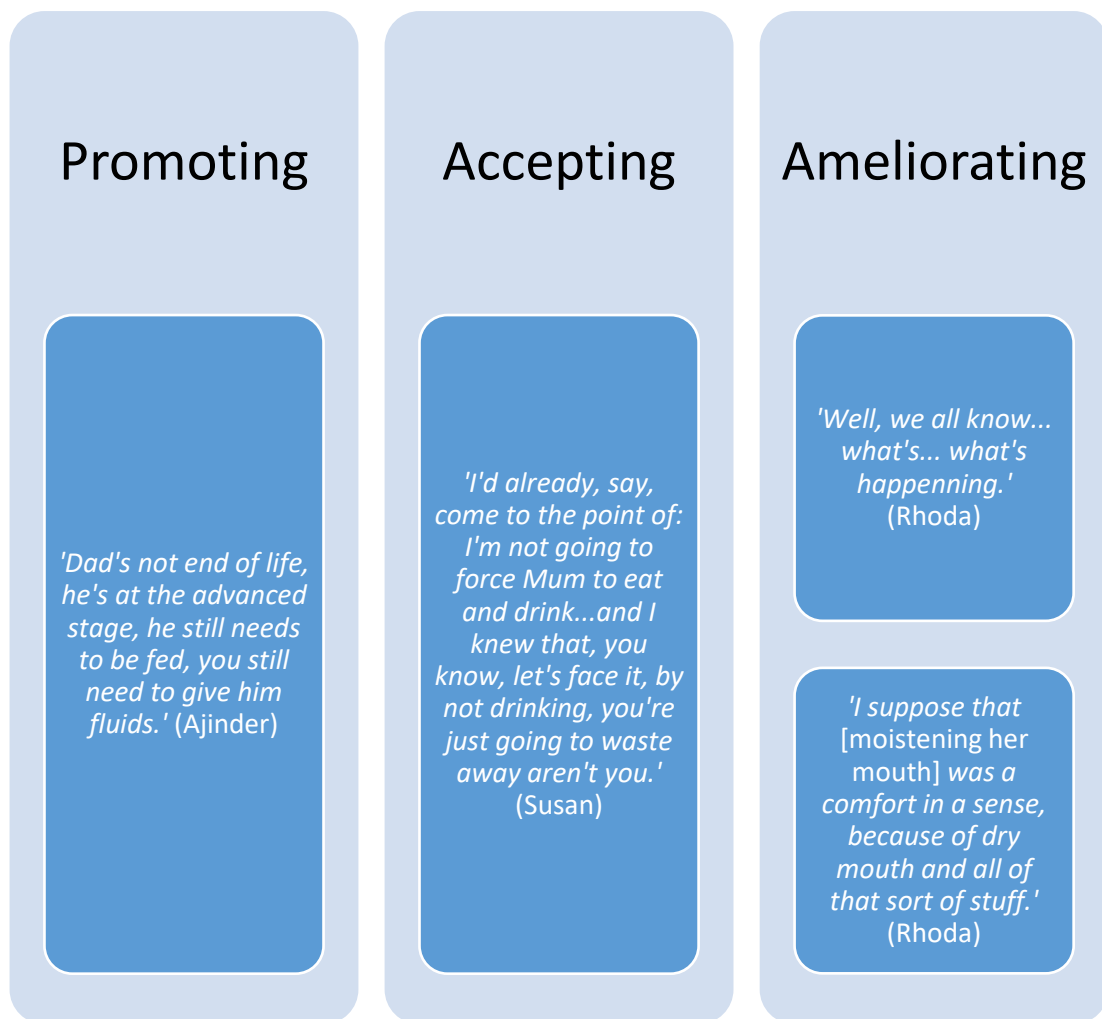


Figure 13: The approaches to diminishing drinking of participants

The variation in family members' approaches to diminishing drinking found in this research is coherent with the pragmatists' plural view of reality: that experience takes multiple but interrelated forms that James termed 'each-forms' of reality (McCready, 2010) (section 2.2.1, p. 26). Furthermore, these forms of reality are continually unfolding within 'a stream' (James, 1907). My grouping individuals' experiences into approaches mirrors James' notion of an 'all-form' of reality in which the 'each-forms' converge into a singular understanding.

The approaches to care identified within the experience of participants within this research are broadly consistent with approaches found by McClement (2001) in her grounded theory of experiences of inpatients, family members and health carers concerned with the nutritional care of patients with advanced cancer. The sub-themes identified were 'fighting back', 'ambivalence: holding on while letting go' and 'letting nature take its course' (McClement & Harlos, 2008). 'Fighting back' is similar to the approach of promoting drinking and fluid intake seen in my findings, and 'letting nature take its course' is similar to the acceptance shown by some participants.

I have identified a third approach to the consequences of diminishing drinking which was not reported in McClement's work (McClement, 2001; McClement & Harlos, 2008). Possibly this third approach was not found by McClement (2001) as over half of the participants were interviewed prior to bereavement. Given I found a trend towards ameliorating later in the dying trajectory, it is perhaps unsurprising that such an approach was not evident in this group. Another finding of mine that differs from McClement's (2001) was the lack of 'ambivalence' in my participants. This may reflect the recruitment strategy since my participants were asked to participate if they had a story to tell, whereas the participants in McClement's (2001) study were directly approached if they met the study inclusion criteria. I did find approaches were transient as individuals and families negotiated and adapted to the diminishing drinking of their relatives.

The approach of family members towards caring for their relative and reasoning behind it may not be obvious to healthcare staff simply from the behaviour of their

family members. They only became apparent to me during the course of listening to participants' stories. Furthermore, the approach of participants changed over the course of their relative's dying trajectory. Most, but not all participants moved towards ameliorating as their dying relative got sicker. Furthermore, some members of the same family group had different approaches, Brenda and her brother for example. As such, the approaches of family members to diminishing drinking are complex to ascertain and understand.

7.4.3 Reasoning

The approach and behaviour of family members towards the diminishing drinking of their dying relatives in hospital is impelled by their interpretation and understanding of it in light of their life experiences, both past and present. These experiences have already been discussed under the three commonplaces in the preceding sections: conceptual understanding, beliefs, social and familial relationships, and the hospital environment (sections 7.1, p. 176; 7.2, p. 179; 7.3, p. 184). Here, I illustrate the connection between the approaches taken to diminishing drinking and their interpretation of it in light of wider experiences of three participants.

Figure 14 maps the different approaches of three participants to their awareness of their relative's dying, their beliefs about causation and reversibility, and their relative's illness and predominant focus of their relationship as they described it.

