'I talk with mum because her mum needs care now.' Having Family Conversations about End-of-Life Preferences - A Constructivist Grounded Theory of Living and Dying between Cultural Traditions in African and Caribbean Heritage Families

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy by Alternate Format - Multi-part Thesis

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Abstract

Evidence suggests that advance care planning family conversations rarely take place in ethnically diverse heritage communities. In our meta-ethnographic review, previous studies suggest conversations about end-of-life preferences between elders and their adult children do not happen for several reasons. Elders trust that family will take care of things without the need for a conversation; Adult children close such conversations to avoiding thinking about the death of their parent; and there is a frequent belief that a divine power like God will be in control at that time. However adult children in ethnically diverse communities feel burdened by being the end-of-life decision makers for their parents, and communication between families and professionals currently is poor. Although these phenomena have been explored in some communities these accounts have been mainly descriptive. The intent of this study was to develop a more theoretical understanding of the perspective's family members have of what influences end-of-life conversations within African and Caribbean heritage families.

The ontological perspective of constructivism, epistemological roots in relativism informed by Bourdieu's theory of a concept of practice, are initially explored to try to make explicit the philosophies that underpin this research. As part of this exploration, a Rogerian concept analysis was conducted to critically trace the evolution of Bourdieu's concept of hysteresis, in the experiences of people from minority ethnic heritage communities, engaging with palliative care at the end-of-life. Under-recognised symbolic violence results in social suffering in relation to some of the values and beliefs expected by providers of palliative care in advance care planning conversations around care preferences. When considering engagement with aspects of palliative care practice, care is needed to understand how many have been historically informed by a small number of cultural approaches. In the absence of an existing theoretical exploration of the complex phenomenon of African and Caribbean heritage community perspectives of family conversations around end-of-life preferences, Charmaz's constructivist grounded theory was used as a methodological approach to create informative theory in this area.

Twenty-one participants, (elders, adult children and adult grandchildren of families of African or Caribbean heritage) took part in five focus groups. Reflective field notes were taken, and comparative analysis was used to create categories which were abstracted and used in theory construction. During the conduct of this study, it was necessary to move from face-to-face data collection to online focus groups. The third paper of this study was developed around the exploration of how a community perspective is constructed by research participants through focus group interaction analysis. Online focus groups potentially allow a wider range of participants to take part, however in this study, moving online reduced the interactions between research participants, and increased reliance on the group facilitator to manage the narrative.

The data collected in this study was constructed into a grounded theory of living and dying between cultural traditions in African and Caribbean heritage families. When exploring perspectives around family conversations around end-of-life preferences, adult children play a major role as they become very involved with final decision making. Cultural norms around conversations within families are shaped by these six constructs: a) preparing for death but not for dying; b) complexity in traditions crosses oceans; c) living and dying between cultures and traditions; d) there is culture, gender and there is personality; e) watching the death of another prompts conversations; and f) a concept of hysteresis cutting through them all. Preparation for after-death processes is celebrated in African and Caribbean cultures, resulting in early exposure and discussion opportunities for these processes. However, due to migration histories, opportunities for generational learning-by-watching of the dying process has often been lost. Understanding the intercultural dynamics around dying and the impacts of a geographically dispersed family. can help both healthcare professionals and families to engage in better person-centred interactions when considering advance care planning activities like family discussions around end-of-life preferences in preparation for future decision making.

Extended Abstract

Key purpose of chapter one - overview of the thesis: is to offer the reader a guide to the rationale for the layout of this PhD thesis and the personal motivation for the study.

Content of chapter one: The content of each chapter of the thesis is outlined including an explanation of what published papers were written as part of this thesis and where they sit in this alternative format PhD. It also contains a reflexive account of some of the salient personal experiences that motivated me to do this study which is the first part of my reflexive account. The second part of the reflexive account is in chapter 8.

Key learning from chapter one: Introduction to the topic of conversations people of African and Caribbean heritage have within their families about care preferences at the end of life.

Key purpose of chapter two - Introduction: To outline the background to the topic, explain the rationale for choosing the study's population, and to clarify how the key terms of palliative care, advance care planning, and ethnicity were defined and interpreted within this research.

Content of chapter two: Introductory literature around the dying experiences of people of diverse ethnic heritage is explored. Discussion of the definition of terms such as palliative care, advance care planning and terminology of ethnicity.

Key learning from chapter two: Rationale for study and an understanding of how common terms are interpreted in this study.

Key purpose of chapter three- Literature Review and Paper 1: To create a deeper insight into existing knowledge on the topic of family conversation around end-of-life care preference in ethnically diverse heritage communities so informing the study aim and objectives of this research.

The content of chapter three: Explains the rationale and process behind the study's meta-ethnography. This method was used to understand how underlying cultural dynamics shape communication and influence factors that support or inhibit end-of-life conversations within families of diverse ethnic heritage. A more detailed outline of this meta-ethnography can be found in the first published paper of the study:

> De Souza, J., Gillett, K., Froggatt, K., & Walshe, C. (2020). Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography. Palliative Medicine, 34(2), 195-208. https://doi.org/10.1177/0269216319887070I

Key learning from chapter three: Establishes what is already known about the ways cultural dynamics shape communication and influence factors that support or inhibit conversations within families of diverse ethnic heritage. Uses the findings to develop the research study aims and objectives

Key purpose of chapter four – Theoretical framing of the thesis and paper 2: Explains how, as a developing qualitative researcher, I explored and defined the ontological and epistemological philosophies that shape this research.

The content of chapter four: Brief exploration of the relativist theoretical paradigm of a constructivism ontology and an introduction to the use of Bourdieu’s concept of practice as an epistemological societal lens with which to explore palliative care and end-of-life values and practices. This chapter includes a potential publication of this thesis, a Rogerian concept analysis of Bourdieu’s concept of hysteresis in relation to people of ethnically diverse heritage and the notions of palliative care and advance care planning. Explains how the concept analysis helped me to illustrate how I see the implicit assumptions that exist in society and in my learned approach to this research area.

Key learning from chapter four: Explores how using Bourdieu's theory can offer a way of looking at the social positioning of palliative care and how this is experienced by people of diverse heritage. This helps to give a deeper understanding of the way in which, I as a researcher, saw the context in which this study is situated.

Key purpose of chapter five- Methodological approach: This chapter This chapter documents the processes and rationale for using Charmaz's constructivist grounded theory as a methodological approach. The approach was chosen to uncover and explain the influences on what shapes end of life family conversations in African and Caribbean heritage families.

The content of chapter five: This chapter explores the process of methodological selection and then a discussion of my interpretation of Charmaz's form of grounded theory. The methods used in the study are described including the setting, study population, sample recruitment, data collection using focus groups, intended methods of data analysis and ethical considerations of the study. The chapter concludes with a reflexive consideration of the research process, documenting how Charmaz and Thornburg's principles were used to assess and maintain the study's methodological rigor.

Key learning from chapter five: The methodological underpinnings and the planned research process of the study.

Key purpose of chapter six –Analysing and synthesising the Findings and Paper 3: To present an in-depth insight into the data collection and synthesis processes.
The content of chapter six: This chapter discusses the conduct of each focus group. It includes examples of the initial data processing and synthesis of findings and explains how this iterative process led to the construction of the grounded theory. The study's third published paper offers a critical discussion of the issues that arose during the data collection process.

De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024a). Changes in participant interactions. Using focus group analysis methodology to explore the impact on participant interactions of face-to-face versus online video data collection methods. International Journal of Qualitative Methods, 23, https://doi.org/10.1177/16094069241241151

Key learning from chapter six: An understanding of the synthesis and constructive process undertaken to create a grounded theory of living and dying between cultural traditions.

Key purpose of chapter seven – Paper 4: To ensure that the findings of this research are disseminated to both healthcare professionals working with people of diverse ethnic heritage, but also to other researchers in the field.

The content of chapter seven: This peer reviewed paper presents the processes undertaken in this study along with a discussion of the implications of these findings to developing new approaches to palliative care practice, policy and education.

De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024b). Living and dying between cultural traditions in African & Caribbean heritage families: A constructivist grounded theory. BMC Palliative Care, 23(1), 176. https://doi.org/10.1186/s12904-024-01503-6

Key learning from chapter seven: How the findings of this study could play a role in developing more inclusive palliative and end of life care practices

Key purpose of chapter eight– Reflexive account: To make explicit the subjectivity of this piece of work by exploring the impact of myself as a researcher and the research team on different stages of the study.

The content of chapter eight: This chapter presents a reflexive account that explores the factors at play throughout the study, including my personal background, and how these elements impacted the choice and development of the methodology and the ultimate construction of the theory.

Key learning from chapter eight: To make any biases explicit and provide insight around the in-study decision making.

Key purpose of chapter nine – Integrated Discussion: This final integrated discussion chapter of this alternative format PhD thesis brings together the themes from across the published papers and the research process, and collates the implications of the study for practice, policy, future research and makes suggestions for further work.

The content of chapter nine: This chapter starts with a summary of the thesis. It includes a discussion of the generated theory and then moves into the questions raised by undertaking this research. The chapter includes an exploration of the strengths and limitations of the study. There is a discussion of the implications of the study findings for society, practising clinicians and for the development of future research.

Key learning from chapter nine:

The value of taking a community perspective from African and Caribbean heritage families is explored. Using the theory, my interpretation of the results highlights the multilayered and multifaceted experiences of communities of people who have a migratory history and so carry traditions and values from different places. I explore the sense of hysteresis this can engender. I also explore how the intergenerational transition, at a community level, of those traditions and values is interrupted when dying happens in different geographical areas where there may be limited opportunities for family to observe the dying processes of the previous generation. Who does the end-of-life decision making depends on a wide variety of factors and often proximity overrides gender and family positioning, if family members are paying for care, they will gain a place in the decision-making process.

In conclusion current models of palliative care have a focus on promoting autonomy, of which advance care planning is a popular part. There is an ongoing debate about the usefulness of advance care planning. However, with a greater level of understanding and sensitive discernment, more culturally attuned end-of-life conversations and wider palliative care practices can be developed.

This final integrated discussion chapter is followed by the appendices which contain evidence of ethical clearance, copies of the participant information and consent form, details around the publication of the papers, and a lesson plan of an education initiative which is an outcome of conducting this study.

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Acknowledgements

Completing this PhD has been a time of growth and development in my approach to the speciality of palliative and end-of-life care and my role as a palliative care educator and now researcher.

Firstly, I would like to thank all of those who took part in this study, your contributions were invaluable. Thank you for being prepared to share these important aspects of your life journey's.

I would like to thank the many friends and colleagues who have encouraged me along the way to ask the questions and delve deeper. There are too many to mention but all who have worked with me through my role at King's College London know that you have been an important part of this journey and I am so looking forward to picking up the friendships that have had to be sacrificed whilst this work was ongoing.

I would like to acknowledge the phenomenal support I have had from my supervisors, Professor Catherine Walshe, Professors Katherine Froggatt and Dr Yakubu Salifu, together with the other teaching and academic staff at the International Observatory on End-of-Life Care at Lancaster University. You have been inspiring and supportive through this learning journey and have transformed my understanding of research. I would also like to thank my critical friend and colleague, Dr Karen Gillett, who played a uniquely supportive role in this study.

I would like to acknowledge the role my nursing history has had on getting to this point. I remain a product of the exemplary nursing education I received at the Polytechnic of the South Bank in the 1980's creating my first understanding of the need to base knowledge in well conducted research. Thanks to my peers, Annie, Paula, Helen and Sarah who remain some of my greatest supports. I would also like to acknowledge my MSc dissertation supervisor Professor Rosemary Crow at the University of Surrey, and to particular colleagues, Dr Bill Williams and Dr. Jenny Oates who in the words of Kenneth Doka (1989) enabled me to 'add a sociological voice' to all the work that I do and to understand the many ways that the norms about social support and social capital influence what it is to be human living in society.

Finally, I would like to thank my family. My parents, Harold and Joy, you are both the most inspiring people I have ever met. My children, Tara, Sam, Abigail and my wider family and friends who supported me, I could not have asked for better. And lastly and most profoundly my husband, Adam, who has been my rock and safe place throughout this process, you have supported me with unbounded patience and care, for which I will always be grateful.

Declaration of Contributions:

Name: Myself, Joanna De Souza (Candidate)

The ideas behind this PhD came from myself. I developed the initial proposal and conducted the research. I did all the primary research, analysis and synthesis of initially the literature and then the study, including the organisation of the focus groups and analysis/synthesis of the data collected. I also was the main writer on each of the articles written as part of this multi-part thesis.

I declare that this thesis is my own work and has not been submitted in substantially the same form for the award of a higher degree at this institution or elsewhere.

Signature: ______ Date: ____05.01.24_

Included papers:

Papers
De Souza, J., Gillett, K., Froggatt, K., & Walshe, C. (2020). Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography. *Palliative Medicine*, *34*(2), 195-208. https://doi.org/10.1177/0269216319887070 Cathrine Walshe, Katherine Frogatt, (PhD supervisors) Karen Gillett (critical friend) & Joanna De Souza (PhD student) worked together on the design of this meta-ethnography. All authors read and approved the final manuscripts for this published paper.
De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (to be submitted to the *International Journal of Nursing studies*) Experiences of Bourdieu's notion of Hysteresis in relation to Palliative Care and Advance Care Planning Conversations in Minority Ethnic Heritage Communities. A Rogerian Concept Analysis Joanna De Souza (PhD student) developed this concept analysis. Cathrine Walshe, Yakubu Salifu, (PhD supervisors) Karen Gillett (critical friend) reviewed the work. All authors will read and approve the final manuscript before it is submitted for publication.

De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024a). Changes in participant interactions. Using focus group analysis methodology to explore the impact on participant interactions of face-to-face versus online video data collection methods. *International Journal of Qualitative Methods*, *23*, https://doi.org/10.1177/16094069241241151 CW, YS, (PhD supervisors) KG (critical friend) & JDS (PhD student) worked together on this project. JDS & KG conducted the focus groups for the study. JDS analysed and interpreted the patient data in discussion with CW, YS, KG. All authors read and approved the final manuscript.
De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024b). Living and dying between cultural traditions in African & Caribbean heritage families: A constructivist grounded theory. *BMC Palliative Care*, *23*(1), 176. https://doi.org/10.1186/s12904-024-01503-6 CW, YS, (PhD supervisors) KG (critical friend) & JDS (PhD student) worked together on this project. JDS & KG conducted the focus groups for the study. JDS analysed and interpreted the patient data in discussion with CW, YS, KG. All authors read and approved the final manuscript.

Role of supervisors Catherine Walshe, Katherine Froggatt and Yakubu Salifu and critical friend Karen Gillett in this study

Literature review

As the primary researcher for this constructivist grounded theory study, I developed the research protocol with some review by my PhD supervisors, Catherine Walshe and Katherine Froggatt. I made the decision to do a meta ethnography (further explored in chapter 2). During this time a colleague whom I was working with at King's college, London, Karen Gillett, who had prior experience of meta ethnography and an interest in my topic became critical friend (Greener 2021). Although more commonly associated with action research, critical friends are a common phenomenon in education in teaching, management and research endeavours. A critical friend can be defined as

"a trusted person who asks provocative questions, provides data to be examined through another lens, and offers critiques of a person's work as a friend. A critical friend takes the time to fully understand the context of the work presented and the outcomes that the person or group is working toward. The friend is an advocate for the success of that work (Costa & Kallick, 1993).

Karen played this role through this research process. As colleagues, the role is reciprocal around other aspects of our academic lives.

Writing up the study as published papers

When I wrote my articles for publication, the first one being the meta ethnography, I included myself, my supervisors and Karen as co-authors on the papers. My supervisors, now Catherine Walshe and Yakubu Salifu offered support during regular six weekly supervision meetings by discussing concepts arising and reading and commenting on the drafts of all four of the papers. Karen provided informal but critical support on some of the process of doing a meta-ethnography, informal discussion about the ideas in the articles and on the final draft of the articles.

Data collection and theory construction

I made the decision to use focus groups for this research and needed to find local co-facilitators to act as observers and to be there to provide support for participants if one should get upset and need one to one care. Although I had a team of 2 co-facilitators set up, in the end due to the timings of the sessions, Karen was the observer on all 5 of the focus groups. Karen made observation notes that became part of the data I held from the focus groups.

As primary researcher I transcribed all the focus groups and checked the transcripts for quality and consistency. Karen and I discussed them along with the field notes she had taken during the sessions. Having observed the process but not taken part, Karen offered a more objective view on the processes that had taken place, I added elements of those discussions to my field work memos when reflecting on each focus group. The transcripts were anonymised using a numbering system (participant 1,2,3…). Data collection and my analysis of the focus group data occurred simultaneously. After completing some initial analysis of each group using NVivo 12 coding systems, I discussed the themes I was constructing firstly informally with Karen as she had also been present in the groups and then more formally with my supervisors during supervision which helped me with the final construction of the analysed themes.

During the period of theory construction, I used my PhD supervision sessions to discuss developments with my supervisors. I also had some informal discussions with Karen as a critical friend when trying to abstract my categories. This is detailed in chapters 5 and 6 and in chapter 8.

I constructed the final discussion chapter and refined this and the final thesis presentation with supervision support from my supervisors. I sought the assistance of an official proofreader to read and assist me with grammar, spelling and structure of the final thesis before submission.

Professor Catherine Walshe (Thesis Supervisor, 2016 to completion)

Catherine reviewed all the work including the initial ethics proposal, subsequent focus group data, materials for all 4 of the articles in this thesis and the final write up.

I declare that my contribution has been correctly ascribed. I consent for these articles to be included for presentation within this PhD thesis and for this work to be published on the PURE repository for Lancaster university.

Name: Catherine Walshe

Signature: ___ _________________ Date: __2.1.25_______

Name: Professor Katherine Froggatt (Thesis Supervisor, 2016 to August 2019)

Katherine reviewed all the early work including the initial ethics proposal and writing of the meta-ethnography. She then retired from the position of dissertation supervision in 2019.

I declare that my contribution has been correctly ascribed. I consent for these articles to be included for presentation within this PhD thesis and for this work to be published on the PURE repository for Lancaster university.

Name: Katherine Froggatt

Signature: Date: 02.01.2025

Dr Yakubu Salifu (Dissertation Supervisor (September 2019 to completion)

Yakubu reviewed all the work from September 2019 which included, observation of the focus group data, its analysis and synthesis, and materials for papers 2,3 and 4 in this thesis and the final write up.

I declare that my contribution has been correctly ascribed. I consent for these articles to be included for presentation within this PhD thesis and for this work to be published on the PURE repository for Lancaster university.

Name: Yakubu Salifu

Signature: _______________ Date: __02/01/2025_______

Dr. Karen Gillett (Critical Friend, 2016 to completion)

Karen was my co-facilitator for the conduct of all the focus groups. She played the role of observer. She also played the role of a critical friend while I was reviewing the analysis and synthesis of the focus group data and the articles submitted in this thesis.

I declare that my contribution has been correctly ascribed. I consent for these articles to be included for presentation within this PhD thesis and for this work to be published on the PURE repository for Lancaster university.

Name: Karen Gillett

Signature: Date: 5/01/2025

Chapter 1: Overview of the thesis

An exploration of the perspectives of people within African and Caribbean heritage families on having end-of-life preference discussions between older people and their younger family members is presented in this thesis. By examining a range of these perspectives, I aimed to construct a theory that starts to explain why or why not these conversations may be taking place and what the perspectives of this group of people are around the notion of family conversations about end-of-life planning. Through my in-depth qualitative research, I hope to contribute to a deeper understanding of cultural nuances, family dynamics and the challenges faced by individuals from these backgrounds, as they are asked to engage with aspects of palliative and end-of-life care; for example, advance care planning or end-of-life decision making in the face of serious, life-threatening illness.

This thesis starts with a positioning of myself as the main researcher and then introduces the research team and the background positions they came from to support the conduct of this research. I am a palliative care educator with clinical experience that includes being a nurse specialist in both bone marrow transplantation in an acute haematology unit and in palliative care in the community. I have also worked in two different hospices in the UK. I live and work in a multicultural neighbourhood in south London, having been born and grown up in Kenya in East Africa. I am a member of a mixed heritage family and attend a culturally mixed Anglican church. My PhD supervisors and my critical friend are all palliative care researchers and educators. My supervisors work in the International Observatory of End-of-life Care at Lancaster University, and my critical friend is a lecturer in Nursing at King's College London.

This thesis is presented in the Alternative Format, following Lancaster University's Manual of Academic Regulations and Procedures (MARP). The thesis includes three published papers and one paper that has been submitted for publication. These publishable papers are all connected with the one empirical study outlined in this PHD. They detail the literature review, theoretical underpinnings, study results and a discussion of an aspect of the methodology. The choice of an Alternative Format for the current thesis was made in agreement with my academic supervisors and the director of PhD studies in the Division of Health Research at Lancaster University.

These papers will be discussed in the thesis (Table 1).

Table 1: Incorporated publications

	Papers	Pages in this thesis
1.	De Souza, J., Gillett, K., Froggatt, K., & Walshe, C. (2020). Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography. *Palliative Medicine*, *34*(2), 195-208. https://doi.org/10.1177/0269216319887070	Page 45
2	De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (to be submitted to the *International Journal of Migrant Health*) Experiences of Bourdieu's notion of Hysteresis in relation to Palliative Care and Advance Care Planning Conversations in Minority Ethnic Heritage Communities. A Rogerian Concept Analysis	Page 73
3	De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024a). Changes in participant interactions. Using focus group analysis methodology to explore the impact on participant interactions of face-to-face versus online video data collection methods. *International Journal of Qualitative Methods*, *23*, https://doi.org/10.1177/16094069241241151	Page 153
4	De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024b). Living and dying between cultural traditions in African & Caribbean heritage families: A constructivist grounded theory. *BMC Palliative Care*, *23*(1), 176. https://doi.org/10.1186/s12904-024-01503-6 CW, YS, (PhD supervisors) KG (critical friend) & JDS (PhD student) worked together on this project. JDS & KG conducted the focus groups for the study. JDS analysed and interpreted the patient data in discussion with CW, YS, KG. All authors read and approved the final manuscript.	Page 168

1.1 Thesis structure

This thesis consists of eight chapters. Chapter 1 is this overview of the thesis. The chapter includes a preface of four narratives that were part of my motivation in undertaking this study. The main introduction as to how and why the research question was initiated is discussed in Chapter 2. This introduction chapter contains a discussion of the definitions of the core concepts that underpin the rationale for this study of perspectives around family conversations on end-of-life preferences or wishes and the way in which it was developed. The concepts of palliative and end-of-life care, ethnicity and end-of-life conversations as part of advance care planning are envisioned differently across the world, and even within countries, so it is important to offer clarification of some of these different views and how these terms are understood and used in this PhD study. The concept of perspectives will also be examined for clarity purposes.