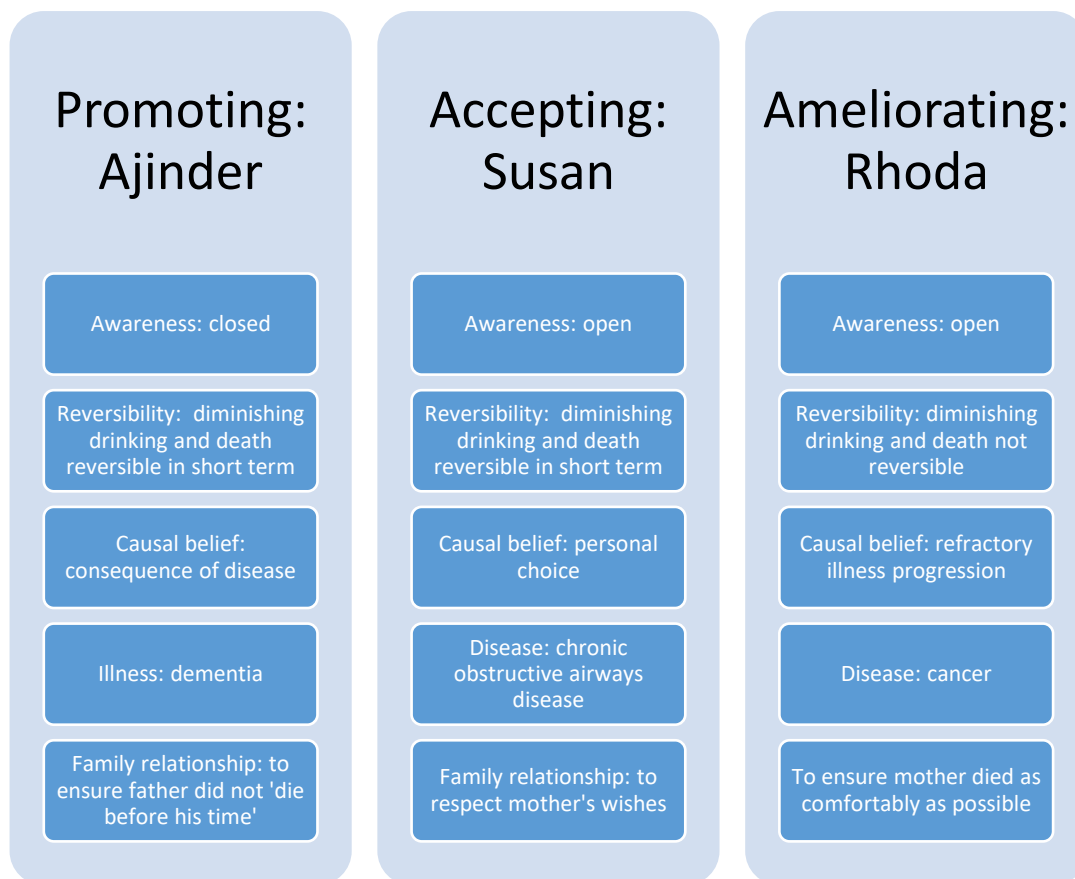


Figure 14: Approach mapped to awareness of dying, beliefs about causation and reversibility, illness and awareness context

Glaser and Strauss (1965) developed a typology of awareness contexts ranging from 'open awareness' in which both the dying person and their family know the person is dying to 'closed awareness' in which knowledge that the person is dying is hidden. While Glaser and Strauss's typology was designed through observations of the interactions between patients and healthcare staff in hospital, it has also been used to describe the awareness of family members (Seale, Addington-Hall & McCarthy, 1997). The mapping shows the links between participants' awareness of dying and their approach to diminishing drinking. For example, Rhoda sought to enhance her mother's comfort because she and her family perceived drinking as an inevitable part of irreversible illness progression. Furthermore they were aware that their mother

was dying and open with each other about this. Derek, Bernard and Mark were also aware that their relatives were dying, at least by the last few days of their admission. They actively sought to ameliorate the effects of their diminishing drinking: they offered drinks via sips or toothbrushes intending to comfort but not extend life. The ameliorating approach is broadly commensurate with that of palliative care in hospices which seeks to reduce the unpleasant effects of disease (Clark et al., 2017). In contrast, participants who took a predominantly promoting approach were not expecting their relatives to die during the admission. Ajinder and Jane (at least initially) maintained that their relatives were not dying, and that fluid was important to support their return to better health.

A link between approach, awareness of dying and disease type is also evident. Derek, Bernard, Rhoda and Mark had relatives with diseases whose illness trajectories are predictable and commonly understood to be terminal diagnoses e.g. cancers and motor neurone disease. Ajinder and Jane's relatives had dementia and heart failure, which are less widely perceived as terminal illnesses and where dying is less predictable (McIlvennan & Allen, 2016; Murray, Kendall & Sheikh, 2005). Given this difference, the contrast between family members' awareness of dying is unsurprising. In hospitals it is likely that family members will have limited awareness of dying as they are widely perceived to be centres for treatment and recovery rather than places in which to die (Clark et al., 2014; Chan et al., 2018; Murray et al., 2005).

Both Raijmakers et al. (2013) and McClement, Degner and Harlos (2003) found a link between family members' awareness of dying and their approach to the declining oral

intake of their relatives with cancer. Those taking a promoting approach believed that general decline was caused by diminishing drinking and those with an ameliorating approach believed that that illness was causing the diminishing drinking. McClement et al. (2003) also linked family members' perception of causality with their approach, with those who believed that declining oral intake was responsible for deteriorating health being more likely to promote intake. This study has shown substantial coherence with previous literature in this regard.

7.5 Conclusion of Discussion: Preserving Identity and Promoting Agency

Narratives are inherently connected to notions of identity (McAdams, 2018; Riessman, 2008; Clandinin, 2013). One function of such narratives is to re-create, define and assert that identity (Bingley et al., 2008; Riessman, 2008). McAdams describes identity as 'a life story, complete with setting, scenes, characters, plots, and themes... a big story, an integrative autobiographical project, a personal myth that situates a person in the world, integrates a life in time, and provides meaning and purpose' (McAdams, 2018, pp.361). Clandinin uses the term 'stories to live by' to describe narratives of identity (Clandinin, 2013, p. 78).

In interpreting and responding to diminishing drinking in light of their life experiences, participants preserve the identity of their relatives and family in the face of advancing illness. Responding to diminishing drinking is a key way in which identity can be promoted because drinking is fundamental to both personhood and family connections, and it endures when many other connectives, such as eating together, have ceased. In addition, participants sought to assert their agency to promote

identity on behalf of their relatives in a hospital context. Participants told stories of how they sought to preserve the identity of their relative and the integrity of their relationship once they became less able, or as Riessman (2015) puts it, their narratives become fractured. For example, Ajinder strove for her father to receive CAH because as an orthodox Sikh he would not want to 'die before his time' and it was her responsibility to ensure this as the eldest child.

Frank (2009) explains that narratives serve to assert personal agency and responsibility because they are driven by the *character* of those involved; character being to do with the moral integrity of that person. In their stories of diminishing drinking, participants assert how their relatives approached diminishing drinking 'in character'. For example, Jane describes her father taking control through stopping drinking; Mark describes how his mother made a strong relationship with the hospital hostess in order to get her cups of tea.

A finding that family members' response to diminishing drinking is to preserve and assert individual and family identity is profound. It hints at its crux: the elusive 'all-form' which James describes as beyond human understanding (James, 1907). Understanding family members' experience of diminishing drinking as one of preserving identity will have wider implications for future practice and research. These will be discussed in the concluding chapter.

Chapter 8: Conclusion

In this final chapter, I reflect on the implications of the findings both for healthcare philosophy and practice in hospital and for further research and policy development. In keeping with the milieu of pragmatism, I consider their instrumental potential to improve the experiences of family members of those experiencing diminishing drinking at the end of their lives. Instrumental potential is not the same as recommendations since it points to possibilities not solutions (James, 1907). I also consider the strengths, limitations and original contribution of this research. I end with concluding remarks.

8.1 Instrumental Potential: Practice

This research has implications for hospital healthcare professionals seeking to support the family members of those whose drinking is diminishing within a dying illness trajectory and increases the limited research available on which they might base their support.

8.1.1 Re-conceptualising

Family members are likely to benefit from a re-conceptualisation by palliative care clinicians, researchers and educators. Diminishing drinking as a phenomenon that occurs alongside diminishing eating, progresses with advancing illness and culminates in the last few days of life is more consistent with the experience of family members than is understanding it as an aspect of the dying process. This is particularly important in the care of those with unpredictable illness trajectories, and where family members

have been caring over a long period of decline. Such a re-conceptualisation may serve to elevate the agency of family members as historians of the course of their relative's diminishing drinking, illness trajectory and identity prior to hospital admission.

8.1.2 Listening with insight

Family members are likely to benefit from compassionate relationships with healthcare professionals seeking to understand the antecedents of their approach to diminishing drinking and hear their wishes for promoting personal and family identity. This research offers insight into how family members perceive diminishing drinking and why they act in the way they do and depicts this in a conceptual framework (see Figure 12, p.189). Although, the framework cannot inform clinicians of the context of any particular family or family member since this is unique, it provides insight about how and why they behave in the way they do. Structured assessment tools are unlikely to be useful in engendering insight of such complex, unique and temporal experiences. This research supports the controversial view purported by Randal and Downie (2006) that assessment tools may impose professional templates rather than listening to and hearing need.

8.1.3 Supporting agency

Family members are likely to benefit from ongoing dialogue about clinical management of diminishing drinking and its consequences in which their experience, expertise and wishes are valued. Recognition of the significance that drinking may hold is likely to support family members, and to minimise tension between family members and healthcare professionals in determining optimal care.

Tailored information about the clinical causes and consequences, explaining options for ameliorating the consequences of diminishing drinking and discussing prognosis is likely to be both wanted and helpful. There is evidence of the value of such information in literature concerned with the preparation and support of family members during withdrawal of life sustaining treatment in intensive care (Coombs, Parker, Ranse, Endacott & Bloomer, 2016). In this research, it is linked to participants moving towards a more accepting and ameliorating approach to diminishing drinking. However, seeking to 'educate' family members is not appropriate if it privileges propositional knowledge over familial knowledge gained through long relationships. Irene illustrates the value of such knowledge: *'he'd always coughed and choked anyway... so I have always dealt with that'*. The risk of her husband choking on a drink did not alarm Irene because it was longstanding. Such enduring experience and family relationships are markers of identity and are not readily changeable through education about propositional knowledge.

Shared decision-making and flexibility regarding the management of diminishing drinking is likely to support family members to preserve identity. Generic and prescriptive care plans, pathways and other 'tools' that have been designed by specialists to be delivered by non-specialists are unlikely to be helpful because, much like assessment tools, they cannot foster identity and their ability to respond to individuals is limited. Instead, individual support offered by skilled healthcare clinicians who are able to listen and respond to family members as individuals is more likely to be genuinely supportive (Randall & Downie, 2006). Approaches seeking to enhance compassionate caring in hospitals by promoting relational encounters while

undertaking everyday practical tasks (Robinson et al., 2020; Kitson, 2018) may be useful in facilitating this.

8.2 Instrumental Potential: Future Research

This research has explored family members' experiences of diminishing drinking and described its implications for practice. Future research is needed that develops, implements and evaluates intervention using the insights of this study in order to better support family members of people with diminishing drinking at the end of their lives in hospital. In Jamesian terms, future research would appraise the utility, or 'cash-value' (James, 1907) of this study by considering whether it engenders positive change, which improves the experience of family members when witnessing the diminishing drinking of a dying relative in hospital.

The participatory action research study that I initially planned is well suited to this and I now have sufficient understanding on which to confidently premise intervention. An action research group within a hospital specialist palliative care service might develop intervention which facilitates re-conceptualisation of diminishing drinking, listening to family members with insight and encourages change in the hospital environment that supports the agency of family members through commissioning and re-configuration of wards. This intervention might be multifaceted: encouraging student and junior nurses at the bedside and involving speech and language therapists, senior doctors and nurses responsible for clinical decision making and support staff responsible for menu and drink availability. Such a study may attract funding since it would address

the research priorities in palliative care identified by Marie Curie (Baillie et al., 2018) and following doctoral completion, I may be in a position to apply for such funding.

8.3 Instrumental Potential: Guidance and Policy

Succeeding the LCP review (Department of Health, 2013), this research supports the renewed emphasis on individually tailored care and shared decision-making (NICE, 2017). It also concurs with recent guidance on providing a supportive environment for the carers of those dying in hospital (NICE, 2020). Guidance that considers drinking difficulties, together with eating, more broadly than the last few days of life is indicated, as published by the Royal College of Physicians and British Society of Gastroenterology (2010) and recently updated by the Royal College of Physicians (2021). Such guidelines, which include but are not limited to end of life care may be particularly helpful for hospital care in cases where there is limited predictability of dying (Clark et al., 2014).

Policy should go further in recognising that family members can be integral to the maintenance of the identity of dying people (van Nistelrooij, Visse, Spekkink & de Lange, 2017) if their agency is supported. Hospital policies should actively facilitate family members to care for their relatives experiencing diminishing drinking in practical ways. Hospital environments could be much more conducive to family members caring for their relatives by closer working between nurses and hospitality services; and by giving access to kitchens (Robinson et al., 2014) and equipment to care for dying family members.