Chapter 3 contains the review of the literature which is presented as a meta-ethnography in the first published paper of the study:

> De Souza, J., Gillett, K., Froggatt, K., & Walshe, C. (2020). Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography. *Palliative Medicine*, *34*(2), 195-208. https://doi.org/10.1177/0269216319887070.

It details the rationale for choosing this literature review methodology and the processes undertaken. A critical discussion is offered of the process of conducting a literature search as a meta-ethnography and the challenges of using systematic literature sourcing techniques to source qualitative research for reviews.

In Chapter 4, the relativist ontological theoretical paradigm of constructivism that underpins this research study is explored. The chapter continues into a discussion of the epistemological theoretical lens of Bourdieu's concept of practice and how this frames the context of this study. The chapter contains a concept analysis using a Rogerian Framework (Rodgers et al., 2018; Tofthagen & Fagerstrom, 2010) of the concept of hysteresis in relation to people from diverse cultures and the way in which the antecedents of palliative care have been developed around quite normative values and beliefs that may in themselves have created structural barriers to access. This is offered as the second potential publication of this thesis. This publication has been prepared to be submitted to the International Journal of Nursing Studies which is a journal which has published previous concept analysis papers. The discussion that is offered positions this research study in its societal context.

The choice of constructivist grounded theory as a methodology is explored in Chapter 5 (Bryant & Charmaz, 2010). The methods used in the study are also described including the setting, study population, sample recruitment, data collection using focus group, intended methods of data analysis and ethical considerations of the study.

The following chapter, Chapter 6, includes a detailed reflexive account of how the focus groups were conducted and the initial data collected. During the study there was a need to move from conducting focus groups face-to-face to online focus groups. The third published paper of this study is a critical discussion on what impacts this has on the dynamics of a focus group.

De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024a). Changes in participant interactions. Using focus group analysis methodology to explore the impact on participant interactions of face-to-face versus online video data collection methods. *International Journal of Qualitative Methods*, *23*, https://doi.org/10.1177/16094069241241151

Chapter 7 starts with the presentation of the fourth published paper of this study. This paper is a presentation of the overall study including both the data collected and how this was constructed within grounded theory.

De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024b). Living and dying between cultural traditions in African & Caribbean heritage families: A constructivist grounded theory. *BMC Palliative Care*, *23*(1), 176. https://doi.org/10.1186/s12904-024-01503-6

A discussion of how the theory was developed from the original raw data is expanded upon in this chapter as only limited detail could be included in the published paper.

Chapter 8 is a discussion of the reflexive processes I undertook while developing and conducting this study to enable this process to be transparent. It is a subjective piece of work, so this reflexive chapter explores the influences on me as a researcher and some of the thinking that was done through the study.

This is followed by the final discussion chapter of this thesis, Chapter 9. This chapter starts with a summary of the thesis. It includes a discussion of the generated theory and then moves into the questions that were raised by undertaking work in this area. The chapter contains an exploration of the strengths and limitations of the study. There is a discussion of the implications of the study findings for society, practising clinicians and for the development of future research. It also includes a critical evaluation of the theory-generating process and a concluding discussion to this thesis.

This chapter is followed by the appendices which contain evidence of ethical clearance, copies of the participant information and consent form, details around the publication of the papers, and a lesson plan of an education initiative which is an outcome of conducting this study.

1.2 Preface – reflexive statement

This study really came about due to a number of sensitising experiences or events in my career as a palliative care educator and a member of a multicultural society living in south London. The following excerpts detail some of these sensitising experiences and also offer some context to who I am and my perspective on having end-of-life planning conversations.

Working in and teaching palliative care in a culturally diverse city like London has raised my awareness as to how differently the process of dying is perceived and dealt with by healthcare professionals, patients and families from different cultural backgrounds. My interest in the topic of end-of-life family conversations was stimulated by four sensitising events (Charmaz, 2014). (All patients and study participants mentioned by name in this thesis have been anonymised.)

Event 1

> *During a gap year between school and university, whilst I was living with my grandparents in the UK, a friend advised me of a job going locally as a nursing auxiliary in a local hospice. She recommended it, I am not really sure at that point I knew what a hospice was, but it paid well enough for me to be able to earn my airfare home to Kenya where my parents lived for the following summer, and I could get there on my bicycle. During the nine months I worked in the hospice, I learned a great deal about what could be done to improve people's quality of life when dying and what support could be provided to relatives to reduce the intense distress that sometimes comes with losing someone, particularly when they are dying with uncontrolled symptoms. I also learnt how the death of a family member was easier for some families to come to terms with than others. Spiritual pain, where people sought God to heal the dying person and felt let down and abandoned when this did not happen, was something particularly difficult to see. Apart from a desire to become a nurse, this experience resulted in a career-long interest in palliative care and the reduction of family distress.*

Event 2

> *Teaching a class of post-registration nurses in London on palliative and end-of-life care as part of a module on caring for patients with long-term conditions, I conducted an exercise to get students in small groups to consider and discuss what they might want at their funeral, as a way of thinking about what it felt like to talk about dying. In the discussion afterwards, one of the small groups of African students confessed they had not discussed the topic at all and had decided to do something else as they voiced a traditional belief that talking about your death may somehow bring it on. They recognised this as part of their cultural folklore rather than really believing it for themselves; however, they were not keen to engage with such discussions.*

Event 3

> *During another session with pre-registration graduate nursing students around how modern healthcare practices decrease social exposure to death, we explored conversations students had had at home around dying. Some students talked about having discussed their donor cards etcetera with parents; however, when the conversations moved to discussions brought up by elderly relatives about end-of-life choices there was general laughter at how we as the younger generation generally stop those conversations. Afterwards one of the African students came to speak to me about how she had never thought about how taboo it was for her to have such conversations at home; she had grown up with*

messages about how talking about death would somehow bring it on. She had only just begun to think about how that did not make sense with her current understanding of illness.

Event 4

Ahmed was a friend who was a psychology lecturer, he had a diagnosis of multiple myeloma. I got on well with him and his wife Zainab as we shared an East African Asian heritage and were similar in age with young children. Ahmed and I also shared student stories and a knowledge of haemato-oncology from my previous role as a bone marrow transplant coordinator, he was aware I now taught palliative care. We often talked about his experience of his illness. He was unable to have a related donor stem cell transplant as his sister could not reconcile her Muslim beliefs with giving her stem cells to her brother. She lived abroad and felt overwhelmed with what her brother was telling her about his illness. Ahmed was very philosophical about this as he had a good understanding of her beliefs, even though he did not share them. There was no-one on the bone marrow registers who was a good enough match for him. This was difficult for Ahmed and for the staff in the haematology unit who had got to know him well.

Over the time I knew him, he had several courses of chemotherapy including salvage therapy after disease relapse. He developed a strong rapport with his haematologist, a fellow Muslim. Over time, Ahmed's health began rapidly deteriorating. He was admitted to hospital. Zainab would make all his food and take it in daily. She made soups from a variety of vegetables as they had read, they could reverse the cancerous activity. They were keen for him to be well enough for the next chemotherapy trial he was due to start soon. In my eyes he was dying, the nurses on the unit found it more and more difficult to spend time in Ahmed's room; he was keen to talk about his next treatments and to take every precaution to prevent himself from missing this opportunity. He requested his two children, who were at secondary school, did not visit as they put him at greater risk of catching an infection.

The nurses found his pain and symptoms difficult to manage and wanted him to meet with the palliative care team, but Ahmed and his wife did not want to do this. They became angry with a nurse who suggested it yet again on a day when the pain was bad. My relationship with them also became difficult as I found it hard to be empathetic with their anger at what they felt was not being done and the distain with which they held the palliative care team, who they felt could offer them nothing.

Ahmed and his wife explained to the nursing staff that they strongly believed that Allah was in control of life and death, and they would be attempting to take

> *control if they were to plan for dying. Ahmed's death came a couple of weeks later and it was a distressing time for everyone involved, particularly as a decision had been made by the clinical team not to give the trial chemotherapy the week before because they were worried about his ability to tolerate it. Ahmed and his wife were angry and disappointed. They wondered if they had made the wrong decision about relying on public funded care rather than pursuing private healthcare as several relatives had done for other conditions.*

It is these experiences that led me to an interest in exploring this high level of what I perceived as death anxiety and how this had an impact on family conversations about dying and ultimately on choices around care preferences in all the families in my vignettes. I was interested in exploring whether there were ways to facilitate more peaceful and less anguished deaths for people from these communities where cultural norms made talking about dying so taboo. I approached an ex-colleague, Professor Froggatt who had done some work looking at different cultural attitudes to palliative care with the start of a PhD proposal, and she and one of her Professorial colleagues, Catherine Walshe at Lancaster University, agreed to supervise me and so my PhD journey began.

Chapter 2: Introduction

2.1 Introduction

Serious health related suffering frequently occurs in the short time period before someone's death (Cardona-Morrell et al., 2016; Sleeman et al., 2019). Many people receive treatments at the end of life that do not provide a relief from suffering so are considered non beneficial or futile in the last six months of their lives (Cardona-Morrell et al., 2016). Making decisions about what may constitute the best care for people at the end of life involves difficult decisions that can result in conflict between healthcare professionals, patient and families (McDermott & Selman, 2018). The goal of palliative and end-of-life care is to offer a range of support to help develop individualised person-centred care pathways that relieve some of that suffering using interventions that improve people's symptomatic experiences and enhance communication between all involved during this difficult time. In 2014 the World Health Organisation called for palliative care to be integrated as an essential element of the healthcare continuum (Meier et al., 2017). However, only 66 countries in the world have a dedicated section within government seeking to deliver that vision, with a smaller number of countries not having any kind of palliative care health policy in place (Clelland et al., 2020).

The UK has played a role in leading the international provision of palliative care in developing one of the first national palliative and end-of-life health policy (Department of Health, 2008). In 2015 the United Kingdom (UK) was ranked top of the World Quality of Death Index, in part due to its provision of palliative and end-of-life care in a wide variety of settings (Economist Intelligence Unit, 2015). However, good dying experiences are not uniformly experienced amongst all in many countries, including in the UK where palliative care provision is universally available. One of the social demographics that emerges as significant in resulting in a reduced quality of dying, in studies where it is measured, is that of ethnic heritage (Calanzani, 2013; Johnson, 2013; Koffman et al., 2014). This is due to a range of different factors which are explored in more detail in chapter 4 in this thesis.

Discrepancies continue in rates such as numbers dying on life sustaining measures, take up of advance care planning and palliative and end-of-life support based on people's ethnicity (Cardona-Morrell et al., 2016; Kimpel et al., 2023; Koffman et al., 2014). Barnato et al. (2009) refer to it as the 'acute care default' near the end of life where a preference for more aggressive care at the end of life when facing serious illness may be more common in black patients than white.

Patients from ethnically diverse cultures tend to be involved in fewer conversations about end-of-life care preferences, and there is a greater tendency by clinicians and family members to disregard their preferences when care decisions are being made (Fazil et al., 2015; Mack et al., 2010). Contributing factors to the lack of good outcome conversations include a sense of discrimination, fear of death, religious beliefs, cultural patterns, avoidance to protect self and others, a lack of trust in medical facilities and healthcare professionals' own difficulties with discussing these matters across cultures (Depaola et al., 2003; Fazil, 2018; Sanders et al., 2018; Venkatasalu et al., 2013; Willmott et al., 2016). Investigations of this have led to a greater awareness of how different processes impact on areas like access to palliative and end-of-life care services, symptom management and helpful communication. These aspects urgently need addressing to ensure equitable ways of improving dying experiences (Bullock et al., 2022; Hussain et al., 2021).

One of the components of modern palliative care is the encouragement to consider values and preferences around care at the end of life prior to the time arriving, when people may not be able to make their preferences and wishes known (Thomas et al., 2017). It is part of rebalancing death and dying from being considered a medical failure. This is important at a time when knowledge and medical expertise can prolong even the frailest of lives, but often due to a plethora of medical devices and processes (Sallnow et al., 2022). These are interventions not everyone who is dying would want if they could voice their preference. Making pre-emptive choices about what we want at the end of life is a complex task and some would argue raises unrealistic expectations about what can and can't be controlled or pre-empted (Morrison et al., 2021). Many people prefer not to dwell on the idea of being incapacitated and entertain a more fatalistic approach to life hoping that somehow everything will be okay (Peterson et al., 2018; Pollock et al., 2024). Some studies however have shown that having pre-emptive conversations with family or healthcare workers or writing down preferences results in better goal concordant care (Chiarchiaro et al., 2015; Lenko et al., 2024)

Many factors affect both the choices we make, but also whether we want to make or express, any particular choices (Bullock et al., 2022). In studies exploring people's ideas about a good death and in what they would want for themselves given a choice, most would choose a peaceful death in familiar surroundings with family present, having had a chance to put their affairs in order (Meier et al., 2016). For many, there is an expectation that family members will be involved in end-of-life decisions, if the person themselves cannot be, due to ill health (Samanta & Samanta, 2013; Sanders et al., 2016; Sharma et al., 2012). This is particularly emphasised in people from a wide range of ethnically diverse heritage populations. Although this is an expected and desired outcome, little is said in these families by way of discussing this assumption or planning for it (Johnson et al., 2016). As such this knowledge is unconstructed and unexplored and so remains somewhat unknown.

Studies have shown that for people in both the USA and the UK, access to palliative care for ethnically diverse communities is impeded at system and community levels (Bajwah et al., 2024; Shabnam et al., 2022). This is in part due to structural factors such as socioeconomics and language, both in terms of language barriers but also in the way language is used when things are offered. However, recommendations for improvement are mostly at an individual level. A better understanding of both systematic influences, and individual preferences, is required when developing better palliative and end-of-life services and interventions for people of diverse ethnicities.

2.2 Context of current study

A report commissioned by Public Health England (PHE) in 2013 found that there were a growing number of black and minority ethnic elders who would require palliative and end-of-life care in the next decade in the UK population (Calanzani, 2013). Public Health England identified that those families made limited use of existing palliative and end-of-life care services and achieved poorer outcomes, including symptoms being less well controlled at the end of life. Access to services may be correlated to socioeconomic status as much as ethnicity and culture (Koffman et al., 2007); however, death anxiety, lack of awareness of formal advance care planning, and physician avoidance of family discussions around the end of life, have been identified as factors that particularly impact on access to services by people from black and ethnic minority heritage communities (Bullock, 2011; Periyakoil et al., 2015; Sanders et al., 2016).

A priority setting exercise to determine the research priorities in palliative and end-of-life care in the UK (Best et al., 2015) resulted in a consensus of 23 research questions with a selection of the top ten unanswered questions that warranted the most immediate exploration and research. Question 2 of the priority setting exercise asked how access to palliative care services could be improved for everyone, regardless of whom they were or where they were in the UK. Question 3 asks for evidence of the benefits of advance care planning or other approaches to incorporating patient preferences and who should be involved in this. The PHE report found that black and ethnic minority groups were underrepresented in the studies that exist in these areas (Calanzani, 2013). Disparities in access to palliative care services, end-of-life care planning, and higher levels of dying while receiving life sustaining treatments, was identified for people of black and ethnic minority heritage in the PHE report. Difficulties in communication between healthcare professionals and patients and their families was one of the most reported issues.

2.3 Ethnicity and choices at the end of life

For several complex reasons including a higher level of religiosity, a higher level of death anxiety has been identified in ethnically diverse heritage populations than the white majority population (Bullock, 2011; Depaola et al., 2003; Johnson et al., 2016; McDermott & Selman, 2018; Ohr et al., 2017; Sanders et al., 2016). This has been found to inhibit discussion of death in families. The lack of planning conversations may be an influence on the higher rate of people from ethnically diverse heritage communities dying in hospital and dying whilst still receiving life sustaining therapies than their white counterparts (Barnato et al., 2009; Chiarchiaro et al., 2015; Fazil, 2018), with adult children commonly becoming surrogate decision makers. Such decision-making can be burdensome to surrogate decision-makers, who may have different views about what might be the best onward treatment options, but with little real knowledge of what their now incapacitated parent, would have chosen for themselves (Braun et al., 2008; Parks et al., 2011b). To explore this phenomenon of what helps and hinders family conversations about values and preferences, an inductive approach was needed to explore this unknown.

The limitations of discussions about end-of-life issues are multifactorial. For many, these are seen as being within the healthcare domain and there is an expectation that they will be conducted appropriately by healthcare providers when needed (Canny et al., 2023; Neuberger, 2013). For others they are seen as something more in the domain of society than healthcare (Sallnow & Paul, 2018; Sallnow et al., 2022). However, this is still an area that causes distress and is not always done in a timely way to enable people to voice preferences and be involved in decision making about their care options at the end of life (Willmott et al., 2016). A lack of prior conversations about care preferences also results in distress and conflict between family members (Chiarchiaro et al., 2015). This further reduces quality-of-life at the end of life when lack of preparatory conversations results in late transitions of places of care with confusion around what the gaols of care now are (Makaroun et al., 2018).

Following their study on end-of-life conversations with south Asians in end-stage renal failure, Wilkinson et al. (2016) question whether it is about ethnicity or if organisational culture around having these discussions is the biggest factor inhibiting these discussions taking place. Others suggest this reluctance by healthcare professionals to raise end-of-life preference conversations, stem from perceptions that health literacy, not race, predicts end-of-life care preferences (Volandes et al., 2008).

In some studies of ethnically diverse heritage communities, there is a strong desire for family-based decision-making, rather than autonomous decision-making, around healthcare decisions, with an expressed trust that family will make the right decisions when needed (Frey et al., 2014; Samanta & Samanta, 2013). Physicians report avoiding end-of-life planning conversations with minority heritage families due to perceptions around the difficulties scaling down treatments can generate for families and for subsequent care delivery (Frey et al., 2014; Periyakoil et al., 2015; Willmott et al., 2016). This included physicians, who were themselves from ethnically diverse heritage backgrounds, who reported concerns about offending cultural norms and managing difficulties around truth telling. A lack of understanding of the perspectives of people from ethnically diverse heritage communities about the way in which end-of-life planning conversations may be best approached and handled, is a key challenge for the initiation and provision of best practice of culturally sensitive end-of-life care (Periyakoil et al., 2015).

Whilst there is an increasing amount of literature exploring the views of different ethnic groups on these topics, one group whose views are not widely available in current literature is that of people with an African or Caribbean heritage living in the UK.

2.4 Making a start on the project and deciding the focus

I knew that I approached this study with a particular world view. Since starting in my profession of nursing, having had my gap year exposure to the hospice, I have had a strong belief that not all deaths are bad deaths. I feel that palliative care can play a role in helping people to achieve as good a death as possible. I also believe and value that people can work through social and spiritual crises to come to a place of greater acceptance of dying, if symptoms can be better controlled and there is a greater openness in families and communities that a person is on a dying trajectory. People applying a palliative care approach, when practised well, utilise a wealth of knowledge that has been developed to help patients and families in this area.

As outlined in Chapter 1, my own experiences of working with people of African and Caribbean heritage alongside the lack of research evidence of the views of this group of people led me to develop the following study intention. Through this study an understanding of how the experiences, contexts and social processes of people of African and Caribbean heritage shape their views of taking a family approach to planning conversations for the end of life is investigated.

Initially, as part of the process of deciding what the study questions for this PhD may be, it was important to explore some of the assumptions I as a researcher held. It was also important to find out what was known through previous research about my area of interest and what questions we had as a research team. I started with a story board (Figure 1). It felt important to explore several aspects of this subject matter. I had a particular interest in understanding what it means to people in these communities, and what their values and beliefs are around end-of-life planning conversations.

Questions that seemed important to consider by searching current published literature included:

1. Are the perspectives of ethnically diverse heritage populations any different to the majority population in the UK regarding attitudes and perspectives around end-of-life family conversations?

2. What does it mean to talk about ethnically diverse heritage populations, who are they, and how does their history impact on aspects like attitudes to dying, and attitudes to prospective care planning conversations?

3. What populations have already been explored, are there any voices not represented in this conversation in the research literature?

Some of these more profound questions around beliefs and values of different populations, and the values on which palliative and end-of-life care have been developed, are discussed in the concept analysis in chapter 4. This discussion explores the hysteresis experience of some people of ethnically diverse heritage in relation to the way in which palliative care and future planning conversations are presented.

Figure 1: Initial study storyboard

2.5 The role of adult children in end-of-life conversations

When I started this journey in 2016, there were only a limited number of studies in the UK around diverse cultural experiences of elements of palliative care including early end-of-life conversations. Systematic reviews highlighted that much of the literature they synthesised came from the USA (Dixon et al., 2015; Evans et al., 2011; Ladd, 2014; Sanders et al., 2016). There was some consensus summed up by Sanders et al. (2016) who suggest that in black and ethnically diverse heritage communities, families play an integral role in the lives of patients and there is nearly universal trust in families to take responsibility for primary decision making. This is matched by high levels of distrust in the healthcare system and intentions of clinicians due to the historical legacy of slavery, medical abuse and structural racism that these communities have experienced in the USA (Hong et al., 2018).

My initial explorations of the literature in this area alongside my clinical experiences led me to a focus on the role adult children play in these end-of-life decision making situations. So often adult children become the default decision makers for their parents as their parents deteriorate. The existing literature focuses on the views of the older people rather than exploring why adult children play such a significant role in end-of-life decision making in ethnically diverse heritage families (Sanders et al., 2016). There was little research exploring the perspectives of adult children on the decisions that need to be made or whether their perspectives differed from those of their parents. Additionally, there was little research on whether adult children ever discuss end-of-life issues prior to the older person becoming infirm. I carried out a brief review of the literature as part of developing the initial ideas around my PhD application. The methodology of this review was presented as a poster at the European Oncology Nursing Society Conference October 2016 (Appendix 1). Descriptive themes generated from the review process highlighted the perspectives of both older adults and their adult children of black and ethnically diverse heritage on end-of-life decision making.

Synthesis of the papers in the review highlighted that there is a higher rate of dying in hospital, and preference for life sustaining treatments therapies in deteriorating situations, amongst people of black and ethnically diverse heritage than their white counterparts

(Hanchate et al., 2009; Johnson, 2013). Also, that a higher proportion of people from black and ethnically diverse heritage populations die whilst still receiving life sustaining therapies (Barnato et al., 2009). There is a stated belief in and a desire for a family based decision-making model around healthcare decision making with an expressed trust in the family to make the right decisions when needed.