8.4 Strengths and Limitations

In seeking to ground my research in a philosophical commitment to pragmatism rather than a research question, my perspectives both of people and of the way in which they are in the world have shaped the work. The strength of this is that the a priori perspectives are transparent. However, there are also limitations. Pragmatic perspectives are knitted with the findings and conclusion of this research so that they are almost indistinguishable. For example, the findings indicate that diminishing drinking is experienced by family members in multiple ways and that these experiences are shaped by personal and familial history. Similarly, the pragmatic ontology on which the research is predicated asserts that reality is plural and fluid in nature. Hence it could be argued that the research has merely confirmed a priori perspectives. Furthermore, the research design asks participants to reflect back on an emotional experience that had happened a few weeks earlier. Although the interval was shorter than is typical for studies interviewing bereaved people, memory recall following bereavement is influenced by people's frames of references such that reflections are perception (Addington-Hall & McPherson, 2001). Checking the authenticity of the narrative accounts would have been problematic given that perception is dynamic (Addington-Hall & McPherson, 2001).

In defence, pragmatism is an active and enduring philosophy which does not aspire to achieve replicability or generalisability to a whole population or determine objective, fixed truth. The self-determined value of pragmatic research is its potential utility to improve the well-being of others (James, 1907) through building on and integrating with existing knowledge. The ultimate test of rigour in pragmatic research is whether

it is used as a basis for further work, which Riessman (2008) describes as 'pragmatic use'.

Pragmatism has steered this research towards identification of potential knowledge, which may be transferable to other contexts in order to improve the support of the families of dying people. While those most familiar with potential new contexts are best placed to judge the transferability of research findings to such settings (Lincoln and Guba, 1985; Korstiens and Moser, 2018), the broader insights gained through this research may be transferable. These include, but are not limited to, the basis of family members' conceptualisation of diminishing drinking, the worth of listening with insight, and supporting identity and agency. These insights may be applicable to a variety of people involved in supporting families including clinicians, educators and commissioners. For example, educators may use the model: the responses of family members' experiences of diminishing drinking in hospital presented in Figure 12 (p.189) to explore the phenomenon with clinicians working in hospitals in order to facilitate development of insight.

8.5 The Original Contribution of the Research

The research makes an original contribution to palliative care knowledge regarding family members' experiences of diminishing drinking. The literature review found no studies specifically focusing on this topic although wider applicable literature was identified. This study offers a unique insight into family members' experiences of diminishing drinking, which has the potential to inform new palliative endeavour in the field. This research also makes an original contribution to the methodology of

palliative care research. Despite the apparent synergy between palliative care and pragmatism as detailed in section 2.2.2, in-depth application of pragmatic thinking to research endeavour in palliative care is rare. Where studies do exist, pragmatism is used to justify methods and focus on utility (Morgan et al., 2021). By contrast, this study is imbued with pragmatic philosophy. As such, it provides an exemplar of how palliative care might be framed and executed within a pragmatic paradigm, enabling appraisal of its value to wider palliative research.

8.6 Reflecting Backwards and Forwards

I started thinking about this research in earnest some seven years ago. It was rooted then in my experiences of palliative care nursing, education and indeed my own family life. As Clandinin would put it, I was also 'beginning with living with stories' (Clandinin, 2013) of diminishing drinking, albeit it from different perspectives to family members. My own stories bestowed assumptions that I carried through the research design and analysis. At the outset, these were opaque but their impact on the research is apparent when looking backwards.

I assumed that diminishing drinking is progressive but that it occurs within the last few days of life when a patient is moribund. This assumption was based on my clinical experience within palliative care and the literature. It led me to design research focused on this period using retrospective interviews with bereaved relatives. Looking backwards it is striking that family members have a different experience. Family members refocused my gaze upstream to the antecedents of their experience of their relatives dying in hospital.

Similarly, I held assumptions about the scope of family members' experiences of diminishing drinking in hospital. Although not evident to me at the time, looking back I had scoped it as occurring in layers as depicted in Figure 15 below:

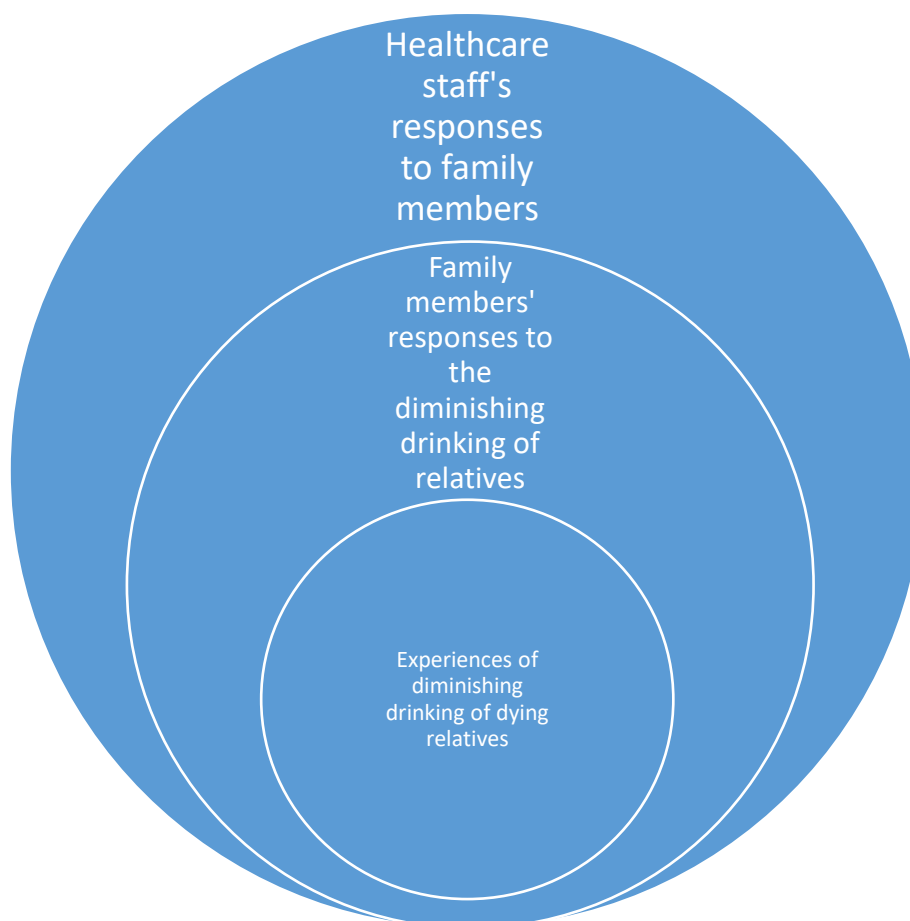


Figure 15: Underpinning assumption regarding the scope of family members' experiences of diminishing drinking in hospital

These assumptions were based on my clinical experiences and intrinsic desire for a 'schema' to order complexity. Although tacit, this schema is evident in the sorting of resonant threads into strands (section 6.2, p.131). While this schema is one way of understanding the complex interplay of patients, family members and healthcare staff

it shaped the resonant findings in my order. In hindsight, another approach may have better privileged the participants in this regard.