In some studies, the role of family in end-of-life decision making in diverse populations was explored in more depth (Bullock, 2011; Glass & Nahapetyan, 2008; Gutheil & Heyman, 2006b; Ko & Berkman, 2010; Moore et al., 2003; Parks et al., 2011a; Venkatasalu et al., 2013). These studies describe the role of adult children in blocking conversations about dying, initiated by their elders or by others due to their own death anxieties. This, coupled with the reluctance of the elders to burden their children with discussions about end-of-life preferences, leads to a lack of knowledge of the end-of-life preferences of these elders when their capacity is reduced and decision making needs to take place, with potentially a lack of congruency between the wishes of elders and the decisions made by their children on their behalf (Frey et al., 2014; Parks et al., 2011b).

Studies found in the 2017 search were mainly descriptive and there was no deeper and more inductive exploration of data in these studies of end-of-life communication between elders and their children either here or in the USA as described by Sanders et al. (2016). This stimulated me to consider doing a more ethnographic review of this literature, looking for meanings or elements of understanding in the interplay of these findings. The next step was to conduct a systematic literature review relating to end-of-life conversations in families of ethnically diverse heritage. I used Noblit and Hare’s process of meta-ethnography to create a range of constructs that clarified the dynamics at play (Noblit, 1988). The meta-ethnography approach taken is discussed in the next chapter, Chapter 3, alongside the related published paper.

Together with evidence of socioeconomic disadvantage leading to low levels of health literacy, and some evidence of high religiosity in these communities, favouring choices for more aggressive end-of-life care, there does appear to be a higher level of general death anxiety in these communities than in the white majority population (Hong et al., 2018; Johnson et al., 2016). The impact of having a high level of death anxiety is that it inhibits discussion of death. These factors also result in more limited completion of written advance care plans in these communities with a preference for more verbal conversations with family members; however, there is limited evidence of these conversations influencing end-of-life decision making. In their illuminative piece of work, Sanders et al. (2016) caution that the studies they reviewed offer contradictory findings which, when examined in greater depth, showed less cultural differences than is commonly reported. More detailed examination is needed with consideration of aims wider than whether advance directive documentation has been completed or not.

2.6 Exploration of concepts used in this work

Prior to exploring the literature that relates directly to the topic of family conversations around end of life, some common concepts that are used in the study are explored in this section. They will include the demographics and terminology used around ethnicity, palliative and end-of-life care, advance care planning and public health palliative care. The explorations include a discussion on definitions of these potentially ambiguous terms which include statements about how these terms have been understood and interpreted in the writing up of this study.

Ethnicity nomenclature

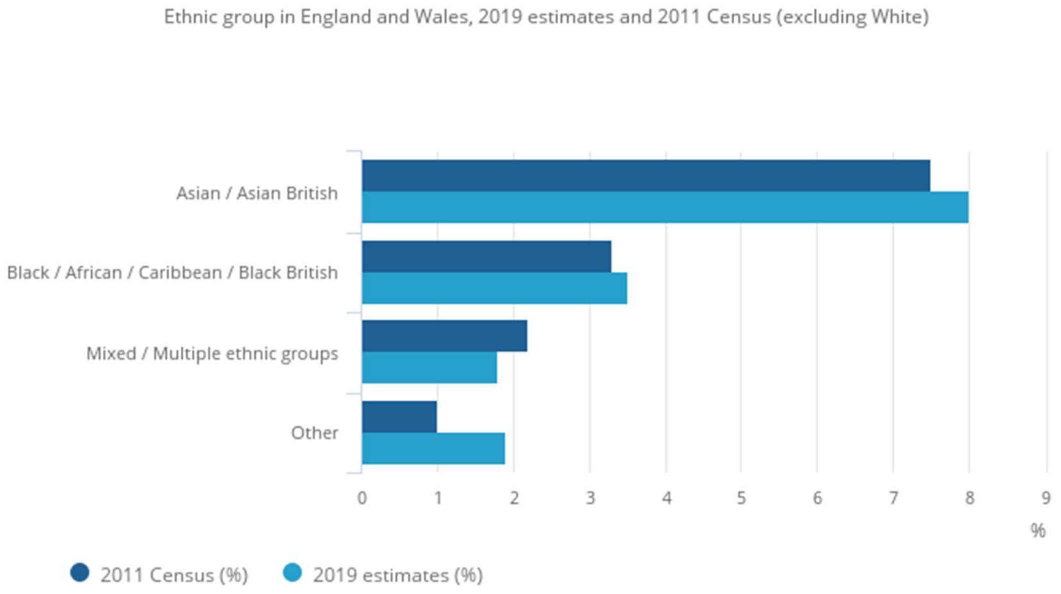
Terms such as black and minority ethnic (BME) or black, Asian and minority ethnic (BAME) are difficult and do not wholly describe diverse groups of people. Ideas of identity are complex and one of the risks that needs to be overcome when undertaking research with ethnic minorities is that assumptions about homogeneity may be made (Williams et al., 2012). This work is focused on understanding the experiences of people who come from communities who have experienced first or second-generation migration over the last 30 to 40 years into societies where palliative care and advance care planning is an established part of the health service offer. To denote populations who have experienced this migration into countries such as the UK, the term of ethnically diverse heritage will be used (Islam et al., 2023). It is acknowledged that this is complex, dynamic and risks assuming a conformity that does not exist. Care is needed to recognise these limitations.

This study began in 2016 and this conversation about terminology is one that is changing as people understand the implications of using particular terms. For the first part of this study, early story boards, the literature review process and resultant meta-ethnography were conducted using terms like black and minority ethnic (BME). This is retained in this piece as that work is now complete and published. Latter parts of the thesis use the term of ethnically diverse heritage. I acknowledge this results in some discrepancies through this piece of work which can be jarring to the reader. This is one of the limitations of doing a piece of work over a long-time frame when the field of practice and the doxa used is changing.

Ethnicity demography

In the UK where this study was undertaken, 84.8% of people in the census described their ethnicity as white (ONS, 2019).

Excluding white populations, the ethnic breakdown in the UK is illustrated in Figure 2:



Source: Office for National Statistics – 2019 population estimates by ethnic group, experimental statistics

Figure 2: Ethnic diversity in the UK

However, in London those identifying as White British accounted for 43.4% of the population, the other most common ethnic groups in London were Other White (14.6%), Black African (7.9%) and Indian (7.0%).

Although there have been studies exploring perspectives on end-of-life conversations in some ethnically diverse communities in the UK, mainly south Asian, the perspectives of this significant community of Black African, Caribbean and Black British is limited.

Palliative and end-of-life care

Definitions of palliative, end-of-life, terminal care and hospice are subject to constant debate. Whether they refer to the same fundamental principles of care or whether they each refer to care relevant to a different part of the illness trajectory is hotly debated. Whilst there is a desire to have a universal definition, there has been a constant debate about the scope of palliative care. In part this focus on definition is part of a move to enhance access to a care approach that focuses on symptom control, effective communication and dignity for people facing serious, life-threatening illnesses (Ryan et al., 2020). The first international definition by the World Health Organisation (WHO) in 1999 defined palliative care as a needs-based service and as 'an active total care for people "not responsive to curative treatment" that improves the quality of life of patients and their families'. In 2002 the wording of the WHO definition of palliative care changed to an 'approach' rather than 'active total care' and proposed that palliative care can be delivered by all healthcare workers, with specialist teams only required for complex palliative care needs. This palliative care approach uses a 'team approach', and the population served was changed to those 'facing the problems associated with life-threatening illnesses'. Palliative care prevents and relieves suffering, through the early identification, and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual' (WHO, 2020).

This new WHO definition suited countries where palliative care was developing as a universal service, such as in the UK, branching out from being centred on patients with cancer to include patients with a range of long-term conditions like heart, respiratory and renal disease. The demand for palliative care was high but provision was constrained by the limited availability of specialised teams. These teams played a crucial role in not only delivering direct patient care but also in education. A key responsibility of specialist nurses was to extend palliative care knowledge and skills by training the wider healthcare workforce, ensuring the broader adoption of a palliative approach across various settings. However, despite this focus on education, the scarcity of specialised resources remained a major barrier to comprehensive palliative care delivery.

Of people who could benefit from palliative care, 86% do not currently receive it because it is either not available or because access to palliative care is limited by a range of factors, including an assumption it is only appropriate in the last days of life (WHO, 2022). Limited availability of specialist palliative care drives the continuing debate over the best way to define care given to improve the way people die (Hui et al., 2013; Wee, 2016). The International Association for Hospice and Palliative Care developed a consensus-based definition of palliative care that associated it more closely with care throughout the trajectory of serious illness, particularly as there was evidence that early introduction of palliative care as a symptom management approach improved outcomes for people with cancer, including length of life (Radbruch et al., 2020). Their definition returned to elements of the WHO 1999 definition where palliative care could also be seen as supportive care:

> Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers (Radbruch et al., 2020).

As this did not concur with all voices in the UK and Europe, the European Palliative Care Association conducted a Delphi exercise involving 109 international palliative care experts to create this consensus definition based on the World Health Organisation (WHO, 2002) definition:

> Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount…..Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death (Payne et al., 2022, p. 685)

End of life was defined primarily in terms of time, with individuals often considered to be at the end of life when they are thought to be in their final year. However, it is acknowledged that predicting this time frame is challenging and can vary significantly (Department of Health, 2008; Wee, 2016). End-of-life care decision making refers to decisions made by people for themselves or made by proxy decision makers such as family members. In many countries there is legal provision that suggests others can only make decisions when that person has lost the capacity to make decisions for themselves due to their deteriorating ill health (Mental Capacity Act, 2005). In some countries such as the UK, hospice care refers more specifically to care provided by multiprofessional teams linked to a specific community facility or hospice, which are often voluntary aided organisations (Hui et al., 2013; Meghani, 2004). However, in other countries end-of-life care is called hospice care where it is commonly considered to be care developed for people with a prognosis of six months of less.

Another way to conceptualise what is meant by the term end of life is to consider some of the lifespan development models from the domain of psychology. In Erikson's lifespan development model, the final stage is characterised by the conflict between ego integrity and despair (Erikson, 1994). This stage typically occurs in late adulthood and involves individuals reflecting on their lives and determining whether they are satisfied with their accomplishments or filled with regret. For people living with a life limiting diagnosis in the deteriorating stages of their illness, Erickson suggests that in this last developmental stage of their lives it can be valuable to have the opportunity to work through the crisis by evaluating life; engaging in activities to promote ego integrity, such as mending relationships; putting their life into order; and perhaps doing things they have not had the chance to do before. Palliative care is about good symptom control and open conversations that may enable people to do some of this developmental work as they approach the end of their lives. Erik Erikson's final developmental stage, ego integrity versus despair, can therefore be linked to the end of life. Although normatively describing older people, this end-of-life stage is also applicable to people coming prematurely to the ends of their lives as similar life jobs are a positive way of managing this difficult period in life.

In this study, with Erikson's last developmental stage providing a lens to consider this through, the EAPC consensus definition of palliative care is used (Payne et al., 2022). In this definition the term palliative care will encompass hospice and end-of-life care and be considered to refer to a period of up to about a year, although for people with a known deteriorating illness this may be longer.

Advance care planning and family conversations

Debate exists concerning the value of advance care planning, whether it is too centred around unhelpful concepts like the notion of a 'good death', and whether it achieves any significant outcomes (Borgstrom, 2020; Collier & Chapman, 2023; Morrison et al., 2021; Pollock et al., 2024). How advance care planning might relate and apply to family conversations is important to explore and a core part of the rationale for this study. This is developed more fully in Paper 2 through a concept analysis which unpacks the experience of hysteresis that can occur around notions such as future death planning. To add clarity to this exploration, some discussion of the definitions and understandings of terms, such as advance care planning, used in this study are outlined. How family conversations are a core part of advance care planning and the notion of the impact of early conversations on achieving a good death is also touched upon, both with some consideration of how culture plays a role and how this may differ between generations.

Definitions

Advance care planning is a broad term that covers elements from light spontaneous conversations within families and between friends about things people may want in the future and perhaps at a time when they are no longer able to express themselves, to more formal written advance care plans that have legal standing and direct impact on types of care given by healthcare professionals at the end of life. These latter written documents are referred to as advance directives and include directives such as do not resuscitate orders (Mental Capacity Act, 2005).

Whilst there is a focus in some research on the completion of advance directives, advance care planning encompasses a much wider range of activities that range from conversations about values and preferences with family, friends and healthcare professionals to much more formal documents, such as advance directives to refuse treatments like cardiopulmonary respiration and intubation. The consensus definition is:

> Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be considered should they, at some point, be unable to make their own decisions. (Rietjens et al., 2017) e546

History and aims

Preparing to enable a peaceful death has shaped the development of palliative care since its origins in the hospice movement in the 1960s. In the USA, the Patient Self-determination Act was passed in 1990 which legislated the requirement for healthcare facilities to advise patients, on admission, of their rights to be involved in health decision making and to make a legally standing advance care directive (Carr, 2011). The aim of this legislation was to promote conversations around preferences for care and preferred limits of care and allow people's wishes to be considered even if they lost capacity as they moved towards the end of their lives. During the 1980s and 1990s writing advance care plans, in the form of living wills, became popular in many parts of the world particularly for people affected with illnesses like HIV and AIDS. However, in the UK, it was not until the Mental Capacity Act (MCA, 2005) was passed that these advance care plans had any legal standing.

The Mental Capacity Act (2005) allows people to complete written signed and witnessed Advance Directives to Refuse Treatments (ADRTs). If a person later down the line lacks capacity to decide for themselves, these can be used to prevent the use of treatments such as cardiopulmonary resuscitation and artificial feeding being administered if it is not what they would have wanted. Advance statements about treatments or circumstances the person might desire can also be recorded but these are not legally binding and serve simply as a voice as to what that person may have chosen for themselves if they had capacity to do so at the time. If these refer to wanting treatments, this option should be considered but ultimately the medical team will make the decision about what treatments are in the best interest of the person and therefore whether they should or should not be administered at the time.

The Mental Capacity Act (2005) was followed by the first national government policy for the provision of palliative and end-of-life care in the UK, The End-of-Life Care Strategy, (Department of Health, 2008). This strategy (Department of Health, 2008) was a pathway created with the aim of establishing better and wider access to palliative care. The first step on the pathway recommended the initiation of open and informative conversations at an early stage of the dying process. This first step was pivotal to enabling the expression of preferences and allowing actions to take place to enable those preferences to be worked towards, shared and developed with professionals and family members. Following this type of conversation, a written or verbal advance care directive or plan is used to start establishing services early and to document the type of care the individual wishes to receive and their preference for place of care in case they lose capacity or are unable to express a preference (Henry et al., 2008).

More recently, using a multidisciplinary Delphi exercise, advance care planning was defined ‘as a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care, with a goal that they can receive future medical care that is consistent with their wishes’ (Sudore et al., 2017). The emphasis has become more about having conversations and discussions about wishes, than the need to have a written care plan. In their review, Fleuren et al. (2020) found that five underlying goals of advance care planning include respecting individual patient autonomy, improving quality of care, strengthening relationships, preparing for end of life, reducing over-treatment.

Outcomes

Early studies, conducted mainly in the USA, focused on measuring outcomes like the uptake of medical treatments or completion of forms and place of care at the point of death (Brinkman-Stoppelenburg et al., 2014). Studies demonstrated lower use of life prolonging medical treatments where there was a do not resuscitate form in place; It was noted many of these studies were quantitative observation studies so it is not known whether the form completion influenced care decisions or whether forms were completed on seriously ill patients for whom lower intensive care would have been chosen anyway.

It was rarer for studies to report on outcomes around symptom control, patient and family satisfaction or fulfilment of previously stated end-of-life wishes (Brinkman-Stoppelenburg et al., 2014). Their systematic review showed a higher use of palliative and hospice services following a limited form of advance care planning such as the completion of a do not resuscitate form. Early palliative care referral did result in fewer emergency hospital visits, subsequent hospitalisations, intensive care admissions and hospital deaths (Hui, Kim, et al., 2014).

Advance care planning for people with dementia is one that is increasingly studied. This is a field where early advance care planning with people before they lose capacity has been found to be less useful than advance care planning with families when it is clearer what people's end-of-life needs may be (Bavelaar et al., 2023). They found that family caregivers had less anxiety about upcoming decision making and better satisfaction with care being offered after an advance care planning intervention. This raises the question about whether advance care plans can be a way of tempering the stress or burden of surrogate decision making for family members or whether in other situations they do not offer that support.

A recent study exploring the views of patients, their caregivers and the public using deliberate group discussions found that participants felt planning conversations around wills and funerals were helpful but believed that treatments and the process of dying were too unpredictable to plan for (Wilson et al., 2024). However, adding to the complexity of this, participants felt that thinking about death and dying issues was easier as an abstract concept than it would be when people were thinking about their own bereavement (Pollock et al., 2024), so there remains indecision about what is helpful and at what point in time and with whom the most helpful discussions are with.

Public health palliative care

There remains a tension between death being a social process and led by agents in society and one in which health professional care in the form of palliative care should play the lead

(Kellehear, 2024; Sleeman et al., 2021). Public health palliative care grew out of a movement designed to counter the increasing medical dominance over the field of dying in the form of professional driven palliative care (Sallnow et al., 2016). Death is an important part of normal human existence and plays a significant part in the way in which society functions both by how death is recognised, managed and remembered, and in the way cultural norms govern bereavement (Conway, 2008; Walter, 2017). Public health palliative care explores how communities can lead and work together with professional palliative care to help with the relief of suffering that is common with modern dying where people are increasing dying after long periods of deteriorating illness.

Since the End Of Life Care Strategy (Department of Health, 2008) there has been a widely growing movement in the UK of raising public engagement with the concept of dying and the skills to talk about death and facilitate more planning and less fear, with the aim of achieving better dying and more opportunity for people to die in the place of their choosing (Conway, 2008; Dying Matters Coalition, 2018). This has developed into a movement of public health palliative care. The importance of raising public engagement with the concept of dying and helping the public to develop the skills to talk about death, has been recognised as an essential step to achieve better dying (Sallnow et al., 2022).

As part of this study, this question about domains of influence will be explored. Are end-of-life family conversations helpful? Are they happening and if so in what form? Are they best as societal family conversations amongst all families or as conversations initiated by health professionals in the face of life limited deteriorating illness?

Chapter 3: Literature review

3.1 Introduction

As an initial exercise in undertaking this study of family conversations around end of life, I completed a literature searching module at Lancaster University, which was delivered online to a group of PhD students who were spread out across the globe. The module involved a high level of collaborative learning and asynchronous group work. This allowed us as students to explore a range of different literature review methodologies and to consider collaboratively which methodologies best suited each type of review question. During this process both realist reviews and meta-ethnography inspired me as they each held context as an important factor to consider. They also both promoted an inductive approach to seeking a deeper understanding of the literature being reviewed rather than a descriptive thematic analysis. Realist methods offer a possibility of exploring a wide range of sources (Booth et al., 2016). This was an attractive possibility as I had already found some reports I would like to include. However, this is an area where some systematic reviews existed, and I was keen to draw something that was perhaps deeper than a description of what the literature has to say.

The aim of this review was to explore what is known about the views articulated by elders of black and ethnically diverse heritage communities and their children about having end-of-life conversations within the family. Such views are potentially wide ranging and influenced by several cultural factors. Studies in this area carried out in the USA identified the pivotal role adult children play in influencing the discussions held in families around end-of-life care planning (Glass & Nahapetyan, 2008; Gutheil & Heyman, 2006b).

Studies that identified causal mechanisms for a lack of family conversations were qualitative or mixed method studies but contained little exploration of this factor and there is limited association with related theory. For this reason, meta-ethnography using the structure provided by Noblit (1988) was chosen to explore the current literature around this topic. Gaining a deeper understanding of this aspect of end-of-life communication is valuable in highlighting what Noblit and Hare call a line of argument or salient understanding which can be used to explore culturally appropriate methods to improve end-of-life conversations within families (Calanzani, 2013; Sanders et al., 2016).

3.2 Meta-ethnography

Meta-ethnography was developed by Noblit and Hare (1988) as a systematic approach to synthesising qualitative data, offering a structured way to compare and contrast findings from multiple studies. Meta-ethnography is designed to recognise the unique nature and context of the qualitative studies being reviewed. Rather than creating an aggregation of the study findings, the process of meta-ethnography is to construct an interpretation of firstly the authors' interpretations of their study findings and then a reflexive interpretation by the meta-ethnographer (Hammersley, 2012).

Meta-ethnography involves re-analysing qualitatively collected data to inductively identify patterns and concepts (Campbell et al., 2011). These findings are then aligned with relevant theories to develop explanatory understandings through a process of induction, thereby promoting conceptual development using a meta-ethnography of what is understood about the influence of families and their attitudes to and participation in the end-of-life planning of their elders could be used to shape the current study. I considered it would enable a better understanding of what the core issues worth further exploration in the current study might be.

3.3 Aim of the review

The aim of this meta-ethnography was to identify and explore communication patterns and factors that support or inhibit end-of-life conversations within families and by taking a meta-ethnographic approach, elucidate understanding of any underlying cultural dynamics that influence these interactions (Noblit, 1988). Drawing on Bourdieu (1990)'s concept of practice, this meta-ethnography was developed to achieve a better understanding of the habitus people have with regards to family members living to older age and potentially approaching dying, and how these impacts on the end-of-life care conversations that take place. The aim was to identify the 'storylines' of the studies being synthesised to look for common metaphors, concepts and ideas; Noblit and Hare (1988) describe this as a line of argument. This was achieved by integrating ideas, exploring the metaphors that were used and developing concepts from the different perspectives of the original studies (Britten et al., 2002) . To gain an understanding of perspectives, only qualitative studies were synthesised. The synthesis also included findings offered in the grey literature as some of the more recent work in this area in the UK has been produced in report form rather than in journal articles.

Paper 1 is an outline of this process of meta-ethnography, as published in the Sage Journal, Palliative Medicine. During the inductive process of this meta-ethnography of 13 qualitative studies, four storylines were developed. ‘My family will carry out everything for me, it is trust’; ‘No mum, don’t talk like that’; ‘I leave it in God’s hands’; and ‘Who is going to look after us‘. The presentation of this paper is followed by a more detailed reflection on this meta-ethnographic process than space allowed for in the paper.