Although I held some research knowledge, my knowledge of pragmatism and in-depth research design has been accrued with and throughout the study. Had I previously held such epistemological knowledge, the research might have been different. In hindsight, I would have designed and executed the research more collaboratively to research with participants, returning to their stories several times to authenticate my analysis with them despite the hurdles of memory perception outlined above. I was surprised by their enthusiasm for this study and their desire to share their experiences in order to help others. However, I am delighted to have recruited such resilient people and shared their profound insight into everyday experience of diminishing drinking.

While this research, in all its facets, has been shaped by my assumptions, it has also shaped me. As I look forward, I remain committed to knowledge as plural and fluid, grappling with the struggle of holding it long enough to use for benefit before letting it slip away as it must. Holding such knowledge, even for a moment, is a privilege. Laying it down, so that one can reach for the new, is wise.

8.7 Concluding Remarks

My commitment to the philosophical understandings of James and Dewey has driven me to apply their perspectives of knowledge to a contemporary issue in palliative care. I chose to research family members' experiences of diminishing drinking because

there was a need for knowledge that could inform new palliative endeavour in the field.

On the face of it, drinking is an everyday, simple activity that is commonplace within the lives of individuals and families so that it is almost inconspicuous. Hitherto it has received limited attention as a discrete phenomenon in the professional palliative care literature. However, the subject is profoundly significant to many family members. Drinking is a foundational activity which is physiologically essential for human life. It is also imbued with meaning within individuals, families, societies and institutions. Drinking is an enduring connective across time and place through which family members promote and preserve their relative's identity in the face of advancing illness (van Nistelrooij et al., 2017). When drinking wanes, its diminishment brings profound losses to family members. Their responses reflect the unique experiences, beliefs, understanding and context of their lives.

Healthcare professionals do much to support family members experiencing diminishing drinking of their dying relatives in hospitals. However, there are challenges inherent in the hospital environment and the prevailing healthcare practice which limit the support they give. The findings have provided insight to inform the nature of support for family members regarding the diminishing drinking of their dying relatives.

Moving forward, the research calls for a realignment of the professional conceptualisation to reflect the experience of family members. Authentic support

requires renewed emphasis on aiding families based on attentive listening to their experience with insight of its antecedents gleaned from the stories of others at practice and policy levels. Authentic support of family members requires respecting their role is preserving and promoting the identity of their relatives in the face of advancing illness. It also requires fostering the agency of family members in the care of those dying with diminishing drinking in hospital environments.

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Appendices

Appendix 1: Glossary of Terms Used by Clandinin

Clandinin (2013) uses distinctive terms to describe concepts which are important within her method. The ways in which I have interpreted them in this study is given below.

Borderlands: Spaces around boundaries where there is ‘the possibility for multiplicity of experience’ (Clandinin, 2013, pp. 137). These may be physical boundaries but are more likely to be conceptual, such as those around different approaches to a phenomenon.

Chronicles: The sequence of events or stories relating to a particular topic presented chronologically.

Field texts: records of interviews or other data collection methods including artefacts of the experience. Clandinin (2013) uses the term ‘field texts’ in order to emphasise their subjective and relational construction, distinguishing them from objective ‘data’.

Interim texts: reports of working analysis that are not yet the final research report.

Final text: the final report of findings.

Narrative accounts: Accounts of the participant’s experience in their own words but edited by me to include only stories pertinent to the research puzzle.

Narrative threads: Threads emerging within the narrative account of a single participant. The point(s) within the story or stories of a participant.

Resonant threads: Threads which occur across the accounts of several participants.

Stories: specific tales within the field texts which loosely follow the traditional idea of a story with a beginning, middle and end. They contain a point (thread) which the teller wishes to convey.

Strands: Categories within the research puzzle which reflect the purpose of the research.

Appendix 2: Health Research Authority Ethics Approval Letter



Skipton House
80 London Road
London SE1 6LH

Ms Annie Pettifer
Lancaster University
Bailrig
Lancaster
LA1 4YG

23 August 2017

Dear Ms Pettifer

Letter of HRA Approval

Study title:	The experiences and needs of family members when witnessing the diminishing drinking of a relative dying in hospital: a narrative inquiry
IRAS project ID:	221699
Protocol number:	NA
REC reference:	17/NW/0392

Sponsor

**Research Integrity and Governance Officer, Research
Services,**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities.
- *Confirmation of capacity and capability* – this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* – this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Page 1 of 8

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.

- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **221699**. Please quote this on all correspondence.

Yours sincerely

Miss Helen Penistone

Assessor

Email: hra.approval@nhs.net

Copy to: Dr Diane Hopkins, Lancaster University

Miss Elizabeth Adey, Heart of England NHS Trust

Appendix 3: Participant Invitation Letter



Faculty of Health and Medicine

Lancaster University,

Lancaster, LA1 4YG

Date

Dear Sir or Madam,

Firstly, I would like to offer my sincere condolences on your recent bereavement.

I am writing to ask you to consider taking part in a research study. The study is to find about the experiences of family members and close friends of people in hospital who drink less and less in the last few days of their life. Hopefully, this study will eventually lead to more effective support for family members in such situations.

Information about the study and what participation involves can be found in the participant information sheet enclosed. It also covers what to do if you would like to take part in the study or simply explore it in more detail. If I don't hear back from you within three weeks, I will assume you do not wish to participate in the study and will not be in touch with you again.

Thank you for considering this matter,

Yours sincerely,

Annie Pettifer, PhD part- time student, Lancaster University,

Email: pettifer@exchange.lancs.ac.uk

Participant Information Sheet

The experiences of family members when witnessing the diminishing drinking of a relative dying in hospital: a narrative inquiry

About the Researcher

My name is Annie Pettifer and I am conducting this research as a PhD student at Lancaster University. I am an experienced registered nurse and nurse teacher and have specialised in the care of dying patients.

About the research study

Many people approaching the end of life drink less and less and some become unable to drink water, tea any other drink they would normally have. The purpose of this study is to understand the experiences and needs of family members and friends of people in hospital who drink less and less in the last few days of their life. It will use narrative inquiry, a form of research that focuses on the accounts of people who have particular experiences.

Why have you been approached?

You have been approached because you are a family member or close friend of someone who has recently died in the hospital. You may have noticed your relative or close friend drinking less and less over a period of a few days before they died. If you did, please consider taking part in the study. If not, please disregard this invitation. Up to two family members or friends of the same person can take part and will be interviewed separately.

What will I be asked to do if I take part?

I will ask you to tell me about your experience of being a relative or close friend of someone drinking less and less before they died. I will record this interview at a time

that is convenient for you, in the period up to four months from now. It could take place in your home, the hospital or in another private meeting room, such as within a local library, as you prefer. I expect it will take about an hour but could take up to two hours. I am able to travel within 40 miles or so of Coventry depending on transport links.

Do I have to take part?