3.4 Paper 1: Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography

Poster presentation; European Association of Palliative Care conference 2018 (Figure 3)

Submitted to Palliative Medicine: 20.11.2018

Editorial acceptance and sent for peer review: 07.12.2019

Application for APC waiver supported with confirmation of student status: Yes

Reviewers' comments received: 30.06.2019

Response to reviewers: 20.08.2019 (Appendix 4)

Paper accepted: September 2019

Reference:

De Souza, J., Gillett, K., Froggatt, K., & Walshe, C. (2020). Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography. *Palliative Medicine*, *34*(2), 195-208.

Figure 3: Poster Presentation EAPC 2018

'No Mum, don't talk like that'

Perspectives of Elders from Black and Minority Ethnic communities on End-of -Life conversations with their Adult Children

A Meta-ethnography

Joanna De Souza [1] Karen Gillett [2] Catherine Walshe [3] Katherine Froggatt [4]

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Background

- Poorer outcomes for people from black and minority ethnic (BME) groups in end of life care persist.
- More BME people die on life sustaining measures & engage less in advanced care planning resulting in higher levels of distress for families.
- End of life decision making for BME elders is often carried out by adult children.
- Family members have poor congruency with their elders around end of life decisions.

Aims

To explore the perspectives of Black and Minority Elders about their experiences of conversations with their children about their end of life care preferences

Literature search

- Cinahl, Medline and Psych Info were searched
- Citation snowballing - *reference lists of retrieved articles and related literature reviews were searched by hand*
- Information foraging - *the works of known writers in the field were further explored*
- Limits were applied. 14 empirical qualitative studies conducted in the USA, Canada and the UK were synthesised.
- Populations : five African American, three South East Asian, six Latino

Methods – Meta- ethnography

1. Getting started
Scoping the field

2.Defining the area of interest
Systematic literature search

3. Reading the studies
Reading and rereading, recording metaphors

4. Deciding how the studies are related
Exploring similarities and differences

5. Translating the studies into each other
Seeking meaning of the metaphors

6. Synthesising translations
Developing the storylines

7. Expressing the synthesis
Publication and publicity

Conclusion:

Understanding the perspectives of elders and their adult children on end of life conversations, a research priority in enabling better outcomes for dying people in BME communities.

Emergent Storylines

My Family will do right by me.

Trust : ***'I will depend on my children. I trust my children the best.'***

Elders had confidence in family to provide care and make decisions for them at the end of life, even when acknowledging those decisions may be different to the ones they would make for themselves.

No Mum ! Don't talk like that !

Protection: ***'Mom, please don't talk about such things.'***

Elders want to protect their children from having to think about difficult things. When they did speak of their own end of life, the children protected themselves by closing down the conversations, acknowledging it was too difficult to think about.

I leave it in God's Hands

Religiosity & Fatalism: ***'You just have to put your faith in the Lord.'***

Believing that God or life itself will decide when the time for dying is imminent inhibited end of life planning conversations.

Who will take care of us ?

Ambiguity & Change: ***'Kids are different now, they have their own lives.'***

Some elders expressed an awareness that as they and their families assimilated into new cultures, things were changing. This was a signal that they would also need to change and hold different expectations of their children.

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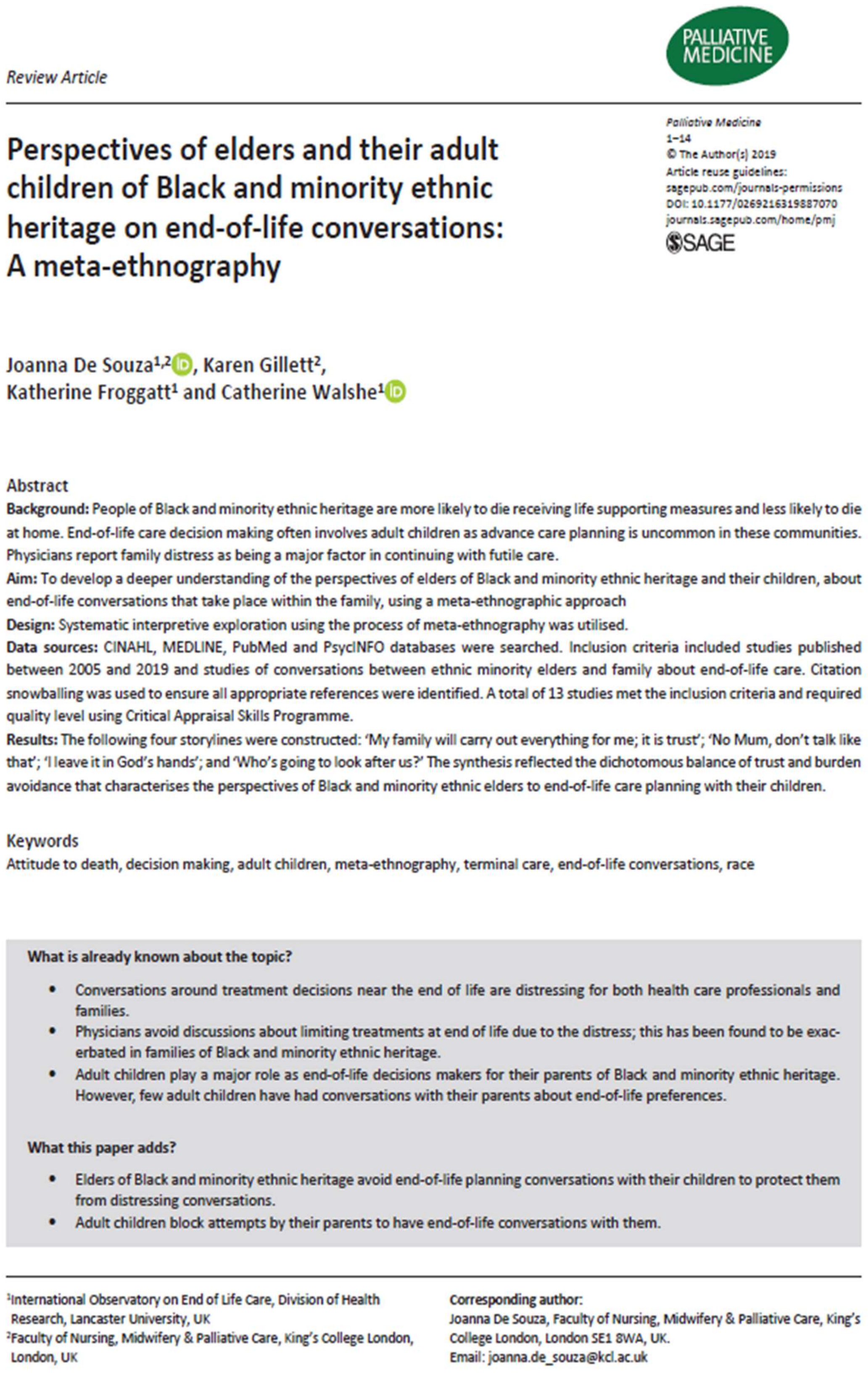

Review Article

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Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography

Joanna De Souza[1,2], Karen Gillett[2],
Katherine Froggatt[1] and Catherine Walshe[1]

Abstract

Background: People of Black and minority ethnic heritage are more likely to die receiving life supporting measures and less likely to die at home. End-of-life care decision making often involves adult children as advance care planning is uncommon in these communities. Physicians report family distress as being a major factor in continuing with futile care.

Aim: To develop a deeper understanding of the perspectives of elders of Black and minority ethnic heritage and their children, about end-of-life conversations that take place within the family, using a meta-ethnographic approach

Design: Systematic interpretive exploration using the process of meta-ethnography was utilised.

Data sources: CINAHL, MEDLINE, PubMed and PsycINFO databases were searched. Inclusion criteria included studies published between 2005 and 2019 and studies of conversations between ethnic minority elders and family about end-of-life care. Citation snowballing was used to ensure all appropriate references were identified. A total of 13 studies met the inclusion criteria and required quality level using Critical Appraisal Skills Programme.

Results: The following four storylines were constructed: 'My family will carry out everything for me; it is trust'; 'No Mum, don't talk like that'; 'I leave it in God's hands'; and 'Who's going to look after us?' The synthesis reflected the dichotomous balance of trust and burden avoidance that characterises the perspectives of Black and minority ethnic elders to end-of-life care planning with their children.

Keywords

Attitude to death, decision making, adult children, meta-ethnography, terminal care, end-of-life conversations, race

What is already known about the topic?

- Conversations around treatment decisions near the end of life are distressing for both health care professionals and families.
- Physicians avoid discussions about limiting treatments at end of life due to the distress; this has been found to be exacerbated in families of Black and minority ethnic heritage.
- Adult children play a major role as end-of-life decisions makers for their parents of Black and minority ethnic heritage. However, few adult children have had conversations with their parents about end-of-life preferences.

What this paper adds?

- Elders of Black and minority ethnic heritage avoid end-of-life planning conversations with their children to protect them from distressing conversations.
- Adult children block attempts by their parents to have end-of-life conversations with them.

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- **Elders of Black and minority ethnic heritage express a preference for end-of-life decisions to be made by family proxies acknowledging that these decisions may not reflect their own preferences.**

Implications for practice, theory or policy

- **Focus is needed on the role played by adult children about their perspectives on having end-of-life conversations with their parents. This could lead the way for innovative community engagement in the development of public health palliative care that may result in more effective end-of-life care planning and engagement with palliative care provision.**

Introduction

Conversations around treatment decisions near the end of life are distressing for both health care professionals and families.[1,2] In Western societies, autonomous decision-making models for health matters are favoured. However, at the end of life, without early conversations having taken place, decision making is often left to family members, many of whom have little awareness of the preferences of the older person who is now dying.[3] In situations involving people of Black and minority ethnic heritage, formal end-of-life planning has been found to be low.[4,5] The aim of this synthesis is to develop a better understanding of the experiences and preferences of elders of Black and minority ethnic heritage and their children around end-of-life care conversations within their families. This may inform ways of facilitating earlier family-based conversations around illness progression and potential outcomes and perhaps provide a first step towards improving the difficult conversations that need to happen when someone is dying.[6]

Background

Impact of conversations on decision making at end of life. Many people receive treatments that do not prolong life nor provide a relief from suffering so are considered to be non-beneficial or futile in the last 6 months of their lives.[4] While improving the quality of the dying experience is an issue that is faced by all communities, people of Black and minority ethnic heritage are more likely to die receiving life supporting measures[5] and least likely to die at home.[7] One of the main drivers leading to the instigation of futile treatments is families' insistence.[8,9] The difficulties clinicians have in conducting potentially distressing conversations with Black and minority ethnic families about limiting treatment is often a deterrent to engaging in them at all.[9] Research with people of Black and minority ethnic heritage illustrate poor communication between health care professionals and families, and a lack of culturally competent end-of-life skills among these professionals when dealing with matters at the end of life.[10]

In part, difficult conversations at the end of life arise when family conversations about the end-of-life wishes of the dying person have not taken place and cannot now be elucidated due to their deteriorating condition.[2] Many older people feel they do not need to discuss their end-of-life preferences with their families because their children will know what they would want.[1,11] In general, older people do not want to live a long lingering existence and White majority populations find doing some kind of advance care planning is a comfort.[11] However with people of Black and minority ethnic heritage, discussing dying is thought to be taboo more often than in the White majority population which results in much lower levels of evidence of end-of-life family conversations.[8,11,12] These geographical differences in the way communities discuss dying are illustrated and explored in some recent studies which show greater levels of end-of-life planning conversations taking place in societies that favour autonomous models of decision making over more collective societal and family-based decision-making norms.[13–15]

Research exploring end-of-life conversations and decision making in a variety of Black and minority ethnic communities reveals high levels of fear,[16–18] worry or anxiety about dying which can inhibit a desire for palliative care. Fear can also inhibit discussions within communities or families about the potential death of a family member.[8,12,19,20] Anxieties around end-of-life care are complicated by a prevailing distrust of written advance care plans and a lack of expression of preferences by the elders themselves.[21–23] All these factors contribute to the difficulties encountered both by families and by health care teams when end-of-life care decision making is required in health care settings.

There is also a consistent desire by elders of Black and minority ethnic heritage and families for family-based decision making around health care decisions that can be in conflict with the prevailing model of individual autonomy.[8,24] Many elders of Black and minority ethnic heritage express trust that their family, in the majority of cases this being their adult children, will make the right decisions when needed.[12,19,20] However, poor congruency between the wishes of these elders and those of their children around end-of-life treatment preferences has been demonstrated.[3,25] Assumptions that elders of Black and minority ethnic heritage have a preference for continued interventions have not been supported by research.[8]

The complexities involved in achieving good dying among diverse populations has received much international attention over the past 15 years; however, the nature of

Table 1. Process of meta-ethnography.

Phase 1: Getting started	A scoping literature search identified adult children as an inhibiting factor in the end-of-life planning of Black and minority elders.
Phase 2: Defining the area that is relevant to the initial interest	A systematic and purposive search was undertaken using a variety of searching techniques.
Phase 3 Reading the studies	Deep inspection of the literature was conducted first and second constructs were identified using QSR International's NVivo 11 Software for coding. Metaphors identified.
Phase 4 Deciding how the studies are related	Consensus on how studies related to each other and which key metaphors in each stage would be chosen was discussed by team.
Phase 5. Translating the studies into each other	Re-reading and discussion were used to explore each study in relation to the others with a focus on the key metaphors. Reciprocal translations and refutational translations were noted.
Phase 6 Synthesising translations	Reinterpretation of metaphors and generation of cohesive storylines
Phase 7 Expressing the synthesis	The four storylines that were created are discussed in this article.

the interactions and conversations that take place between elders and their adult children and the impact this has on subsequent end-of-life decision making has not been considered in depth.[1]

Definitions. To ensure consistency with public body work in the United Kingdom and contemporary culture as portrayed by the main stream media, the term people of Black and minority ethnic heritage has been used in this work, however, with an acknowledgement of the limitations of such terms. One of the risks that need to be overcome when undertaking research with ethnic minorities is that assumptions about homogeneity may be made.[26] Ideas of identity are complex ones and there is now a greater respect for the issues it can bring for people labelled by others.[27]

Over the last decade, there has been an increasing debate over the best way to define care given to improve the way people die, with particular disparities around the terms palliative and end of life.[28,29] For the purpose of this review, end of life was defined as the time when people are considered to be in the last 6 months of life, acknowledging this timing can be difficult to predict. End-of-life conversations refer to conversations regarding preferences around place of care, decisions about end-of-life care interventions and important end-of-life rituals. Care decision making can refer to decisions made by people for themselves or made by proxy decision makers when that person has lost the capacity to make decisions for themselves due to their deteriorating ill health.[30]

The review

Selecting meta-ethnography and getting started

The aim of this review was to explore the views articulated by elders of Black and minority ethnic heritage and their children about having end-of-life conversations within the family. Meta-ethnography was chosen as the method to enable an in-depth exploration and greater understanding of prospective family conversations around end of life. The process of meta-ethnography aims to facilitate a greater understanding of a social phenomenon by synthesising the findings of qualitative studies retaining the rich context of the data through a seven-stage synthesis process (Table 1).[31,32] It is designed to develop new overarching concepts and theories with an emphasis on preserving original contexts within the synthesis of data from multiple studies.[33]

The data in existing studies consist of two forms: first- and second-order metaphors (see Table 2 for definition). A collaborative process of discussion of these metaphors was undertaken by the review team to seek links and translations between the studies being explored. The final stage involved developing overarching lines of understanding called lines of argument or storylines as a review team with an overall aim to develop new understanding rather than new knowledge.[34,35]

This collaboration aims to be reflexive with an acknowledgement of the inherent culturally laden assumptions that each reviewer brings to the process of interpretation. The interpretations are open to further discussion and debate by the reader.[34]

The main purpose of this review is to increase the understanding of the ways some families of Black and minority ethnic heritage operate around end-of-life conversations. It is hoped that the findings of the review will help to identify ways of engaging people of Black and minority ethnic heritage to think about strategies to enable better awareness of each other's preferences at end of life. An additional purpose of this review is to increase professionals' understanding of end-of-life communication in and with Black and ethnic minority families. The following aim and review questions were formulated.

Review aim. The aim of this study was to develop a deeper understanding of the perspectives of elders of Black and minority ethnic heritage and their children,

Table 2. Definition of terms.

Metaphors	These are ways of communicating knowledge about a concept that is symbolic of the interpretation the writer has given to the concept. Metaphors are therefore knowledge that is again open to reinterpretation.
First-order constructs/ metaphors	Quotations from primary study participants as reported by study authors.
Second-order constructs/metaphors	Interpretation of those findings made by authors of the original study.
Reciprocal and refutational translations	Process by which studies are read comparatively seeking insights from one study that help to illuminate aspects of another. Reciprocal translations occur when similar metaphors are found and assimilated. Refutational translations occur when the metaphors in one study contradict the metaphors in another.
Storylines (third-order constructs or lines of argument)	Interpretations of the synthesis team undertaking the meta-ethnography which have been drawn together to form a new interpretation.

Table 3. Search terms – facet analysis.

Search 1

1. Cultur*,
   MESH terms: culture, cross cultural, ethnography,
   OR Race MESH: Black, White, Asian, Hispanics
   OR Black and Asian Minority Ethnic OR Ethnic* OR race
   AND
2. end-of-life
   End of life OR palliat* to include MESH terms: palliative care, terminal Care, terminal care (Saba) Or attitudes to death OR death
   AND
3. Conversations
   MESH terms: advance care plan* OR advance directive* OR decision making OR expression of wish* OR communication

about end-of-life conversations that take place within the family, using a meta-ethnographic approach.

Review questions

1. How do older people of Black and minority ethnic heritage describe their experiences of having end-of-life conversations with their adult children?
2. How do children of elders of Black and minority ethnic heritage describe their experiences of having end-of-life conversations with their parents?
3. What influences do these experiences have on the way these elders feel and think about initiating discussions about their end-of-life preferences?

Deciding what is relevant

Search strategy. CINAHL, MEDLINE, PubMed and PsycINFO databases were searched for articles from 2005 to 2019; 2005 was used as a starting point as Jones[36] in the United Kingdom and Kwak and Haley[37] in the United States both published reviews of the current state of literature exploring ethnic differences in end-of-life experiences. Key words were matched to MeSH terms (Table 3). Seven studies were identified.

Generating a useful search was complex with search terms such as 'adult children' and minority generating large volumes of irrelevant hits. We found the most effective ways of choosing ethnicities to search was to use the term RACE which gave the MeSH headings of Black, White and Asian. We also included Hispanics as so many studies are done in the United States with this group. An analysis of all the MeSH terms linked to the initial 14 studies found by all types of searching was conducted; however, this identified that the chosen studies did not share any MeSH identifiers beyond generic terms such as human.[31,38] Two of the main studies in this area[39,40] had no MeSH headings associated with ethnicity, and Yonachiro-Cho had no end-of-life MeSH terms. Qualitative studies are not always identified by traditional search methods such as MeSH identifiers. Creative and purposeful searching is required. Citation snowballing[41] and information foraging[42] including Google Scholar searching were also employed to identify a further eight studies that fitted the inclusion criteria (PRISMA flow diagram; Figure 1). In total, 15 studies were selected for quality appraisal.

Study selection. Studies that had a focus on conversations about end-of-life planning between elders and their adult children were included. Inclusion and exclusion criteria were applied (Table 4).

Assessment of quality. The papers selected were assessed for quality using the critical synthesis form for qualitative studies, which is an adapted form of Critical Appraisal Skills Programme (CASP);[43] the scores were included in the data analysis table (Table 5).[52] Two UK-based studies were excluded at this point as they were written up as reports and did not contain enough details on methodology or results to be assessed and used.[53,54] Thirteen studies were included in the synthesis.

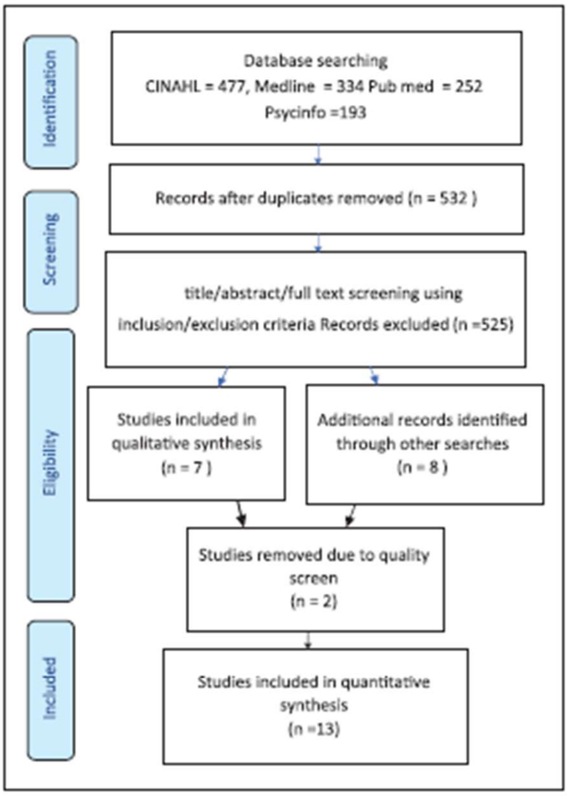

Figure 1. PRISMA 2009 flow diagram.

Reading the studies

Data extraction and synthesis. A data extraction form informed by the work of Campbell et al.[31] was used and results tabulated in chronological order (Table 5). Noblit and Hare[34] suggest reading should be in the form of deep introspection of the literature, exploring both the narrative patterns and also the meanings that are created in the mind of the reader. A more detailed data extraction table of the first- and second-order metaphors, using QSR International's NVivo 11 Software,[55] was conducted by J.D.S. and developed through discussion between the members of the review team (Supplemental Table 7).

Determining how the studies are related

A decision was taken to focus on the first-order metaphors (direct reports from study participants) to explore the conversations and experiences expressed in the studies as they offered rich insights into the experiences of the participants.[52] First-order metaphors had been widely used to illustrate the findings of the original studies by the study authors, as a result there were limited second-order metaphors (author interpretations) developed. The second-order metaphors were included where they offered further insights.

Translating the studies into each other

Review team discussions, using a concept mapping process, enabled the process of translations. Contextual notations helped to elucidate patterns that were more represented by particular ethnic groups or in particular geographical locations. An example of this was the difference in attitude towards healthcare professional instigated advance care planning. There was more distrust of the system in the United States than in other countries, and attitudes towards advance planning were more positive in south East Asian heritage in the United States and Canada where educational levels were higher. These differences allowed for both reciprocal translations and refutable translations to take place (Supplemental Table 7).

Table 4. Inclusion and exclusion criteria.

Inclusion	Exclusion
1. Empirical research	1. Systematic reviews and quantitative studies
2. Published in English	2. Studies focused on people with an established life-threatening condition where end-of-life care planning is specifically linked with deteriorating illness
3. Published in peer reviewed journals	3. Studies where language was a significant barrier
4. Published between 2005 and 2019	4. Studies where study questions relate to advance care planning initiatives or advance care planning tools
5. Data that were specifically attributable to people from Black and minority ethnic groups living in higher income countries which have established palliative care provision.	
6. Involving community dwelling elders over the age of 60	
7. Studies where discussions about end-of-life between elders and family members are discussed	

Table 5. Included studies.

Study details	Aim	Participants	Study design/method	Key findings	CASP score/13
Bullock et al.[44] USA	To identify themes that characterise what matters to African American elders who are faced with issues of death, dying and end-of-life care	African American elders (22) Median age 64 15 females 7 males All Christian Community dwelling	Grounded theory: Purposeful sampling Focus groups	Spirituality; burden on family members; trust; health insurance coverage; cultural concerns	11
Gutheil and Heyman[40] USA	To understand Hispanic elders' and adult children's concerns about end-of-life planning	Hispanic elders (10) Median age 66 Children (10) All female All Christian Community dwelling	Grounded theory (Strauss and Corbin): Focus groups	Communication; control; burden; spirituality; religious issues; importance of family relationships; communication regarding end-of-life planning	13
Glass and Nahapetyan[39] USA	To explore informal family communication about end-of-life preparation and preferences	Elders (15) Median age 78.6 Adult children (15) 13 White, 4 Black, 1 Asian All female Religion not detailed Community dwelling	Constructivist Open end interviews	Protection of the children; trust in others to make the decisions; preferences unknown; family rarely together; fear of death.	12
Ott[45] USA	To give voice to a culturally specific group by learning about their attitudes, opinions and experiences with living will documents	African American Elders (28) Median age 76.2 63% female 37% male Christian (26) No religion (2) Nursing home residents	Exploratory descriptive Focus groups	The value of artificial life supporting treatments; communication about end-of-life preferences; involvement of family members in end-of-life decisions; physician involvement in end-of-life decisions; the value of a living will	12
Cohen et al.[46] USA	To explore knowledge and attitudes and barriers to advance directives	Latino (20) Cambodian (19) Age mean 58.4 Religion not detailed Community dwelling	Exploratory Open ended Focus group Thematic analysis	Integration of belief systems: (a) religion, (b) destiny, (c) ideas about suffering; importance of quality of life; processes/preferences regarding decision-making: (a) family roles, (b) providers roles, (c) confusion/uncertainty regarding ACD and (d) openness to ACD	12
Ko and Berkman[21] USA	To examine the role of adult children in end-of-life decision making among Korean American older adults and how culture affects this process	Korean elders (23) >65 years Christian 17 Buddhist 3 No religion 1 Community dwelling	Grounded theory (Strauss and Corbin): Individual interviews and focus groups conducted in Korean	Diversity of opinion among participants: (a) Are children resistant or receptive to discussing parents' end-of-life treatment preferences; (b) whether older adults or their children should make decisions about end-of-life treatment; (c) whether decision making should be the responsibility of the eldest son or of all the children; (d) whether children would implement the parent's preferences for end-of-life treatment	12
Bullock[22] USA	Promote cultural competency in end-of-life care inclusive of extended family networks (part of a larger study)	African American elders (102) 84 females 15 males 98% Christian White elders (100) 75 females 25 males 98% Christian All over 55 Community dwelling	Exploratory mixed methods study Demographic questionnaire Focus groups with follow-up interviews Thematic analysis	African American compared to White; lack of trust in Dr decisions more; palliative care not enticing as corresponds with reducing life sustaining treatments; collective approach to decision making; fatalism; to plan or hasten death seen as anti-Christian	11

(Continued)

Table 5. (Continued)

Study details	Aim	Participants	Study design/method	Key findings	CASP score/13
Crump[47] USA	Exploring African American seniors' perspectives to inform health care professionals of decision making for patients who are seriously ill	African American elders 45 females 7 males All Christian Community dwelling	Community-based participatory research with focus groups with video prompted discussion	Primary themes: Trust; fear; relationships; lack of information/knowledge Secondary Themes: Deterioration of family/community; past discrimination; experiences; self-fulfilling prophecy; religion	11
Sharma et al.[48] USA	To examine the perspectives of South Asians living in the United States regarding end-of-life care	Asian Indian elders (12) 41–76 years 6 females 6 males Children (15) 23–36 years 7 femlaes 4 males Hindu (25) No religion stated (2) Christians and Muslims excluded	Thematic analysis Focus groups followed by demographical questionnaire	Attitudes towards death: Indian culture more accepting of death than US culture; family duty; preferences for information disclosure and decision making illustrated changes in societal structures; less reliance on children in terms of expectations but still looking for a family-based communication model	13
Venkatasalu et al.[49] UK	The perspectives of older South Asians towards talking about death and dying	South East Asian elders (55) 52–78 years 12 Muslim 3 Sikh 12 Hindu 5 Christian 1 non-religion 21 not detailed Community dwelling	Grounded theory (Charmaz): Focus groups followed by interviews	Avoidance as a cultural norm; avoidance as protection; assumption children will talk but not wanting to have conversations as it would upset them	12
Yonachiro Cho et al.[50] 2016 USA	To explore the knowledge, attitudes and preferences of Chinese Americans towards ACP.	Chinese American elders (34) 22 females 12 males 9 < 65, 25 > 65 Religion not specified Community dwelling	Grounded theory (Strauss and Corbin): Focus groups	Knowledge of advance directives; health as a factor in end-of-life decision making and communication; communication of end-of-life care preferences	13
Biondo et al.[51] Canada	To gain an understanding of the barriers and facilitators to participating in ACP and to determine the ways this community would like to engage in ACP	South Asian community members (57) 22–82 years 28 females 10 males Sikh, Muslim, Hindu Numbers not specified	PACER Co-design method Narrative synthesis using story analysis	Concept of ACP – foreign to this community – associated with organ donation and estate planning; barriers to participation in ACP – cultural aspects, religious beliefs and immigration challenges; eager to learn about ACP	13
Boucher[52] USA	How cross culturally shared characteristics of family involvement in health decisions, respect and duty, religiosity and fatalism might influence attitudes towards planning and decision making related to death and dying	Dominican elders (23) Puerto Rican elders (28) 38 females 13 males Largely identified as Catholic Community dwelling	Grounded theory (Charmaz and Sabrani): Semi-structured interviews	No significant differences found with apriori themes which included the following: Family involvement in health decisions/filial piety; religiosity/ spirituality/fatalism; accessing/using end-of-life care; autonomy; influence of death/dying on own future care decisions; death/ dying is a private matter. Stronger evidence of death denial than in previous findings	13

ACD: advance care directives; ACP: advance care planning; PACER: Patient and Community Engagement Research.

Table 6. Storylines.

Storyline 1	'My family will carry out everything for me; it is trust': trust, dependence and importance of family
Storyline 2.	'No Mum, don't talk like that': burden and protection
Storyline 3	'I leave it in God's hands': spiritual reassurance
Storyline 4	'Who's going to look after us?' ambiguity and change

Findings

Synthesising translations

Following the process of translation, overarching lines of argument or storylines were suggested by members of the review team. The studies were re-read as whole to consider what new interpretations were congruent with the primary data. Noblit[35] describes these as a new storyline which offers a new overarching interpretation of what is being related by the original study participants. Final extrapolation of the storylines took place following further discussion by the review team (Table 6).

The storylines

The storylines illustrated first the role elders envisioned their children will play in end-of-life decision making 'My family will carry out everything for me; it is trust'. The second aspect was the perception that adult children inhibit end-of-life planning conversations: 'No Mum, don't talk like that'. The third was the sense of fatalism often associated with religious beliefs: 'I leave it in God's hands'. The fourth is the recognition of change and realisation that things may need to be done differently: 'Who's going to look after us?' These storylines are explored below.

Storyline 1 'My family will carry out everything for me; it is a trust': trust, dependence and importance of family. Elders in all of the studies expressed perceptions of the centrality of family in end-of-life decisions. The metaphor – *'my family will do right by me'* – captured the sense of trust these elders had in their children's role as carers and decision makers for them at the end of life and the assumption that their children would be proxy decision makers for them 'when the time comes'. There was often no mention of spouses playing this decision-making role.[8] This sense of trust was linked to the metaphor *'Basically, you have to take care of me'*. It came from traditionally held views that as they had cared for their parents, their children would do the same:

> Yo te pari y tu tiene que cuidame a mi . . . basically, you have to take care of me. (Puerto Rican elder,[52] p. 360)

This sense of responsibility being taken to the point of complete dependence and a reluctance to accept outside carers is a feature found in other studies of Black and minority ethnic elders coping with severe illness:

> There was a common understanding among families that if a family member became sick, . . ., the family/children would naturally take care of them: I told my doctor that I have kids who will take care of me and I am comfortable with them . . . I don't need home care. (Canadian South East Asian elder,[51] p. 916)

In the studies of African American communities, there was less notion of familial responsibility, but more emphasis on community:

> There was a sense of comfort in knowing that there would be people of their own race or ethnic group available to care for them during the time of death and dying. 'Usually black people are all one . . . if you don't belong to a church, then you have a friend'. (African American elder,[44] p. 12)

A sense that the children would know the right thing to do without any prior discussions was expressed both as first- and as second-order metaphors:

> 'I did not have a specific conversation with them, but they know what I want'. 'My people will take care of me. They know'. (African American elder,[45] p. 120)

On questioning, we found many of them did not have a conversation with their families about their own wishes:

> Leader: Well, have you talked to them?
>
> No, but they know what is best for me. (Canadian South East Asian elder,[45] p. 120)
>
> When anyone in the family is faced with a difficult situation, everyone intuitively knows what their role is and what to do, and then right decisions are just made without us planning ahead. (Canadian South East Asian elder,[51] p. 915)

This lack of discussion was a form of protection practised by both parties:

> I don't think people ask where you die. I think the family makes that decision, family would come forward to take responsibility and make any necessary decisions on behalf of their older relatives, and thus shelter their older relatives from topics perceived to be unpleasant. (Asian elder,[49] p. 399)

For some, this felt secure because it was in fitting with cultural expectations. However, what appears clear is these decisions by family members may be incongruent with the preferences of the elders themselves. Elders in seven of the studies expressed a preference for limiting life sustaining therapies at the end of life:

> I don't want those machines . . . if I am sick. (Hispanic elder,[40] p. 62)

Storyline 2. 'No Mum, don't talk like that': burden and protection. This storyline offers insights from the experiences of these elders of the conversational dance that goes on between elders and their adult children, each looking to protect the other from what they perceive to be difficult burdens. There was an interesting mix of some elders not wishing to burden their children with end-of-life conversations and those not wanting to burden them with end-of-life decisions. In the two studies which included adult children's perspectives,[39,40] the children spoke of not wanting the burden of their parent's end-of-life decision making. Several of the study authors,[21,40,44,47,49,52] discussed this notion of burden and protection to be one of the most influential factors in conversations with children about end-of-life care planning.

A resonating metaphor in this storyline of protection and burden was the role adult children play, in limiting conversations about dying initiated by their elders or by others.[3,21,22,40,39,57] Although Hispanic elders *were* comfortable to discuss end-of-life issues with their children, the responses they met was illustrated by the following:

> They don't want to hear us. (Hispanic elder,[40] p. 62)

This culture of inhibiting conversations was prevalent in many of the studies, across different ethnic groups:

> When I tried to talk about this topic, my children were not willing to listen to me. They said, 'Mom, please do not talk about such things. They get angry when they hear me saying such things'. (Korean elder,[21] p. 170)

> When I anticipate any unfortunate scenario, I am immediately told to shut up and not to dwell upon it. (Canadian South East Asian elder,[51] p. 916)

The elders felt the children did not want to have the conversations their parents were hoping for. An elder reported their child had expressly said,

> No Mom don't talk like that. (Hispanic adult child,[40] p. 62)

The child explained that it came from a fear of losing their parents:

> We're all educated, but we don't want to talk about that [end of life] . . . Mom and Dad are not going to die. (Hispanic adult child,[40] p. 64)

One child suggested this reluctance to discuss dying was not just about facing the death of her parents but also linked to a cultural norm of avoiding conversations about dying:

> may be a taboo across the generations. (Hispanic adult child,[40] p. 65)

> This is classic of the Latino family, the hiding. (Hispanic elder,[40] p. 62)

Adult children are not the only people reluctant to talk about dying to protect others from burden. The first-order metaphor **'if I talk about this they will suffer'** was identified by elders in nine of the studies who spoke about not wanting to burden their children. Some elders were concerned that they were creating suffering and burden merely by discussing end-of-life issues. This was described by an elder:

> If I tell them, they're going to suffer; then I would suffer more seeing them suffer. (Hispanic elder,[40] p. 61)

This element of protection seemed to stem from three orientations. Avoidance as protection,[49] where the issue is protecting the children from having to think of these difficult things; avoidance as a cultural norm;[49] and finally a reluctance to play the role of a God who is viewed as the one who can give or take life and whose will cannot be known in advance.

In all nine of the studies where personal preferences regarding decision control were raised, elders felt that end-of-life decisions should be made by the patient. However, several participants based this preference on a desire to spare family members the emotional burden of having to make difficult end-of-life decisions rather than on a desire to promote patient self determination.

Storyline 3. 'I leave it in God's hands': spiritual reassurance. When exploring what elders said about end-of-life decision-making responsibilities, many referred to their religious faith.[22,39,40,44,46,51,52] African American, Hispanic and Cambodian elders frequently used spiritual references to characterise how they cope with illness and death.[22,39,44,47,48] Their sense of faith was pervasive in their conversations:

> You just have to put your faith in the Lord. (Hispanic elder,[44] p. 9)

For many, this was intertwined with a sense of divine control illustrated by this quote:

> God would 'take care of everything'. (Canadian South East Asian elder,[51] p. 916)

Some people expressed a more fatalistic view that life and death matters were beyond people's own control so necessitated little formal decision making regarding the future:

> I live in life's terms. If it happens, it happens. (Latino elder,[52] p. 359)

Storyline 4. 'Who's going to look after us?' Ambiguity and change. As part of the process of meta-ethnography, it is important to consider the metaphors that contradict the emergent storylines. These may be in the form of first-order metaphors or the more interpretive second-order metaphors. This final storyline resonated against the general themes of the others. While elders talked of trust and faith in their children as their decision markers, in some cases there was an open acknowledgement that the children may not respect their wishes:

> Even if I make a will indicating not to use life-sustaining treatment, there will be no one who will follow my will. Even if there is a will, they will all gather and discuss it together. (Korean elder,[23] p. 174)

One elder explains how this incongruence was not a major problem:

> I don't think we can force them to simply follow what we wish just because we want them to. We also have to consider their wishes. If children try their best, but parents die, there is nothing they can do about it. However, if we die because they turned the ventilator off because we asked them to do it, I think they will regret what they did after we die. They might think, I should have made more efforts to save my parents' lives. (Korean elder,[21] p. 175)

An awareness of the complexity of reasons that wishes maybe questioned is captured by this second-order story:

> One elder said her sister blamed her brother for carrying out their father's wishes. Her sister went all the way to their brother's house 'saying that he killed our father'. (Hispanic elder,[40] p. 64)

These elders demonstrate a clear awareness of the complexities of this difficult work of end-of-life decision making and many seemed comfortable with this potential incongruence with their own stated wishes.

In most studies, an awareness that immigration and changing times might change cultural traditions was apparent. This was strongest in the South Asian heritage where there was more of an awareness of the cultural assimilation that was taking place. These populations had higher levels of tertiary education so this may be an influencing factor.[51] In the earlier studies, there is a brief acknowledgement of why things are changing with geographical reasons for the families not living so close to each other:

> Family rarely together. (African American elder, p. 4)

> They're not around much, but I told them. (African American elder living in a care home,[45] p. 120)

In the later studies, it is discussed more descriptively:

> But then we have also expectations when we grow old and if we are in that situation. 'Who's going to look after us?' It's very selfish for us to expect that our children will come or move closer to us just to take care of us. At the same time, we expect that they should be there when we need them. So it's more like an issue of moving from India to the US. Like those questions will never come to my mind if I was in India. (Canadian Asian Indian elder,[48] p. 314)

> 'Kids are different now' and 'they have their own lives'. (Latino elder,[52] p. 360)

Others acknowledged that they themselves need to change and adapt, but that this may be difficult:

> It's very selfish for us to expect that our children will come or move closer to us just to take care of us. At the same time, we expect that they should be there when we need them. (Latino elder,[48] p. 315)

There was a growing receptivity to planning around end-of-life decision making particularly as a result of having been exposed to a culturally sensitive explanation or demonstration of advanced care planning. Many of them had a wealth of ideas of how perhaps culturally sensitive advanced care planning education could reach people in these diverse communities:

> Such a great thing we are doing by bringing this awareness and that more should be done. (Canadian South East Asian elder researcher,[51] p. 917)

> Maybe you can have . . . like you have diabetes class, maybe you want to have a class for this [advance care directives] where you get ten or twenty people in the same place with somebody who's knowledgeable. (Cambodian elder,[46] p. 1430)

Discussion

Expressing the synthesis

The aim of this review was to gain a deeper understanding into the perspectives of elders of Black and minority ethnic heritage and their children about having family conversations around end-of-life issues. Although the review sought the views of both elders and their children, most of the studies found reflected the views of the elders. From their responses, four storylines were constructed. The storylines illustrated the dependence and desire to rely on family proxies for end-of-life decision making with an understanding that proxy decisions may not reflect elders' own preferences: 'My family will carry out everything for me; it is trust'. The second aspect was the role adult children play in inhibiting end-of-life planning conversations: 'No Mum, don't talk like that'. The third was a continued relationship with a spiritual sense of fatalism often associated with religious beliefs: 'I leave it in God's hands'. The fourth is the recognition of change and potential desire for doing things differently: 'Who's going to look after us?'

The storylines around the importance of family, the preference for informal rather than formal end-of-life planning and thoughts of planning being linked to religious views about God's timing are themes that had been identified in previous systematic reviews.[8,12,20,58] Reliance on and expectation of adult children to play a major role in end-of-life decision making is perhaps cross cultural.[1,11] However, in these studies of elders of Black and minority ethnic heritage, the absence of demonstrable involvement of spouses may reflect a phenomenon found in some studies where children born in the host culture hold a better understanding of the underlying cultural language and rules and so become the cultural interpreter and tour guide through not only the health system but also other societal processes. Facilitating more family-based conversational processes may need to be more creative than only occurring when family members can attend face-to-face health care appointments.

Protection is a major factor identified by elders of Black and minority ethnic heritage in these studies that prevents early end-of-life conversations. Elders want to protect their children from having to think about these difficult things such as the idea of their parent dying. In many cases, this is not an unfounded worry as when they raise the topic of their lives coming to an end with their children, they report the authoritative manner in which the children themselves close down those conversations. The interactions taking place here and the perspectives of both elders and children have been only sparsely explored with only one study indicating the burden this can then become for the children concerned.[39] Further research work is needed in this area in different cultural contexts to explore how anxiety around end-of-life conversations can be reduced.

Religiosity is a complex factor in relation to preparation for dying. In her review, Johnson et al.[59] found significant emotional distress regarding the acceptance of death in spiritual leaders and parish visitors in African American communities in the United States and suggest that 'health care providers should not be surprised when the same person views death as a transition to a better life and as something to be avoided by obtaining medical interventions' (p. 146). Spiritual fatalism that is accompanied by limited health literacy – particularly around serious illness and palliative care – plays alongside a sense that God is in control and will provide the support that is needed negating the need for anticipatory conversations.[60] Further research is needed to understand how religious communities explore end-of-life preparation and how work with leaders in these communities can be used to build better dying, rather than faith practices acting as barriers.

The fourth storyline captures a refutable metaphor.[34] This storyline of 'Who's going to look after us?' changes direction from ideas expressed in the majority of studies and offers a sense of change in the perspectives of elders as they undergo a process of acculturation[61] into the prevailing majority cultures and start to see the role the children will play in their future care changing. This is a theme starting to emerge in many of the studies particularly in South East Asian cultures.[11,62] The storyline of an expectation of children caring for their parents fully as they age is changing to being one where parents are becoming concerned about the burden this may place on those children and one, they want to avoid. Gott et al.[63] in their quantitative study with older people from a Maori heritage raises the need for a greater understanding of this changing storyline and for the development of culturally appropriate end-of-life care planning support.

People from Black and minority ethnic heritage appear to respond poorly to generic end-of-life planning initiatives through the media or governmental institutions. However, those who had been exposed to specifically targeted culturally adapted education demonstrated a desire for engaging with more formal ways of documenting preferences and initiating discussions.[48,51,52,55] There is a need to develop a more co-operative and culturally resonant way of approaching the subject of end-of-life and how communities understand the challenges and opportunities and would wish to respond in ways that may be most effective for them.[64]

What this synthesis adds

This synthesis offers an insight into the background of the prevailing preferences held by elders of Black and minority ethnic heritage and what appears to be a reluctance to discuss end-of-life issues within the family. A complex interplay between avoidance as protection[49] and a spiritual assurance of a world view that one's children will be there to make the right decisions and that God has a plan shape the resultant silence. This insight can guide a more culturally sensitive approach to how to empower elders of Black and minority ethnic heritage and their adult children to engage in end-of-life conversations prior to situations where a serious deteriorating illness makes these types of conversations often more emotionally difficult.

The role that adult children play in shaping end-of-life conversations with their elders has emerged as a significant factor that merits further exploration. Understanding these dynamics is an important priority in helping to improve the current inequalities that existing in the achievement of enabling good dying across all communities.

Finally, the synthesis provides a clearer picture of the increasing receptivity of elders of Black and minority ethnic heritage to education initiatives around advance care planning as they recognise the need to be more self reliant as they age and face end-of-life issues.[54,55]

Limitations of the review

Methodologically, the literature searching for qualitative studies has been demonstrated to be challenging using online databases.[42,44,53] Although multiple searches were conducted, some studies may have been missed. In addition, the processes of translation of studies are complex[65] and reflexive. As this is an iterative and interpretive piece of work, the studies chosen and the ways in which metaphors were selected are reflective of the interests of primarily the first reviewer who led the process but moderated by the review team.[34] Evaluating the integrity and reliability of meta-ethnographies has been limited so far. The use of EMERGE reporting guidelines for metathnographies[66] should help to enhance clarity of reporting and inclusion of the aspects important to the process. These guidelines were considered in the writing up of this meta-ethnography.