No. It's completely up to you to decide whether or not you wish to take part. If you decide to, you can change your mind and withdraw at any time. Should you change your mind after the interview starts, you may withdraw any contribution you have already made up until two weeks afterwards.

Will my contribution to the study be anonymous?

Direct quotations from your interview may be used in the reports, presentations and publications from the study, but they will have been anonymised, so your name will not be attached to them. Your contribution to the study will not be identifiable as coming from you personally, except to a professional transcriber and myself.

The interviews will be recorded and stored securely and only the transcriber and I will have access to them. The professional transcriber will have signed an agreement to keep the interviews confidential. The interviews will be anonymised by removing any identifying information during the transcription process. The recordings will be destroyed once the PhD has been awarded and completed. The anonymised transcripts will be stored securely on an encrypted and password protected computer only accessible to myself, the transcriber and the study supervisors at Lancaster University.

All hard copy information relating to the study will be kept securely in a locked cabinet. This includes the expression of interest forms, containing contact details. Only I will have access to these documents. The expression of interest forms will be shredded once the interviewing phase of the study is complete. All other hard copy information related to the study will be shredded once the research report is complete. Electronic

copies of the typed interviews and any other information related to the study will be kept securely on the Lancaster University secure computer system for 10 years following completion of the project. They may be re-analysed during this time, if they might usefully inform another, related research project. At the end of this period, they will be destroyed.

In exceptional circumstances it might be necessary to tell someone else something you have said and identify you. These are that if what you say in the interview makes me think that you, or someone else, are at significant risk of harm or if what is said in the interview makes me think that someone has been poorly cared for. If this occurs I will need to speak to an appropriate person about it. This person may investigate further. If possible, I will tell you if any of this applies.

What will happen to the results?

The results of the study will be summarised and written into a PhD thesis that will be publicly available and shared. They may be submitted for publication, presented at healthcare conferences and used in educational work with healthcare staff. You will be offered a summary of the results.

What are the possible disadvantages and risks of taking part?

Talking about your experience may be distressing. It may raise new thoughts and feelings, which might be uncomfortable. Should you feel distressed, the interview can be paused or stopped completely. Information about support is available in the hospital bereavement pack and will also be available from me.

Are there any benefits to taking part?

There are no direct benefits to you. However, the study may help healthcare staff to support family members of dying patients more effectively in the future.

Who has reviewed the project?

This study has been reviewed and approved by the Greater Manchester East Ethics Committee. Reference: 17/NW/0392.

How should I proceed?

If you are interested in participating in the above study, please complete the expression of interest form and return it to me in the pre-paid, pre-addressed envelope provided. Should another member of your family, or a close friend of the person who has died, wish to be interviewed please ask them to read this information sheet and complete the second expression of interest form. I will use the details on the form to contact you by phone or email to arrange a suitable time to discuss the study requirements and to answer any questions you they may have before deciding whether or not to participate in the study. If I don't receive the expression of interest form within three weeks, I will assume you do not wish to participate in the study and will not be in touch with you again.

Where can I obtain further information about the study if I need it?

If you have any questions, please do not hesitate to contact me at:

Annie Pettifer, Faculty of Health and Medicine (Division of Health Research)

Lancaster University, Lancaster, LA1 4YG Email: pettifer@exchange.lancs.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of study and do not want to speak to the researcher, you can contact:

Professor Steve Jones Research Director Faculty of Health and Medicine, Lancaster University, Lancaster, LA1 4YG

Tel: +44 (0) 1524 593382, Email: s.jones7@lancaster.ac.uk

If you wish to speak to someone outside of the End of Life Care Doctorate Programme, you may also contact:

Professor Roger Pickup, Associate Dean for Research,

Faculty of Health and Medicine, Lancaster University, Lancaster, LA1 4YG

Tel: +44 (0) 1524 593746, Email: r.pickup@lancaster.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 5: Expression of Interest Form



Expression of Interest Form

The experiences and needs of family members when witnessing the diminishing drinking of a relative dying in hospital: a narrative inquiry.

If, you are interested in taking part in this study, please complete this form and return it to me at Coventry University in the pre-paid, pre-addressed envelope provided.

Name:

Mobile phone: _____ Landline: _____

If you prefer telephone contact, do you have a preferred time when I should telephone? If so, please give details:

Alternatively, would you prefer me to contact you by email initially to arrange a convenient time for me to telephone? If so please give your email address:

Email: _____

Thank you very much for considering participating in this study.

Annie Pettifer

Division of Health Research, Faculty of Health and Medicine,
Lancaster University, Lancaster LA1 4YG

Email: pettifer@exchange.lancs.ac.uk

Consent Form

The experiences of family members when witnessing the diminishing drinking of a relative dying in hospital: a narrative inquiry

Before you consent to participating in the above study, please read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please contact the researcher: Annie Pettifer

Contact details: Annie Pettifer

Division of Health Research

Faculty of Health and Medicine

Furness College

Lancaster University

Lancaster LA1 4YG

Email: pettifer@exchange.lancs.ac.uk

		Please initial
1	I confirm that I have read the information sheet (Appendix 2) and fully understand what is expected of me within this study.	
2	I confirm that I have had the opportunity to ask any questions and to have them answered.	
3	I understand that the interview will be audio-recorded on an encrypted and password-protected small recording device.	
4	I understand that the audio recordings will be transferred to Lancaster University's password-protected server as soon as possible. They will be kept on the server with all working data. They will be transcribed and anonymised, either by the research or a professional transcriber. They will be analysed by the researcher. The raw audio data, transcripts and analysed data will be kept for 10 years. They may be re-analysed during this time, if they might usefully inform another, related research project. At the end of this period, they will be destroyed.	
5	I understand that my participation is voluntary and that I am free to withdraw without giving any reason up until two weeks following the interview. I understand that, after this time, the information I have provided for the study will be included in the study and it will not be possible for it to be withdrawn.	
6	I understand that the information I provide will be pooled with other participants' responses, anonymised and may be published.	

7	I consent to information and anonymised quotations from my interview being used in reports, conferences and training events.	
8	I understand that any information I give will remain strictly confidential unless it makes the researcher think that I, or someone else, is at significant risk of harm. In this circumstance, the researcher will speak an appropriate manager about it and they may investigate further.	
9	I consent to take part in the above study.	

Name of Participant:

Signature:

Date:

Name of Researcher: Annie Pettifer

Signature:

Date:

Appendix 7: Confidentiality Agreement

Confidentiality Agreement for Transcription

The experiences of family members when witnessing the diminishing drinking of a relative dying in hospital: a narrative inquiry.

Principal investigator: Annie Pettifer

All participants in the above-named study are anonymised. Therefore any personal information or any of the data generated or secured through transcription will not be disclosed to any third party.

By signing this document, you are agreeing:

- not to pass on, divulge or discuss the contents of the audio material provided to you for transcription to any third parties
- to ensure that material provided for transcription is held securely and can only be accessed via password on your local PC
- to return transcribed material to the research team when completed and do so when agreed in password protected files
- to destroy any audio and electronic files held by you and relevant to the above study at the earliest time possible after transcripts have been provided to the research team, or to return said audio files.

Your name (block capitals) _____

Your signature _____

Date _____

Appendix 8: Interview Guide

The experiences of family members when witnessing the diminishing drinking of a relative dying in hospital: a narrative inquiry.

Interview guide

Research question and (abridged) objectives

What are the experiences and needs of family members when witnessing the diminishing drinking of a dying relative in hospital?

The research objectives are to:

Describe the accounts of family members of witnessing dying patients' diminishing drinking in hospital including:

- care offered to palliate dying patients
- support offered to family members
- expressed needs of family members
- recommendations of family members.

1. Introduction

Aim: To introduce the research and set the context for the preceding discussion

- Introduce self
- Introduce the study
- Key points:
 - Purpose and length of the interview
 - Voluntary nature of participation and right to withdraw

- Recording of interview
- Holding, analysing and reporting of data
- Anonymity and its limitations
- Consent form
- Any questions?

2. Background and personal circumstances

Aim: To introduce respondent and their relative

- Personal circumstances
 - Main family member
 - Main activity or occupation
 - Household
- Type of deceased relative
 - Nature of relationship

Example: *Please start by telling me a little about yourself and your relative.*

3. Narrative account of dying relatives' diminishing drinking

Aim: to map the chronology of events concerning the diminishing drinking

- Initial awareness of diminishing drinking

Example: *When did/how did you first become aware that your relative's drinking had changed?*

- Ongoing account

Example: *Please tell me what happened to their drinking over the next few days.*

4. Beliefs about diminishing drinking

Aim: to identify family members' beliefs about fluids and diminishing drinking

- Beliefs about the nature of fluids
- Beliefs about consequences of not drinking
- Beliefs about family and professional responsibilities to care for those not drinking

Example: *What did you imagine was the effect of not drinking on your relative?*

5. Care offered to dying patients and support offered to family members

Aim: to map family members' understanding of the care professionals offered dying relatives and the support professionals offered family members.

- What healthcare professionals did for dying relatives
- What healthcare professionals did for family members
- What effect did this have?

Example: *What helped you with this issue?*

6. Family member' expressed needs and recommendations

Aim: to identify family members expressed needs and recommendations

- Family members' needs
- Family members' recommendations

Example: *Is there anything else you would have liked to happen?*

7. Closing steps

Thank the participants

Is there anything else they would like to add?

Do they have any further questions about the research?

Reassure about anonymity and right to withdraw.

Ask if they would like to be informed of research findings in a short report. If so, take email address or other preferred method of contact.

Appendix 9: Distress Protocol

Distress Protocol

This distress protocol is to be used in interview situations to monitor participants' experience of distress and to guide the response to this distress. (Protocol based on the work of Draucker et al., 2009).

a) Indications of distress during the interview.

Researcher will be aware of and alert for indications of emotional distress OR the exhibiting of behaviours suggesting that the interview is too stressful such as uncontrolled crying, incoherent speech, indications of flashbacks etc. If distress is detected the researcher will:

- stop the interview
- offer support and allow the participant time to regroup
- assess mental status (Tell me what thoughts you are having, what are you feeling right now, do you feel able to go on with the rest of the day, do you feel safe?)
- determine if the person is experiencing acute emotional distress beyond what would be normally expected in an interview about a sensitive topic. If detected, stop the interview completely.

b) If distress reflects what may be expected in an interview about a sensitive topic, the researcher will offer support and extend the opportunity to:

- stop the interview completely, or
- stop and re-group and then make a decision to stop, or
- stop, regroup and continue.


c) If distress at any level is detected, at either stop point (as above) or at the end of interview (if continued) the following actions will be taken:

- The participant will be encouraged to contact their regular health provider (GP, nurse, consultant for example) for follow up, as appropriate.
- The participant will be encouraged to use local bereavement services. The details of these are provided within the participant information sheet and also given by Heartlands Hospital bereavement service.


The researcher will offer to contact the participant the following day to see if they are okay.

d) If severe or acute emotional distress is detected or continues after the interview has stopped, in addition to point c) above:

- The researcher will request permission from participant to contact their regular health provider OR
- If there are any concerns about their immediate safety, the researcher will contact their regular health provider without their permission or dial 999 for assistance.



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The experiences and needs of family members when witnessing the diminishing drinking of a dying relative: an adapted meta-narrative review

Annie Pettifer^{1,2}, Katherine Froggatt¹, Sean Hughes¹
Coventry University¹, International Observatory on End of Life Care at Lancaster University², UK

Background

Dying people usually drink less and less in the last few days of their lives. Family members can be concerned and distressed by this. Palliative care seeks to support family members alongside dying people. However, meeting the needs of family members concerned about diminishing drinking can be challenging.



Method

CINAHL, Medline, PsychINFO, ASSIA and Scopus databases were searched. Identified literature reviews were treated as Pearls and their references and citations were searched. Eligibility criteria included all research, of any design, conducted from 1982 - 2017.

Review Question

'How have family members' experiences and needs when witnessing diminishing drinking of a dying relative been researched, and what is known about them?'

Retrieved studies were categorised into three narratives. These narratives were then synthesised into a meta-narrative.


Key Findings

Of the 338 retrieved papers, 22 met the inclusion criteria. No research specifically exploring family members experience and needs about diminishing drinking were found. However, they have been explored within three related, but broader narratives (Table 1).

The applicability of the research is limited by its focus. However, the overarching meta-narrative indicates that family members' experiences and needs may vary with their views of several factors (Figure 1).


Table 1: Narratives about the experience and needs of family members when witnessing the diminishing drinking of a dying relative

Figure 1: Factors influencing family members.



	Narrative A: Experience and needs	Narrative B: Experience of intervention	Narrative C: Experience of professional support
Number of articles	5	16	1
Focus of research	Cancer-cachexia	Decision-making about clinically assisted hydration	Professional support in a hospice context

For further information contact:
Annie Pettifer: a.pettifer@lancaster.ac.uk
www.lancaster.ac.uk/176m/research/ice/c/



Conclusion

There is a paucity of research specifically exploring the experiences and needs of family members' when witnessing diminishing drinking. Further research should consider the phenomenon separately from declining eating, separately from decision-making about clinically assisted hydration and outside a specialist palliative care context.

Appendix 11: Poster Presented at National Institute of Health Research and West Midlands Cares Research Conference, Birmingham 2018



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The experiences and needs of family members when witnessing the diminishing drinking of a dying relative

Annie Pettifer^{1,2}, Sue Bevan³, Dawn Chaplin³, Alyson John³, Chantal Meystre³, Katherine Froggatt¹, Sean Hughes¹
International Observatory on End of Life Care at Lancaster University¹-Coventry University¹,
University Hospitals Birmingham NHS Trust²

Background

Dying people usually drink less and less in the last few days of their lives. Family members can be concerned and distressed by this. Palliative care seeks to support family members alongside dying people. However, meeting the needs of family members concerned about diminishing drinking can be challenging particularly in the hospital environment.