Conclusion

This meta-ethnography indicates the potentially inhibitory influence of adult children in the preparatory end-of-life decision making of their parents, particularly in Black and minority ethnic communities. It demonstrates the complexities of this influence when those children become the primary decision makers for their parents who are dying. It has explored a number of the reasons why there has been little discussion of the older person's preferences, and the whole situation invokes a high level of anxiety for those adult children. Culturally curated education has been found to be helpful. Further exploration of what this might look like is needed, and how this may be also targeted at a range of family members. Understanding the perspectives and experiences of adult children of people from Black and minority ethnic heritage about having end-of-life conversations may be a useful next step in developing this work.

Authors' contribution

This expression of synthesis was written by JDS with contributions from the review team, KG, CW and KF. All authors have made a substantial contribution to the synthesis process and to the construction and review of this paper.

Data sharing

All the data used were from published studies that had themselves obtained ethical approval for their study dissemination.

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Supplemental material

Supplemental material for this article is available online.

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3.5 Reflections on the process of meta-ethnography

Reflections on developing a search strategy

Finding a suitable, formal way to structure search questions when exploring a qualitative concept is a subject under debate (Booth et al., 2016; Campbell et al., 2011; Greenhalgh & Peacock, 2005). Whilst there are several alternatives that have been tried, Booth (2016) recommends a modified PICo (population, interest, context). It continues to maintain sensitivity which some others compromise and allows for better specificity than the original PICO. A PICo framework was used to identify the facets that were used to explore the question (Table 2).

Population: Black and minority ethnic communities

Phenomenon of interest: end-of-life conversations

Context: adult children, family

Deciding on the population

Deciding which cultural groups to explore when doing the searches for the meta-ethnography was problematic. Entering specific groups like 'Asian' did sometimes bring up another paper, but some of the themes really resonated across cultures because they were about moving from traditional cultures where disclosure is not the norm to ones where it is becoming more so, and also the changing roles of families in providing for elders. Although this has also happened for white families, for ethnic minority immigrants this has happened more quickly and across only one or two generations. A decision was made to search for all terms related to ethnic minorities.

Table 2: Facet analysis

Boolian OR		OR		OR
BME ME Ethnic minority Ethnic* “minority group” Race	AND	‘adult children’ Son Daughter Family proxy	AND	end-of-life conversations advance care planning advance directives death and dying attitude to death decision making expression of wishes

On searching the second column, the search picked up many paediatric studies adding several irrelevant ones even when the limit of ‘all adult’ was used; this added to the labour of the screening process. Further elements that were removed included BME and ME and minority as these were not found to be useful and picked up studies discussing a smaller number of people. The most useful terms were ‘black and minority ethnic’ and ‘minority groups’. Campbell et al. (2011) and later Booth (2016) discuss the challenge of ineffectual searches and highlight how it is important to do a variety of searches to capture qualitative studies as they are not always caught by traditional searching methods. They suggest searching a range of databases as well as hand searching relevant journals.

Supplementary sources

The systematic search revealed only a handful of relevant studies, and the majority were found using purposeful searching techniques. Noblit and Hare (1998) discuss the dilemma of whether an exhaustive systematic search, based on positivist paradigms, is suitable for this type of integrative synthesis or whether data saturation can be reached before this and purposeful searching is then more appropriate. Toye et al. (2014) and Benoot et al. (2016) argue that although literature access and quality synthesis has evolved since the original framework in 1998, this still may be a valid standpoint and appeared to be the case in this synthesis.

To ensure that the literature found is comprehensive and valid in addition to database searching, both Campbell et al. (2011) and Booth (2016) recommend a multi-pronged approach to searching the grey literature. Greenhalgh and Peacock (2005) describe one aspect of this as citation snowballing where reference lists of retrieved articles and related literature synthesis are searched by hand. Pirolli and Card (1999) describe 'information foraging' where the works of known writers in the field are further explored, general search engine searches are conducted using key terms and key relevant journals are hand searched (Pirolli, 2007). A purposeful rather than an exhaustive search is required to find the work needed to optimise the synthesis process (Benoot et al., 2016). Using this approach to the search process has generated some articles that were missed using the systematic database search.

I conducted a MeSH term analysis on the nine most relevant articles in the initial scanning of the literature review (Table 3). No terms were found in all the articles. Table 3 illustrates the terms found in three or more of the articles collected.

Developing the search using a MeSH term analysis

Table 3: MeSH term analysis

	Gutheil	OTT	Glass	Venkasamu	ko	Bullock	Bullock	Carr	Kristain
Adult			x		x				x
Adult Children*	X		x		x				
Advance Care Planning*	X		x		x			x	
African American*		x				x	x	x	
Aged*	X	x	x	x	x			x	x
Attitude to Death*		x	x	x				x	x
Communication	X	x	x						
Decision Making*	X	x	x		x			x	
Family*		x				x	x		x
Female		x	x	x	x	x		x	x
Focus Groups	X	x		x	x	x	x		
Humans	X	x	x	x	x	x	x	x	x
Male			x	x	x	x	x	x	x
Middle Aged			x	x		x	x	x	x
Terminal Care/Psychology*	X			x	x	x	x	x	

Including 'adult children' and 'family' as MeSH terms picked up all articles except Carr (2011) and Venkatasalu et al. (2013). The difficulty was that adding an ethnicity term excluded some articles such as Glass and Gutheil which are key studies but do not have a MeSH term associated with ethnicity attached to them. So, I decided to conduct two searches, one to include ethnicity terms and then to repeat the process without ethnicity terms.

Terms added to the search or the inclusion/exclusion criteria following this analysis included:

attitude to death
adult
communication
decision making
family
terminal care*

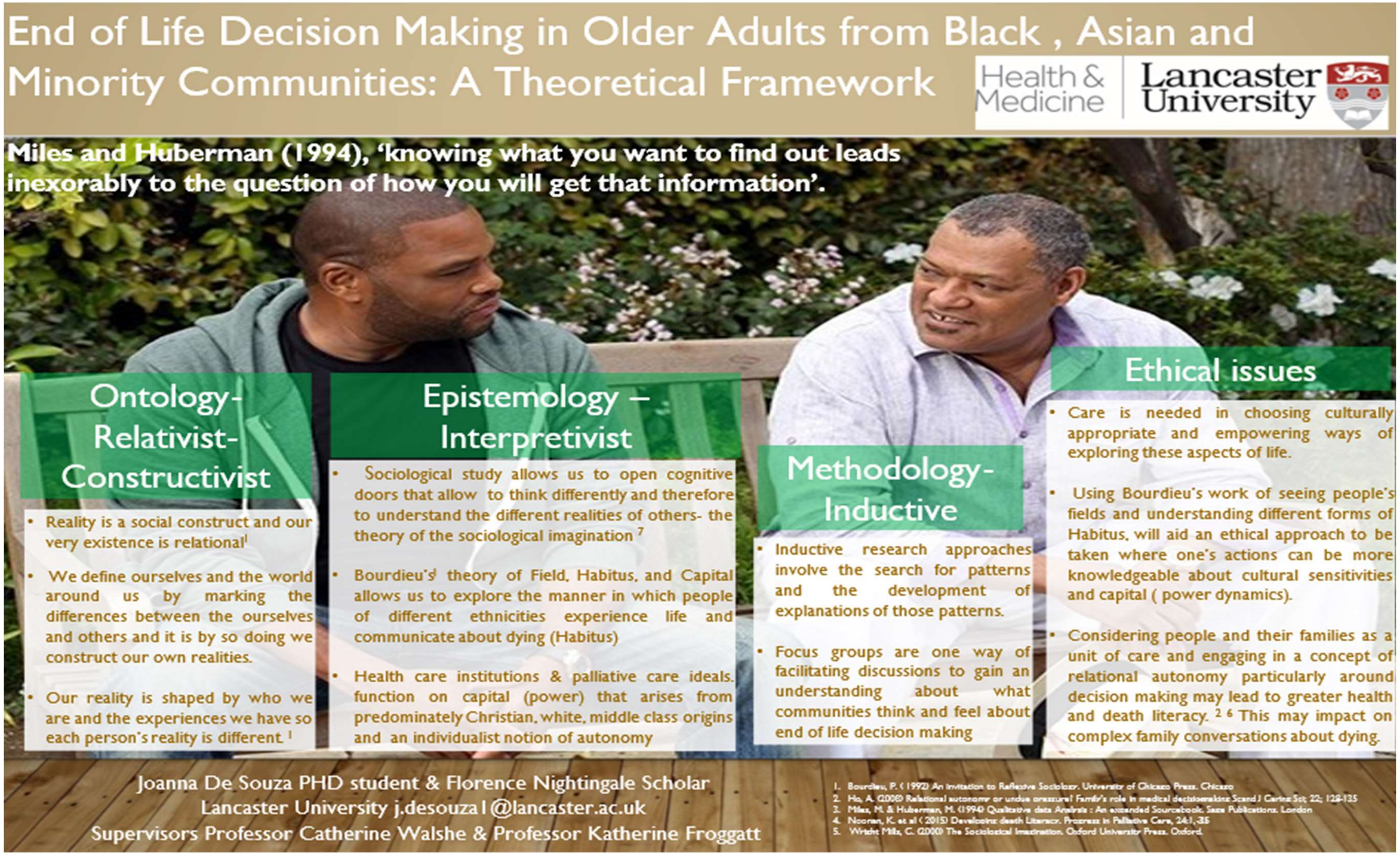
Searching for qualitative literature using database systems that are designed to search for mainly quantitative literature remains a challenge. Exploring other reviews in this area which did not pick up all the studies I covered in my review shows how it is very difficult to achieve a comprehensive review without using information foraging techniques as discussed above.

Chapter 4: Theoretical framing of the thesis

4.1 Introduction

When exploring the topic of conversations families have about end-of-life issues, priorities and wishes, and the ways that people from different cultures address this, I am particularly interested in the role adult children play in these conversations with their older relatives. I am interested in whether adult children facilitate or hinder end-of-life related conversations taking place. I am also interested in how people from African and Caribbean heritage communities understand and make sense of this phenomenon of having family conversations about future care around dying as a community in some ways rather than just individual views and lastly whether these types of conversations are helpful in this community for reducing distress in the dying phase.

Prior to conducting research, it is important to consider and make transparent the underpinning ontological, epistemological and methodological perspectives of the researcher underpinning the research study and the analysis of the data generated. Sociological study allows researchers to open cognitive doors that enable them to think differently and therefore understand the different realities of others, rather than assuming their own reality is the only one. My initial thinking on this was presented as a poster at a university post graduate conference in 2017 (Figure 4).



End of Life Decision Making in Older Adults from Black , Asian and Minority Communities: A Theoretical Framework

Health & Medicine | Lancaster University

Miles and Huberman (1994), 'knowing what you want to find out leads inexorably to the question of how you will get that information'.

Ontology- Relativist- Constructivist

- Reality is a social construct and our very existence is relational[1]
- We define ourselves and the world around us by marking the differences between the ourselves and others and it is by so doing we construct our own realities.
- Our reality is shaped by who we are and the experiences we have so each person's reality is different [1]

Epistemology – Interpretivist

- Sociological study allows us to open cognitive doors that allow to think differently and therefore to understand the different realities of others- the theory of the sociological imagination [7]
- Bourdieu's[1] theory of Field, Habitus, and Capital allows us to explore the manner in which people of different ethnicities experience life and communicate about dying (Habitus)
- Health care institutions & palliative care ideals, function on capital (power) that arises from predominately Christian, white, middle class origins and an individualist notion of autonomy

Methodology- Inductive

- Inductive research approaches involve the search for patterns and the development of explanations of those patterns.
- Focus groups are one way of facilitating discussions to gain an understanding about what communities think and feel about end of life decision making

Ethical issues

- Care is needed in choosing culturally appropriate and empowering ways of exploring these aspects of life.
- Using Bourdieu's work of seeing people's fields and understanding different forms of Habitus, will aid an ethical approach to be taken where one's actions can be more knowledgeable about cultural sensitivities and capital (power dynamics).
- Considering people and their families as a unit of care and engaging in a concept of relational autonomy particularly around decision making may lead to greater health and death literacy. [2,6] This may impact on complex family conversations about dying.

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Supervisors Professor Catherine Walshe & Professor Katherine Froggatt

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Figure 4: Poster presentation of theoretical framework

4.2 Relativist ontology

This research is underpinned by an assumption of a relativist ontology. My understanding of ontology is that it is a philosophical belief about the nature of reality, and whether we can know something independent of our perspectives and consciousness of the subject (Poonamallee, 2009). My relativist ontological belief involves understanding reality as a social construct and that perceptions about existence are relational (Wacquant & Bourdieu, 1992). To exist is to exist socially in relation to others. I have a world view that assumes people define their understanding of themselves and the world around them by marking the differences between themselves and others, and by so doing so construct their perceptions of reality. As a result, people's reality is shaped by who they are and the experiences they have, so each person's perception of reality is different.

To make this clearer and to start to inform my epistemology, I drew on the work of Pierre Bourdieu, a French philosopher/sociologist who offers this theoretical exploration of this relational perspective. Bourdieu's theories lie between the objective (positivist) and the subjective (constructivist) lines of thought. He argues that objectivism makes unacknowledged subjective decisions about things and that subjectivism can neglect to take account for the structures and social conditions that really influence decision making (Rhynas, 2005). Bourdieu believed that separating the two damages social research. When exploring a subject like preparing for dying, which involves people's experiences of physical and social phenomenon whilst living as a member of a migratory minority heritage culture, it is essential to explore the structural impacts this will have on those experiences. Bourdieu's theories offer a helpful theoretical lens through which to do this.

To understand human behaviour, it feels essential to consider the underlying power dynamics at play (Bourdieu & Nice, 1977). This includes exploring how each person's reality is influenced by both their own social capital and that of others around them. A reflexive sociological approach is essential for any social research. This approach recognises the researcher's own influence on their interpretation of findings (Gilbert & Stoneman, 2015).

4.3 Epistemology – Exploring how we know what we know

The aim of this study is to develop knowledge through theory construction around the dynamics that underpin the perspectives of people of African and Caribbean heritage to having family discussions about dying and end-of-life choices. Little is available in the literature about this cultural perspective so it is hoped this study will add some new insights to both healthcare professionals and society in general.

To develop this research study, I have explored some of the factors that may be influential in framing the family discussions around end-of-life care in the introduction and background and add to this in the concept analysis later in this chapter. Epistemology is about the nature of knowledge. People have different ways of viewing knowledge and what knowledge is, often influenced not only by their cultural backgrounds but also the way in which it is portrayed through the educational experiences they have had. To have knowledge about relational societal processes is to understand the subjective experience of reality and multiple truths when this phenomenon of end-of-life family conversations is viewed by people with different perspectives (Crotty, 1998). Having myself come from a social science background of nursing, this description by Crotty resonates with me. Careful reflexivity around assumptions can help to enable an objective position to be reached from consideration of subjective life experiences (Poonamallee, 2009). For the duration of this study, a system of memoing and the completion of a research diary captured my changing understandings of research methodologies, the field of study and of the perspectives of others. This includes both people directly involved in the research such as participants and supervisors but also of other people with whom I discussed the topic. These reflections are discussed further in Chapter 9, the integrated discussion.

4.3.1. Using Bourdieu’s concept of practice as a philosophical lens

Reflexive sociology involves asking questions (Wacquant & Bourdieu, 1992). Bourdieu (1990) theory of a concept of practice explores whether membership of a particular community predisposes people to see and experience the world in a particular way that is relational to other people in that social space. I am aware that my clinical experiences as a community palliative care practitioner working with people dying at home, having previously experienced people dying in hospital, has shaped my philosophies about how the social world of healthcare operates. Having also experienced living between both the English communities of my mother's family and the East African Asian cultures of my father's family, I have developed a perception about how these two cultural groups operate, enjoy social status and consider those who are from cultures outside their own. These perceptions and experiences can be hidden to people from other places/communities in the social space.

The social world can be conceptualised as a series of relatively autonomous but structurally homologous fields of production, circulation and consumptions of various forms of cultural as well as material resources (Navarro, 2006). People's relationships with the concept of death and dying, the conversations they have about it, with whom and about what, and the factors that come into play around end-of-life decision making relate to how they conceptualise this area of life. Culture plays a huge role in influencing behaviour (Malinowski, 1936). Every culture is dominated by control mechanisms or a unique set of regulating ideas that shape individual behaviour (Geertz, 1973). Bourdieu's concept of practice offers a view of culture which is dynamic and affects different individuals within it in different ways. From my personal experiences of attending funerals, even in modern day Britain, there is often a high degree of tradition and expectation of how things should be done to 'honour' the memory of the personal who has died. These expectations are often not explicit and need to be gleaned for the people who hold the symbolic power in that situation. In his explanation of this theory of practice, Bourdieu suggests the way society operates rests on three central concepts, habitus, capital and fields all of which combine to create practice or how society works. Bourdieu proposes that people have an embedded internalised moral structure which he referred to as 'habitus' to handle the social world.

This habitus is not a natural or individual notion but is socially created. Habitus is developed through socialisation; it is not so much a structure as a durable set of ideas that exert influence on moulding the behaviours of each individual (Navarro, 2006). It as an embodied reality that is often unquestioned because of its inherent nature (Rhynas, 2005). It varies across time and place. It is also not fixed or permanent and can be changed under unexpected situations or over a long historical period. Habitus may be described as a series of symbolic cultural schemas that each individual builds up and lives within (Lo & Stacey, 2008a). Like a schema, habitus is endowed with a built-in inertia as it produces practices that have been patterned by layered social structures with a disproportional weight of schemata created in infancy (Wacquant, 2005). People develop a way of thinking about health and illness that is heavily influenced by their habitus. For communities who have come from or still have family members living in places where healthcare is rationed by both availability of curative therapies and an ability to pay, access to health services for the dying is highly desired. Understanding the limits of modern medicine is a form of health literacy that comes with increased access.

Bourdieu suggests practice (or social life) takes place in a field which is a sphere of life or a realm of society. He has described fields as a 'game' with rules, conventions and hierarchies but one in which the outcomes and pathways are not static or defined but change according to the interactions that take place within them (Grenfell, 2014). When individuals enter a field for the first time, they need to learn the 'doxa' of that field to be able to navigate it. Fields are areas of competitive struggle in which a variety of resources (capital) are vied for as the control of them creates dominant and subordinate positions in the field (Navarro, 2006). Those with more doxa have an advantage over those who do not. This may affect people from ethnically diverse heritage cultures accessing a field like palliative care, with which they may be less familiar and may experience a sense of mismatch, or jarring of values and beliefs, around how healthcare should be accessed and utilised. This sense of unease or jarring Bourdieu describes as a sense of hysteresis (Bourdieu et al., 1999; Dumenden & English, 2013). This concept and experience of hysteresis is explored in more critical detail in Paper 2 which follows this discussion.

Forms of valued resources or capital, whether material, cultural, social or symbolic also offer social advantage and power (Bourdieu, 1987; Etherington, 2004; Navarro, 2006). In his book Distinction, Bourdieu explores, by studying practices, how capital takes different forms when it originates in different fields, and how its accumulation creates distinct forms of hierarchy. An individual's habitus can affect the way in which the capital held by others is perceived and given value within the field. Because of the dynamic nature of the value of capital within fields, Bourdieu argues it is not possible to create a static hierarchy or classification system connecting fields as this is not a fixed phenomenon.

One of the long-standing debates in the study of human behaviour is the extent to which an individual has agency and can make self-determining choices about the actions they take, and how much these are conditioned by structures in society (Rutyer, 2012). Giddens (2017) suggests that Bourdieu uses a concept of practice to bridge the structure/agency divide, arguing that it is neither agency nor structure that determines social order but more an active interaction (struggle) between them. The concept of practice allows a dialectic relationship between structure and agency without reducing one to the other (Lo & Stacey, 2008b). Bourdieu (1986) suggests they exist in relation to each other by way of this equation,

$$[(\text{Habitus})\ (\text{capital})] + \text{field} = \text{Practice}$$

where field and capital (power) are part of the structures of society and habitus the way in which the individual has some agency (Rhynes, 2005).

This study focuses on the African and Caribbean communities living in south London and their experiences and perspectives of engaging with conversations within the family about preferences at the end of life or a form of advance care planning which is an aspect of palliative care. From a Bourdieu perspective, the practice of managing end of life takes place in a field of a society where the prevailing culture is of reasonably good access to healthcare when one is unwell. Also, for healthcare interventions to be relatively unrationed (particularly when comparing it to countries from where many of this ethnically diverse heritage community may have family members still living) and for there to be an expectation within the prevailing society of an ethical respect for personal autonomous decision making.

Many people, and particularly many of those in positions of influence on societal decision making, have a habitus where these societal norms will have been internalised since birth, endorsed by their family and educational socialisation, and supported by reasonable levels of social, financial and cultural capital. The fields in which Bourdieu’s concept of ‘practice’ occurs will be known and navigable. In contrast, however, many studies show that ethnic groups are predominately low in economic capital, and this has an influencing role in reducing their social and cultural capital (Ma & Joshi, 2022; Zubair & Norris, 2015). They can be less familiar with the structures and existence of the fields and how they work, and how to navigate them if their socialisation experiences have involved less exposure to the inner workings of these fields. Their habitus, therefore, can be very different to their peers' and neighbours' who may be a greater part of the prevailing societal culture.

> The notion of field reminds us that the object of social science is not the individual, even though one cannot construct a field if not through individuals, since the information necessary for statistical analysis is generally attached to individuals or institutions. It is the field which is primary and must be the focus of the research operations (Wacquant & Bourdieu, 1992) p. 107)

Rhynas (2005) suggests that whilst studying the field rather than individuals can reveal patterns of behaviour, a comprehensive understanding requires examining the experiences of all participants involved. To explore the field of palliative and end-of-life care conversations, it is essential to identify the relevant fields and the perspectives of the various stakeholders within them. Paper 2 uses a concept analysis framework (Rogers, 1989), to consider how people from ethnically diverse heritage cultures may experience a sense of hysteresis with the way in which palliative and end-of-life care is offered and delivered in the UK, with a particular focus on advance care planning conversations.

This raises questions about the most suitable methodologies for investigating the habitus surrounding end-of-life conversations and exploring ways to foster more open dialogue. Such dialogue would allow individuals' end-of-life wishes to be expressed and considered.

4.3.2. Exploring the Critiques of Bourdieu's Theory

Before using Bourdieu as an overarching lens through which to develop this study of end-of-life practices it was important to consider some of the critiques of Bourdieu's theories. The critiques suggest that Bourdieu's theories propose 1. latent determinism, 2. an emphasis on reproduction leaving little room for change, gender and race blindness, 3. an over emphasis on symbolic power, 4. methodological elitism and conceptual ambiguity, and 5. empirical generalisation. These five critiques are briefly explored in the next sections. A final critique, relating to reflexivity, is discussed in Chapter 8.

Critique1: Latent Determinism

The first critique of Bourdieu's work is the suggestion of latent determinism, resulting in a lack of agency (Reay, 2004; Tichavakunda, 2019). They argue that his theory of practice promotes passivity in relation to how power operates in society, leading to the reproduction of social inequality. Bourdieu's ideas about social forces, particularly the different forms of capital (Bourdieu, 2011), cause concern in that they imply capital inequalities perpetually confine individuals to their social positions (Archer et al., 2015; Waitkus et al., 2025). They argue that Bourdieu follows a passive Marxist ideology in claiming that structural forces determine people's places in society, and that they are contained and constrained by the power structures of the fields they inhabit. As a result, people have little choice about their social positions. Studies, in which constructs like structural racism are explored, support the claim of latent determinism, highlighting tangible and symbolic holders of power in society (Bullock et al., 2022).

There is a counter critique that Bourdieu (1998) strays too far from classical Marxist ideologies which emphasise the relationship between labour and production, by introducing various forms of capital that shape power dynamics in more nuanced ways (Seim & McCarthy, 2023). Bourdieu (2011) theory offers a broader narrative involving different aspects, social, symbolic and cultural forms of capital, influencing power structures in society. In this study which explores the views of people of African and Caribbean heritage, this dynamic of power, particularly in setting the narrative around end-of-life family conversations, has been a key consideration during data collection and analysis. I sought to explore the extent to which participants felt a lack of agency, either due to conforming with existing practices in their current countries of residence or their heritage cultures, and to examine other influences shaping their perspectives on end-of-life planning and practices.

Critique 2. Emphasis on Reproduction – Gender and Race Blindness

A further critique related but building on the issue of passivity is that Bourdieu focuses heavily on how participants are shaped by the system they inhabit (Archer, 2010). Consequently, people are seen as resorting to habitual actions rather than acting with self-determination. Archer critiques Bourdieu's view of institutions such as schools and universities, suggesting that he underestimates, the agency people have in shaping these social structures, and consequently, the societies in which they live. Some argue that Bourdieu’s own life disproves aspects of his theory. Born into a family of little wealth or status, he became a university professor and internationally influential sociological philosopher (Grenfell, 2014; Robbins, 2020). Despite lacking insider knowledge of the dominant doxa he navigated and ultimately shaped powerful social structures.

The critique of social passivity is echoed in gender and racial sociology, (Yosso, 2005). Bourdieu gave little attention to female perspectives (Archer et al., 2015). His work such as *Pascalian meditations* (Bourdieu, 2000) primarily examined male perspectives, thus marginalising women’s experiences. While Bourdieu’s concept of symbolic violence is applicable to gender dynamics, he seldom applied it explicitly. The literature on advance care planning has not adequately addressed the influence of gender on who participates in conversations and is viewed as a legitimate decision-maker, particularly within traditionally paternalistic societies (Sanders et al., 2016). In his discussions of cultural capital, Bourdieu concentrated more on domination than exploitation, a focus evident in his work on race (Seim & McCarthy, 2023). The specific theme of gendered domination in decision-making, as it appeared in the current study, will be analysed in Section 6.8.2.

In defence of Bourdieu, scholars argue that his work presents a dynamic and layered picture of society. His consideration of capital being a fluid concept that can be gained and lost and can be influenced by agents within the field rather than only by preset criteria deviates from earlier more rigid class-based theories (Adkins, 2004; Archer et al., 2020; Couldry, 2016). This approach offers a more nuanced view of social power than traditional Marxist dichotomy of proletariat and bourgeoisie (Adkins, 2004; Bourdieu & Wacquant, 2013; Lovell, 2004; Robbins, 2020).

Bourdieu’s concept of habitus relates to how people experience social space and navigate between competing social norms and life experiences. His notion hysteresis describes the lag between habitus and changing conditions illustrating how individual agency shapes people’s positions in the field (Lovell, 2004). Bourdieu argued that he sought to transcend the structure-agency debate by using habitus to show how social agents construct their own worlds. He recognised that the complex interplay of capitals could constrain choices for many (Collyer et al., 2015; Costa & Murphy, 2015).

Although Bourdieu’s focus on gender was limited, his concepts have been useful theoretical tools for feminist and intersectional research (Archer et al., 2020). Bourdieu’s work continues to be useful, even amongst those who have critiqued it (Adkins, 2004; Reay, 2015; Tichavakunda, 2019; Waitkus et al., 2025).

Critique 3. Over emphasis of symbolic capital

The third critique is that Bourdieu overemphasises the impact of symbolic power. His theory around capital and symbolic power may suggest that the aspiration is always to assimilate and to join the ‘game’ to gain capital by learning the rules or doxa so reinforcing existing social structures (Yosso, 2005). Much of the literature on engaging people of diverse ethnic heritage into the Western notion of palliative care and advance care planning, is about working out how to enable people to join the existing ‘game’ and to comply with its rules thereby becoming ‘good patients’. Some aspects of a Western model of palliative care such as the strong focus on autonomy and future planning is often uncomfortably countercultural to people from more collectivist cultures. People choosing not to engage can be seen as difficult or hard to reach.

Bourdieu (1984) responded to these critiques, arguing that symbolic power should not be prioritised over economic factors. He rejected purely Marxist views as overly theoretical and not based on lived experiences (Seim & McCarthy, 2023). Bourdieu saw his work as empirical and practical rather than philosophical (Grenfell, 2014). His ideas have resonated widely, and he is one of the most cited sociologists in the 21st century (Seim & McCarthy, 2023). Waitkus et al. (2025) warn that underestimating the impact that symbolic power has on how society is developing, blinds people to its effects on societal development. For example, they suggest a failure to account for embodied forms of capital in addressing wealth inequalities has contributed to the worsening of health disparities in the UK.

Tichavakunda (2019) argues for melding Bourdieu’s theories and critical race theories (CRT). Using Bourdieu’s combination of the capitals, field and habitus approach, intergroup variabilities can be explored. They suggest this is often missing in critical race theories. While critical race theory focuses on the reflexivity of the individual agents, Bourdieu’s approach compliments it by also emphasising structural influences. In exploring how better dying can be achieved for all in society, it is important to examine both the existing status quo and what new perspectives can offer. The goal is to reduce social suffering and hysteresis through a more inclusive and comprehensive philosophy of palliative care.

Critique 4. Methodological Elitism & Conceptual Ambiguity

Bourdieu's writings have also been criticised for their methodological complexity and conceptual ambiguity (Jenkins, 2013). Many scholars build on the work of Bourdieu using interpretations from secondary sources. Reay (2004) notes a tendency for concepts like habitus 'to be littered throughout academic texts like intellectual hair spray', bestowing gravitas without doing any theoretical work' (Hey, 2003 p423). Jenkins (2013) acknowledges that Bourdieu is 'enormously good to think with'; but criticises the complexity of Bourdieu's language choices, philosophical writing style and translation issues from the French to English which can make his work difficult to access. Jenkins suggests that Bourdieu's complex use of language may reflect his own struggle for cultural capital in intellectual contexts, considering his working-class background, which was unusual in the Parisian academia of the time. Bourdieu's writing style is often complex and dense, which can be a barrier to understanding his ideas, especially for the very people whose social struggles his work aims to explain and validate. The academic language Bourdieu uses might make his work less accessible to a wider audience outside of academia.

Critique 5. Empirical Generalisation

Bourdieu's early empirical work was conducted in colonial Algeria and many of his ideas in his concept of practice were formulated in that context (Bourdieu & Nice, 1977). He later applied this theory to other contexts including higher education in France, a very different societal context (Bourdieu, 1988; Bourdieu & Wacquant, 2013). Bourdieu argued that reflexivity helps prevent the risk of applying theory out of context. Reflexivity is central to his methodology. He suggests researchers should always be aware of their own habitus and the assumptions embedded within the research context. How this methodological notion of reflexivity relates and works with that of Charmaz in constructivist theory methodology used in this study is further discussed in chapter 4.

When recognising the influence of the lens on the society offered by the work of Bourdieu on a study of people of African and Caribbean heritage living in the UK, one final critique of Bourdieu's work relates to the potential limitations of the empirical generalisation of

Bourdieu's work. One argument is that because Bourdieu's work was situated in a French/Algerian context at a time when class, heritage and a particular form of colonialism played such a major role in the construction of society, his ideas do not transfer well to other societies, and in particular to that of the USA where there is a belief that individual agency plays a much more fundamental role than heritage and class (Calhoun, 2006). Others contend that Bourdieu's concepts remain relevant to modern globalised societies including the US and the UK (Tichavakunda, 2019; Waitkus et al., 2025). Waitkus et al. (2025) suggest that ideas of work and income in modern society are far removed from the traditional one source of income from a 9-5 job, making Bourdieu's dynamic approach to capital, field and habitus more resonant than other more traditional class-based concepts of society.

As a nurse, my education included various disciplines - sociology, psychology, philosophy, chemistry, biology and physics. Holistic salutogenic health care requires synthesising diverse knowledge systems. As a result, understanding Bourdieu's work often involves engaging with multiple interpretations and viewpoints. This research has benefited significantly from the insights provided by secondary sources. However, a nuanced analysis of the primary texts presents challenges due to their unique compositional style and the complexity of the theoretical traditions from which they emerge.

To deepen my understanding of how Bourdieu's ideas relate to palliative care and how it is perceived and experienced by people from ethnic and racial heritage minority communities, I was particularly drawn to his concept of *hysteresis*. Having personally experienced cultural clashes and different ways of perceiving the world, which can lead individuals from non-dominant cultures to be viewed through a lens of deficit, I decided to utilise the technique of concept analysis to explore *hysteresis* more deeply. This method, which helps to unpack complex phenomena and lived experiences, offered a way to bring greater clarity before commencing the empirical phase of the study. The concept analysis process and its findings are presented in Paper 2, the next section of this chapter.

4.4 Paper 2: Experiences of Bourdieu’s notion of hysteresis in relation to palliative care and advance care planning conversations in minority ethnic heritage communities. A Rogerian concept analysis

Prepared for submission for publication:

Reference:

De Souza, J., Gillett, K., Salifu, Y., & Walshe, C.

> Experiences of Bourdieu’s notion of hysteresis in relation to palliative care and advance care planning conversations in minority ethnic heritage communities. A Rogerian concept analysis.

Title: Experiences of Bourdieu’s notion of Hysteresis in relation to Palliative Care and Advance Care Planning Conversations in Minority Ethnic Heritage Communities. A Rogerian Concept Analysis

Purpose: The purpose of this analysis is to trace the evolution of the concept of hysteresis in relation to the experiences of people from minority ethnic heritage communities of attitudes to engaging with advance care planning conversation around care preferences and the take up of palliative care at the end-of-life.

Methods: Following the steps of Roger’s evolutionary method of concept analysis, data was collected from a review of databases CINAHL, PUB MED, PsycINFO and SOC Index and google scholar and Lancaster university one search. Data from the literature gathered over a period of between 1990 and 2023 was used to explore the attributes, antecedents and consequences of this hysteresis experience.

Findings /Results: The concept of hysteresis in relation to palliative care and advance care planning conversations is similar to the related concept of temporal dissonance, underpinned by Bourdieu’s concept of practice. The relational interactions between the antecedents of field, habitus, doxa, and capital, the attributes of autonomy, disclosure and anticipatory planning decision making can result in consequences of social suffering, symbolic violence, development of social capital and self-efficacy.

Discussion The findings of this concept analysis suggest that there is a need to revisit how palliative care and advance care planning is both visioned, marketed and how it is practiced. Current practices can result in disenfranchising people as they have been developed based on an ethnocentric set of values which can result in social suffering and symbolic violence when people do not conform to practices that do not attune with their own values. Insight and change by those who carry symbolic capital and influence is needed to offer an inclusive and equitable service that reduces distress and suffering of people of minority ethnic heritage experiencing serious illness and coming to the end of their lives. Having experienced the 'struggles' of hysteresis, people can develop increased social capital and self-efficacy.

Conclusion. This concept analysis process investigates the complex and multifaceted phenomenon of hysteresis that is experienced by people of minority ethnic heritage when facing the end-of life. Progress in changing the nature of palliative care and advance care planning conversations to be more inclusive is needed through increasing awareness, changing doxa, and promoting and embracing change.

Keywords

End-of-life conversations, social suffering, symbolic violence, migration, cultural dissonance, dying.

What is already known

- There are discrepancies in the level of take up of palliative care and formal advance care planning initiatives by people of minority ethnic heritage
- There are debates about the efficacy of advance care planning in achieving its aims

What this paper adds

- The values on which advance care planning can be at odds with communities who favour more relational autonomy and a less controllable future

- Many people, particularly those with migration histories, experience a sense of hysteresis between heritage cultural ideas about health care and the values of the palliative care and advance care planning that is on offer through the health service
- Symbolic capital can lead to a dominance of the doxa of palliative care which can lead to unconscious symbolic violence resulting in social suffering. Experiences of hysteresis and struggle can lead to the development of social capital and self-efficacy

Introduction

Ethnic and cultural differences influence patterns of health behaviours around care at the end of life, the take up of palliative care services and advance care planning (1). In countries such as the United Kingdom and the United States of America, where palliative care is a recognised medical speciality and on the surface is universally available, there is a concern that people of minority ethic heritage make more limited use of the speciality and death can be sudden and unexpected more often causing high levels of distress for people in those communities. Palliative care communities wonder how referrals might be made earlier in people's trajectories so that palliative care interventions may be used to reduce distress in several ways. There are a range of factors that influence attitudes and appetites for palliative care including cultural approaches to conversations about dying, end-of-life values, levels of death anxiety, mistrust of health services, care preferences at the end of life and inequalities in the provision and accessibility of services (2-6).

The view of what constitutes a good death remains a 'contested space' including different cultural views of what death means to people (7-10). Much of the work investigating the components of good dying in the literature has been informed by evidence gathered from mainly white, western communities, rather than coming from a more plural global perspective (11). Independence, individualism, autonomy, fear of relentless efforts extending poor quality life, choice and veracity are the values that shape policy and the provision of palliative care in many western and predominately white led services (11, 12). These values influence the shape of open discussions about prognosis and options, autonomous decision making in the form of formal advance care planning and acceptance of input from health care professionals that are focused on symptom management and comfort rather than cure. How much this approach is helpful or culturally attuned seems mixed. Ethnic minority heritage communities continue to use formal advance care planning in significantly lower numbers than white communities and when they do, it may not always improve outcomes and some favour more aggressive life sustaining care options (13-15).

People experience a sense of unease or mismatch where they are seeking health care but are uncomfortable with some aspects of what is offered to them (16). Where this discomfort is due to conflicts with historical values or beliefs different to those of the prevailing culture, this can be described as hysteresis (17). When people live in cultures whose values call for a protection of those who are ill from the burden of discussing a poor prognosis and predicting dying, the idea of engaging with palliative care and advance care planning is difficult (18). Facing the death of a loved one is a traumatic event for many, causing a sense of hysteresis or a changing from one way of knowing the world to another where that person and all the roles they play in life are gone. The impact of migration experiences on health care decision making is often overlooked but can result in complex choices between different sets of cultural values (15). This concept of hysteresis in this situation is the topic under investigation in this concept analysis.

Ontological theorising

Coupled with the pain and other symptomology associated with dying, suffering at the end-of-life can also be produced by the social: inequality, exclusion, injustice, powerlessness, and persecution (19, 20). To understand and seek to support people in this situation, there is a need to name and understand implicit racism in palliative care if we are to embrace a service that promotes good transnational dying (6, 21). Because of the difficulties of recognising social suffering (17), sociological attentiveness and 'ontological theorising' to the way in which we achieve better dying in multicultural societies has to be cultivated through active and methodological reflexive listening (19, 22). Where the focus of study is in areas subject to social and geopolitical change, concepts are experienced and perceived differently. Concept analysis frameworks can used to take a wide approach to exploration and clarification, including identifying how the concepts involved reflect in real life situations (23).

This concept analysis using a Rogerian (1999) evolutionary approach, is an attempt to critically explore both the experience of hysteresis by people of minority ethnic heritage cultures who are dying, and their families.

In this piece hysteresis and the related concept of temporal dissonance are viewed through the theoretical lens of Bourdieu's concept of practice (17). The relational interactions between the antecedents of field, habitus, doxa, and capital, the attributes or rules of the Field of autonomy, disclosure and anticipatory planning decision making and the consequences of social suffering and symbolic violence in relation to palliative care and end of life conversations are considered. However, through the 'struggles' of hysteresis can come beneficial consequences of increased social capital and self-efficacy (Figure 1).

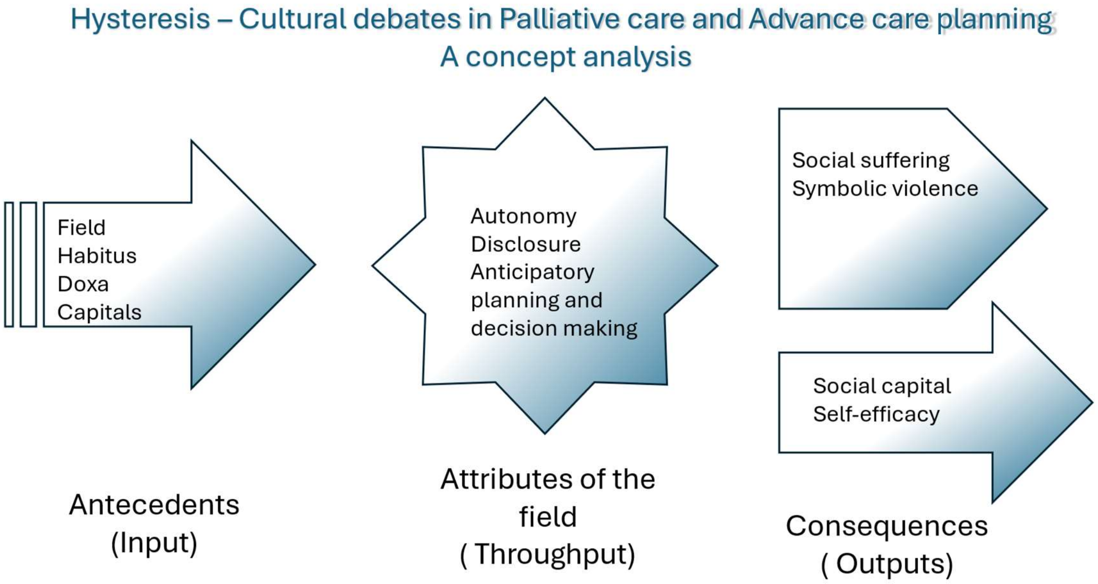

Figure 1 Concept diagram of the concept analysis

Palliative care, advance care planning and minority ethnic heritage

Palliative and end-of-life care are defined differently in different contexts and countries (24, 25), different terms are also in common usage such as hospice, supportive and terminal care. For the sake of brevity, the term palliative care will be used and will encompass hospice and end-of-life care. The definition chosen is based on the World Health Organisation and endorsed by the European Association of Palliative Care.

> *"Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount…..Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death" (25)*

For this piece of work advance care planning will be defined as:

> *"the ability of people to discuss goals and preferences for future medical care with friends, family and or health care providers and to record and review these choices if appropriate"* (26).

This work is focused on understanding the experiences of people who come from communities who have experienced first or second-generation migration over the last 30 - 40 years into societies where palliative care and advance care planning are an established part of the health service on offer. To denote populations who have experienced this migration into countries such as the UK, the term minority ethnic heritage will be used in this work (Advance HE, 2024). Ideas of identity are complex, and it is acknowledged that both terminology and segregation in this way is complex, dynamic and risks assuming a conformity that does not exist. Terms such as minority ethnic are difficult and not ideal, they do not wholly describe diverse groups of people. Care is needed to recognise these limitations (27).

Methods

Structure of the concept analysis

A concept analysis allows investigation, analysis and discussion of conceptual problems to increase awareness, understanding, and ideas to promote resolution of these problems (28). Analysis of a concept is not a conclusion; instead, it provides a basis and direction for further research (Tofthagen & Fagerstrom, 2010). This concept analysis is a means by which to investigate this experience of hysteresis by people from minority ethnic heritage cultures in relation to understandings and experiences of advance care planning as an element of palliative care and its consequences to develop understanding and reveal things that may be hidden to all actors involved in these processes.

Rodgers' (1999) evolutionary method of concept analysis was selected as it values the role of context, theoretical tradition and cultures on the way in which the meaning of concepts evolves or develop over time. Concepts are not fixed entities but are dynamic and context dependant. The practice of palliative care and attitudes to end-of-life conversations across societies are dynamic processes, so Roger's evolutionary method seemed well suited.

Formulating the question

The aim of this paper is to explore what shapes the experience of hysteresis experienced by people of minority ethnic heritage in relation to advance care planning conversations about dying and palliative care.

Table 1 Applying Rodgers's concept analysis template

a) Identify the concept of interest and associated expressions/terminology	**Concept**: Hysteresis in relation to people of a minority ethnic heritage and advance care planning conversations about dying and palliative care Hysteresis is a discomfort/lag between known habitus and transformation of habitus in a new environment **Surrogate terms**: Inertia, cultural lag
b) Identify and select an appropriate discipline and period of time for data collection	Literature search of sociological and medical texts between 1990s and 2023 using CINAHL, Pubmed, Soc INDEX , Google scholar, Lancaster University onesearch were from 1990 - 2023
c) Collect data regarding the antecedents, attributes, and consequences of the concept	Antecedents – field, habitus, doxa, and capital Attributes – autonomy, disclosure, decision making Consequences - social suffering and symbolic violence in relation to palliative care and advance care planning. Social capital and self-efficacy as a result of struggle
d) Identify related concepts	Temporal and cultural dissonance
e) Analyse data regarding the above characteristics	Analysis of chosen papers with a focus on antecedents, attributes and consequences
f) Identify a model case of the concept, if appropriate	Model case identified from clinical practice
g) Identify hypotheses and implications for further development	Contrary case identified from educational practice

a) Identification of concepts of interest; hysteresis

in the social sciences, the term hysteresis refers to a psychosocial lag that occurs where a person's established values misalign with the values held by people who create and control the new social space (29). Many people of minority ethnic heritage have history of migration. There is often a strong influence of heritage cultures on the norms, values and ways of being society in their current communities. These prevailing influences may still inform their world view even if they have never lived in the country of that heritage (15, 30). For many the social space in which their heritage culture was developed may be very different to the social space in which they now reside.