Aim

This research aims to address the question:
'What are the experiences and needs of family members when witnessing the diminishing drinking of a dying relative in hospital?'

Research design

The research aims to gather and analyse 10 -20 narrative accounts of diminishing drinking from bereaved family members meeting the inclusion criteria below:

Inclusion criteria

- Relatives of those who:
- died in hospital
- were hospital 48 hours before death
- were cared for palliatively

Exclusion criteria

- Relatives of those who:
- died suddenly and unexpectedly
- died aged under 18
- died outside hospital

Literature review

An adapted meta-narrative literature review has identified a paucity of research specifically exploring the experiences and needs of family members when witnessing diminishing drinking. Further research should consider the phenomenon separately from declining eating, separately from decision-making about clinically assisted hydration and outside a specialist palliative care context.

For further information contact:
A Pettifer: a.pettifer@lancaster.ac.uk
or h34377@coventry.ac.uk









Relatives are invited to participate in the research in a letter and research information inserted into the bereavement information packs routinely given by bereavement officers. The response rate has been approximately 1%.

Recruitment will be broadened to include an invitation in all bereavement packs and direct invitation by palliative care and bereavement teams.

The research has been approved by Greater Manchester East Research Ethics Committee.

Family Members' Experience of Diminishing Drinking at the End of Life: a Concept Analysis

Annie Pettifer,^{1,2} Katherine Froggatt,² Sean Hughes,²
Coventry University¹, International Observatory on End of Life Care at Lancaster University², UK

Background

People usually drink less and less in the last few days of their lives, a process which may be described as 'diminishing drinking'. Family members can be concerned and distressed by this. A literature review of family members' experience of 'diminishing drinking' at the end of life suggested multiple terms for concepts relating to this process¹ and no agreed terms that are meaningful for clinicians and family members alike.

Method

A concept analysis of family members' experience of diminishing drinking at the end of life was undertaken informed by Rodgers' evolution method². This method focuses on how concepts have been used within a context in order to direct future research and practice.

CINAHL and Medline were searched for literature on 'family members', 'diminishing drinking', 'end of life' and synonyms since inception. The results were sampled across all years, types geographical and professional domains (n=30) and analysed to identify the ways in which diminishing drinking has been conceptualised in literature concerned with the experience of family members.

Results

The literature includes a plethora of terms related to diminishing drinking.

Aim

To explore how family members' experience of 'diminishing drinking' at the end of life has been understood and might be conceptualised in future.

Figure 1:
Terms associated with diminishing drinking, its antecedents and consequences.

Contact:
Annie Pettifer: a.pettifer@lancaster.ac.uk

References:
Pettifer A., Hughes S., & Froggatt K. Family members' experiences and needs when witnessing diminishing drinking at a loved one's end of life: a systematic literature review. 2019. Public access project at 1062 World Research Congress of the European Association for Palliative Care, Bonn, September.

Rodgers B. Concept Analysis for Evidence-Based Practice. Chicago, IL: Rodgers B, Hoyle G. Concepts Development in Nursing 2nd Edition, 2002. Philadelphia, Saunders.


'Terminal dehydration' is the term which has been most clearly defined. Literature has focused on clinical intervention with less consideration of patient and family experiences and supportive care for diminishing drinking and its consequences.

Antecedents Cause	Consequences Condition	Consequences Intervention
<ul style="list-style-type: none"> •Declining oral fluid intake •Decreased drinking •Cessation of intake 	<ul style="list-style-type: none"> •Terminal dehydration •Dehydration •Mouth dryness 	<ul style="list-style-type: none"> •Clinically assisted hydration •Rehydration therapy •Fluid replacement •Hydration


Figure 2: Typology of terms with examples

Conclusion

Further development of the concept of diminishing drinking may support communication between professionals and family members and care in this aspect of end of life care.



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An inclusive approach to recruitment of bereaved family members

Annie Pettifer,^{1,2} Amanda Bingley,² Sarah Brearley,² Sean Hughes,²
Coventry University¹, International Observatory on End of Life Care at Lancaster University², UK

Aim and Background

Evidence from the UK suggests that research into issues surrounding hydration are a priority and the management of hydration in hospitals causes families most concern (Pettif, Hughes & Fogget, 2018). In light of this, researchers exploring the experience of family members witnessing diminishing drinking of dying patients aimed to recruit a diverse sample of people bereaved in hospital.


Recruitment was challenging due to the sensitivity of recruiting those newly bereaved, difficulty in defining 'family' and identifying those who had witnessed diminishing drinking and the limited capacity of clinical staff to undertake recruitment.

Method

To address these challenges, the recruitment design took a population based approach. All family members bereaved in three hospitals were invited to participate in the study via including an invitation pack within the information folder routinely given to families by bereavement officers. The invitation pack included:

- an invitation letter
- a participant information sheet
- two response slips
- a pre-stamped and address envelope

Eligibility was verified through a follow-up telephone call.



Results

The response rate was low at around 1.4% and distribution continued until the target was reached at four months. One respondent did not meet the inclusion criteria on telephone follow-up.

13 family members of 12 deceased patients were recruited: four men and nine women (table 1). Eight were adult children, one a son-in-law and one a friend of the deceased (table 2). English was a second language of three participants. Two were supported by specialist palliative care, 10 were bereaved through non-malignant conditions and 3 from malignancy.

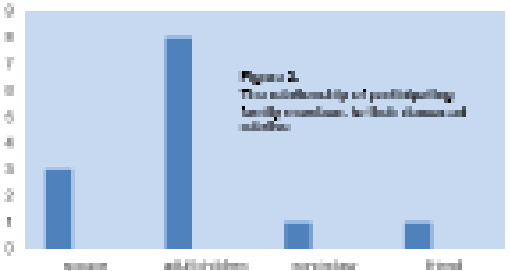


Figure 2.
The ethnicity of participating family members, British standard edition.

Relationship	Count
spouse	3
adult children	8
son-in-law	1
friend	1

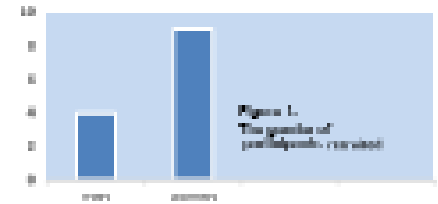


Figure 1.
The gender of participants recruited

Gender	Count
men	4
women	9

CONTACT
Annie Pettifer a.pettifer@lancaster.ac.uk

DISCLAIMER
The views expressed in this paper are those of the author(s) and do not necessarily represent those of the University of Lancaster.