Bourdieu used the concept of hysteresis in a social way to describe the process he saw in his research of people who had experienced migration. Where people faced times of relocation and disruption between one society and another the changes comes with both risks and opportunities (31, 32). Bourdieu's theories resonate as an appropriate theoretical framework for this inductive exploration of migration and integration experiences. The concepts that underpin Bourdieu's theory include the way in which society is developed (field, habitus, doxa). He suggests that different capitals (forms of power) arise from this such as social capital, symbolic capital or power and the result is that people can experience consequences such as symbolic violence and social suffering. These will be further explored in this concept analysis.

b) Data collection – A search of the literature

Papers were sought that included looking at the concept of hysteresis in relation to people of minority ethnic heritage and advance care planning conversations with a sociological cultural underpinning such as Bourdieu's (1996) theory of practice. The inclusion and exclusion criteria are outlined in Table 2.

Table 2: Selection inclusion and exclusion criteria

Inclusion criteria	Desirable criteria	Exclusion criteria
Focus on migrant communities who have different cultural approaches to communication around dying	Focus on sociological concepts of hysteresis, cultural dissonance and culture change including reference to power, symbolic power, social suffering and symbolic violence	Physiological hysteresis Where ethnicity is not explored amongst respondents Focus on normative populations
Palliative and end-of-life care, dying and advance care planning	Papers could be discussion papers, literature reviews or empirical research papers	
Focus on experiences of community's experiences of palliative care		Focus on health care professionals' views of palliative care

Searching for empirical evidence: Identification of sample and setting

Literature was sought that detailing debates, accounts and theories around the experiences of these migrated communities over a timeframe of the last thirty years, i.e. from the 1990's to 2023, since Bourdieu's work has been available and understood in relation to the experiences of migrant communities.

The health online databases of CINAHL, Pubmed, Soc INDEX were searched from 1990 - 2023. Search engines Lancaster university ONE search and google scholar were also utilised to find some leader articles to establish the keyword search (Table 3).

Table 3. Search terms and their derivatives

Palliative care	Advance care planning	Ethnicity	Hysteresis
End of life care	Advance directive	Minority	Bourdieu
Dying	Advance care directives	Ethnic differences	Cultural dissonance
End-of-life	End of life conversations	Ethnic*	power
Terminal care	choice	racial	Symbolic violence
Hospice		race	Symbolic power
		Cross cultural	Social suffering

		migrant	

Whilst all concepts were important to this analysis, searching the main concepts with the assistance of a librarian using all four concepts combined with AND resulted in no papers. Because of this, a more iterative search was conducted. The search terms Bourdieu, symbolic power, social suffering and symbolic violence in relation to health care were helpful terms in finding articles that discusses these types of issues. Once articles were found, a title and abstract search was conducted applying the inclusion and exclusion criteria (Table 2). Seven articles were found that fulfilled at least three of the inclusion criteria and offered useful insights for the concept analysis. When articles were found that related to the topic, a further hand search was done using other related terms contained in the articles and using their reference lists as potential sources of papers. Ten further articles were gathered. Some of the articles sourced this way that were relevant were not ones indexed in major databases. These had no set pattern of MESH headings that could be added to the search. Whist the papers identified in this literature search were used as core sources for understanding this phenomenon, further literature from reference lists was sourced to explore aspects of antecedents, attributes and particularly consequences (Literature itemised in Supplementary Table 1).

c) Data synthesis

Data extraction of the retrieved literature was guided by a Rogerian approach where identification of features of the concept was undertaken; surrogate terms, antecedents, attributes and consequences were identified and explored. The discussion that follows is shaped by the lens of Bourdieu’s theory to form a deeper understanding of the palliative care and advance care planning experiences of people from these minority ethnic heritage communities.

d) Related concepts to the concept of hysteresis

Temporal dissonance and intergenerational cultural dissonance

Engaging with palliative care and formal advance care planning requires an assumption that people can and want to anticipate and plan for their later years and death (18, 33, 34).

Futures are uncertain and the ability to control one's future is tied to structural elements like wealth and societal position and is not the experience of all (30). There also continues to be a dissonance between cultures around the ideology that death can be predicted through clinical signs, many believe that it is entirely in the hands of a higher power (11, 35, 36). These factors result in a temporal dissonance when being asked to consider predicting something in the future that does not feel like something in people's remit to do. Thus, people's world views or habitus can be at odds with prevailing cultural expectations.

Intergenerational cultural dissonance is a concept studied more widely in the education literature in the United States (37). In many studies it is problematised and seen as a risk factor for deviant behaviours. Exploration of intergenerational cultural dissonance in relation to health and aging highlights the challenges that come as people wish to honour traditional values, but they can be in conflict with the new culture in which both generations are now living (30). First generation immigrants can find themselves having expectations of the natural order of growing older and dying within the family not shared by their younger or second generation culturally assimilated children (38).

Elders of minority ethnic heritage avoid end of life planning conversations to protect their children from distressing conversations for a number of reasons including traditional views that suggest it may be taboo to speak about a loved one dying (39-41). They also encounter a reluctance by their children to have such conversations due to distress caused by the notion of losing their parent (40). It appears that not having had any earlier conversations with their children about their preferences can result in older people undergoing more hospitalisation and medical interventions at the end of life when their children become proxy decision makers than they may have wished for themselves. Temporal and intergenerational dissonance is amplified in complex health systems that lack awareness of their ethnocentricity and fail to offer intentional personalised care (42, 43). For those proxy decision makers, differences in familiarity with the hospital systems, perhaps different expectations of the way in which to communicate about decisions making can make the whole process even more distressing and difficult.

e) Analyse data regarding the above characteristics: Antecedents:

The antecedents or phenomena that precede the concept are what exists in society for the concept of hysteresis to occur are **field, practice, capital and habitus.**

Field, practice and capital (power)

Bourdieu (1992, 1986) suggests that living in society resembles a sports game. It takes place on a field or area of practice. Understanding how the field of palliative care and the practice of advance care planning has been built is the first step in this exploratory process of the evolution of this hysteresis experience. It appears that fields are places of struggle (44), they are spaces that have inherent structures of power. At its roots palliative care was first developed in the UK and USA as part of the delivery of our health care services. In the field of palliative care, the planners and decision makers have been historically white, middle/upper class and Judeo-Christian (6). Palliative care as a discipline has developed as a field that in its early stages was particularly non-diverse so there has been limited variety of cultural influence on its development. This has started to change as palliative care develops in a wider range of countries and space is made for actors of different cultures and perspectives to sit in decision making capacities.

How society operates in any field is determined by those in power or symbolic capital in the space (45). This is power given to those whom the others in the space hold in esteem and it buys privilege in that space. This symbolic elite create the rules which they share using their language (in the widest sense) or 'Doxa', which become so internalised it becomes a societal philosophy with inexplicit and unquestioned rules (5, 34). In healthcare, Collyer, Willis (44) describe these symbolic elite as gatekeepers as they determine who is invited to or offered what services.

In palliative care those who understand the language and the rules gain social capital by being able to fit in and become 'part of the crowd' subconsciously privileging those familiar with the doxa of the field and marginalising or excluding those who lack the tools and position to access palliative care provision (6, 44, 46). Many health care professionals from the prevailing normative cultures lack awareness of the exclusivity of the doxa of palliative care as their socialisation into it is an integral part of their habitus (47, 48).

Habitus

When people inhabit a field, each experience it differently according to many factors including their ability to understand the prevailing doxa, and their own symbolic and other forms of power or capital. Bourdieu describes this experience of being in the space or being in that society, as a person's habitus or known reality, embodied in social history (49). Habitus is like one's personalised culture, not static and ''acquired yet entrenched,'' (50).

Negotiating health care can be a minefield for people unfamiliar with the system (16, 46, 51). Palliative care is a particularly elusive part of the health service as it deviates from the curing or saving lives perspective that pervades the majority of the health service. For some communities' pursuit of curative and hospital-based care is favoured over considering palliative care, particularly when dying is seen as within the 'will of God' (5, 35).

People of minority ethnic heritage living in a new home hold values and beliefs linked to their heritage culture, particularly around life transitions, which change and evolve over time in part as they blend that heritage culture with values and beliefs of the host culture (4, 51). Access to the new host culture can be slow and incremental due to both language and social barriers such as racism, discrimination and negotiation of cultural values, particularly around events as socially significant as dying (30, 52). Although their habitus is quite different to the habitus of the status quo, they are expected to both conform to and understand the unwritten rules of the prevailing culture. Groups such as those who are homeless, of different ethnicities or for some reason do not frequent the spaces where palliative care is a known and trusted service, are considered hard to reach or difficult to access (5, 21, 30, 46).

Physicians can find it difficult to communicate about dying with people of their own culture. This becomes more complex across difficult cultural expectations, resulting in physicians often having short and brief conversations rather than conversing on a deeper level (48, 53). Rather than seeing their self-reliance as an asset (51, 54), their lack of access is problematised. The result is often one where they are seen as non-conformists and problematic (33, 55).

Attributes

The rules of the field around **disclosure, autonomy and health care decision making** are explored in relation to different cultural values and preferences.

Disclosure

The process of a parent or family member dying is often intensely distressing and here is a debate about ways to mitigate that distress. Research and practice in specialist palliative care suggests that an early awareness of dying and a freedom to discuss one's hopes and wishes, particularly with family, is an antecedent to being able to achieve a number of these things (56, 57). Care is needed to recognise this research is mainly with majority cultures in high income societies in North America and Europe (57, 58)**.**

Death is difficult in any language, concerns around talking about the impending death of loved ones is universal (47). Some minority ethnic cultures have links with the dead that are active and visible, such as the public advertising and open community funerals of African and Caribbean communities and the ancestral connections of the Māori and Pacific Island communities (59). However, these after-death practices do not seem to make conversations about the dying of a family member easier. Stoicism is valued in some cultures, and many cultures have a complicated and nuanced relationship with this concept particularly around discussions around dying (30, 36, 47). People from a variety of cultures struggle with the concept of palliative care (60), and particularly disclosure and open conversations (36).

The position people hold on health care practices they encounter, such as open conversations around serious illness and dying, are not fixed (61). As migrant communities become culturally assimilated, particularly younger generations, there is some shifting sands between family and community members resulting in differences in people's perceptions about what subjects remain taboo to discuss and what is helpful (18, 51, 54). These shifting sands or inter-generational dissonance result in a further process of hysteresis for families and for individuals themselves.

Autonomy and decision making

Much of the speciality of palliative care and the element of advance care planning is founded on a philosophy of personal autonomy, involvement in health care decision making, open disclosure and preparedness for an uncertain future (62, 63). It is also based on the assumption that people can anticipate and plan for future health events and make anticipatory decisions about them (33, 63). Several aspects of this practice are counter cultural to societies where physician led (64) or family decision making is prized and future decision making may be in the hands of God (1, 33-35).

There are further ethnic differences in the way in which people engage with conversations with family or health care professionals around end-of-life planning including the formal or informal nomination of a health care proxy decision maker (15, 40, 64, 65). In many western cultures there is a movement towards greater individual autonomy particularly when it comes to health decisions, however this is changing at different rates in different societies.

Some health care codes of professional conduct place patient autonomy as a cornerstone of professional care. There is a rhetoric that person centred care is also a dominant underpinning philosophy of modern health care (66). In palliative care, this person-centred care is based on a holistic notion that includes family as part of the unit of care. The focus on advance care planning continues to highlight an underlying belief in individual autonomy as a fundamentally important construct (1, 18). In contrast to this focus on individual autonomy, family and relational identity are important to many patients' autonomous agency and particularly for people from ethnic minority cultures (41, 67, 68). People of all cultures make relational decisions regarding health care choices, for many this sense of relational autonomy may mean they choose by default to leave decision making to trusted others, using family members (40, 64). In some cultures, this is a larger collective process than others and maybe something people choose even when they know the choices others may make for them may be different to what they might make for themselves (13, 40).

This relational autonomy can be a challenge for those in health care whether explicit or implicit (62, 69). Providers of palliative care still hold onto concerns that those who defer to others such as family members for decision making may be acting out of undue pressure to undertake or not undertake treatment options (49, 67), illustrating an often-unconscious normative bias (21, 62). In some families, dissonance arises around the notion of involving professionals in what is perhaps seen as belonging to family such as care at the end of life (41, 62, 68).

The differences in habitus between different cultural groups and normative societal expectations can lead to a hysteresis between people's habitus and cultural expectations and the way in which palliative care is offered and provided (70). This is further complicated by intergenerational dissonance as younger generations culturally assimilate to the host culture (61). For older family members, accepting outside help is complex resulting in poor symptom and disease management and high caring demands on younger family members, notably women (71). There are strong community and family expectations and carers can lack agency to request it for themselves. Wacquant and Bourdieu (72) talk of 'fields of struggle' and issues of power in the creation and maintenance of this complex field which is the society in which we live.

Consequences

The consequences or what happens after or as a result of the concept of hysteresis, are temporal dissonance potentially exacerbated by symbolic violence and social suffering. However, what also can result is a growing social capital and self-efficacy through collective experience and triumph through uncertainty.

Symbolic capital and symbolic power

People or 'social agents' have symbolic as well as observable physical material properties which are affixed to them through their relationships with other people in society (73). It may be argued that professionals who promote this benevolent service of palliative care are held in high esteem by the public in the western world and so gain social and symbolic capital for this. Symbolic power then arises out of symbolic capital as the belief "by virtue of which persons wielding authority are endowed with prestige" (73). Symbolic power can result in symbolic domination or Bourdieu's symbolic violence almost subconsciously.

Palliative care has been developed from a perspective that values autonomy and defines a good death as one that is expected and planned for (57). This is how it is depicted in popular culture. For some whose culture is collective and collusive, this can feel exclusive (34, 65). Those who comply with the normative goals of accepting professional help to achieve good dying are seen positively in this narrative. Those who experience hysteresis and may not want to engage may be seen as deviant (2, 6, 21). The terms 'being in denial' and 'refusing' are often used in healthcare to label and embody this doxa or language of good and deviant patients, symbolic dominance and symbolic violence. Terms such as non-engaging or hard to reach are also commonly used when referring to people of diverse groups who do not feel comfortable with the way services or opportunities to participate in research are offered (21, 58).

An understanding and willingness to engage with palliative care often comes from bonding social experiences (1, 74). These come from experiences of a friend or family member who has experienced palliative care or even through social engagement with local hospice services through fundraising endeavours such as charity shops and sponsored events (74). This builds social capital and with it, symbolic power. People from communities who are less likely to have these types of bonding experiences are likely to be more fearful of engaging with palliative services and acquaint more strongly with a sense of expediated dying (75, 76). Social capital produces and reproduces social inequalities (73). Participation networks are most likely to take place amongst most wealthy and highly educated, and as such those who do participate gain bonding capital and with that develop an excluding doxa and social capital Marginalised communities can be problematised for not participating in what are intended to be supportive informal networks (46, 77).

Social suffering

Bourdieu in the *Weight of the world highlights* the social suffering of those who are unable to adjust to the rapidly changing conditions of their lives particularly when there is serious illness coupled with other lived experiences of inequality (17). Those whose life experiences are shaped by disadvantage through life due to their lack of many types of capital, enter their phase of dying in a disadvantaged state (46, 53). Dying in a society where individuals already feel disenfranchised, due to the impacts of structural inequalities, limits the trust they have that they will receive an equal and non-biased offer of the best personalised care for them, exacerbates their experiences of hysteresis and makes this time even more difficult (6, 16, 19, 30). Social suffering can come from a feeling of hysteresis when faced with the offer of culturally dissonanced ways of doing living, dying, caring and being.

The concepts of dying well contain components shared by multicultural perspectives (57, 78). They include being with and having concern for their families, being relieved from pain and psychological distress, not being a burden to others and being able to engage with emotional, social and spiritual rituals as one approaches the end of life (79). However, to achieve all these things communication around illness and healthcare needs to be open and helpful. Studies exploring the experiences of people from diverse minority ethnic heritage communities find referral to palliative care is often less likely and happens later in the illness trajectory than for their white counterparts (2, 35, 48, 53). The reasons cited include death anxiety, lack of awareness of formal advance care planning and physician avoidance of family discussions around end of life (80). Modern western medicine brings with it the mixed blessings of life prolongation making end-of-life decision making more complex (81). In a culture where autonomy is prized, palliative care favours individual decision making and making pre-planned choice led decisions about living and dying as fundamental underpinning tenets (82) when other models of a more relational autonomy are not engaged with effectively more people miss the opportunity to die well (7, 62).

Symbolic violence

Symbolic violence may seem an unnecessarily provocative term. However, whether physical or symbolic, the exercise of power always has the potential for violence, exercising symbolic power can often lead to activities that result in the domination of others (83). Bourdieu's concepts of symbolic power and symbolic violence suggest that symbolic violence is an effortless force that moulds the world via communication without those involved even noticing it (84).

Seeing people who feel different to oneself as 'the other' and so often deficit is a form of symbolic violence. A common term used in exploring how minority groups preferences or actions differ from normative views is talk of barriers and challenges rather than thinking of these as being equally valuable perspectives (54). Internalising the discourse of the dominant can unconsciously disenfranchise 'the other'.

Repeated attempts to encourage patients with deteriorating illness to make autonomous decisions may make internal family conversations even more complex (63, 67). Different family members may want different things for the dying person, and not all family members may be happy if the patient makes choices to withdraw from treatment (38). For some informal carers accepting palliative care referrals or outside help is complex and some carers lack agency to make that choice (71).

Health care professional communities can also experience hysteresis when asked to explore new models of healthcare and even when new philosophies of health are proposed (85). Although there is a desire to be more inclusive in how aspects of health care, such as palliative care, are offered and delivered when this goes as far as challenging the existing model of delivery, change may be less welcome. From a position of power informal groups of professionals can unknowingly add exclusivity to this field of palliative care and unwittingly increase inequality and contribute to a process of social suffering and symbolic violence.

Social capital and self-efficacy

Caring provides benefits as well as burdens both for individuals, families and communities (86, 87). Being a carer in circumstances where, due to a hysteresis effect, palliative care services are hard to access can be an isolating and difficult experience (51, 71). However, through those adversities, a resilience can develop leading to rises in self-efficacy and social capital. As difficulties are overcome, access to support is gained, relationships are built within communities and the development of new models of palliative care are built within communities which respect the prevailing cultural values.

f) Identify a model case of the concept

Model case

A model case is intended to enhance clarification of the concept being analysed. This case was selected from one of the studies used in this analysis. The participant was a woman of Asian heritage living in the USA.

> *My husband is Caucasian, and we've been married for quite a long time and I remember … before his dad died. His parents were well… they might have been 60s? And he's almost 90 now. They sent them [husband and his brothers], all this detail about the will. His mom had gone through all the photos and each set of boys had all the photos of everything. It was horrible, for me I felt it was horrible. They liked it. I felt like they were saying goodbye ..and that was from when they [the parents] were 60 ! (88).*

Contrary case

Contrary cases illustrate that concepts such as hysteresis do not exist for everyone. Some situations and some people do not experience this concept. As hysteresis is an evolving concept, even for one individual different thing may happen in their lives that changes their experiences and perceptions of the concepts such as being involved in the death of another.

> *"And I feel that my views have completely changed. It's very geographic based. In India…I firmly believed that doctors should not tell the patient. The reasons were very simple. You could assume the support system…People are going to be there with you to help you. So why tell the patient and whatever limited time that person has, and make that time very difficult for him, that he's going to die…Here, my decision has completely changed. If I am here, you better tell me because…I've got to take care of, make arrangements for myself…I cannot depend on many people around me." First-generation male, age 50 (38)*

g) Identify implications and hypotheses for further development of the concept

The purpose of this concept analysis was to engage with active and methodological listening to recognise social suffering and to deepen awareness and understanding and bring sociological attentiveness to the way in which we achieve better dying in multicultural societies (19). It is hoped that this will be useful for health care professionals caring for people and their families to consider and using reflexively to explore personal patient and family interactions with more cultural humility.

The issues raised in this piece include the unintentionally exclusive doxa of palliative care, the role of social capital in understanding that doxa, the resultant social suffering and symbolic violence that can result for people from cultures where different things are valued and considered important when coming to the end of life. In moving forwards, it is also helpful to consider the implications of this sense of hysteresis that can exist for communities of people of minority ethnic heritage in the development of social capital and self-efficacy in this field of end-of-life care planning and most importantly improving the experiences of dying.

Communities themselves have enormous capacity to offer environmental and supportive interventions, how community support of different but more culturally attuned forms around the dying process is built is explored in the building compassionate community's movement (87). For palliative care services to be more responsive to a wider range of community needs, and for a wider range of people to feel comfortable about expressing preferences there is a need to change the doxa or the language in which it is communicated. This in part comes from recognising inequity working on elements such as racism in fields like palliative care provision to reduce the symbolic and social violence experienced by dying people and their families (21).

Changing doxa

Engaging in genuine listening conversations that seek to understand underlying cultures is paramount in developing an inclusive notion of how palliative and end of life care can play a part in achieving good transnational dying (7, 47, 54). It is necessary to develop some common language to discuss subjects as difficult as dying and to include a greater awareness of the rules of promoting good dying from different perspectives. By reducing the exclusivity of the values of palliative care, we start to reduce the symbolic violence. Examples include working on models of relational autonomy, seeing family as cultural assets rather than barriers and moving to a more social picture of palliative care.

Promoting and embracing change

Changing values and attitudes in any societal or professional sphere can be challenging, requiring honest retrospection and acknowledgement of conscious and unconscious bias. It may mean those accustomed to being experts considering a reallocation of what is considered important and sometimes to do things that feel uncomfortable and counter cultural. This is often not easy and not one in which people who are used to holding symbolic power always feel prepared to engage with in a significant way that results in real change. The importance of not being a passive bystander is one that is becoming more evident in current discussions around equality, diversity and inclusion (2, 6, 34, 82). It is important to move from a deficit view of barriers and to look instead at building equitable relationships and harnessing the assets that come from different cultural approaches (54).

Conclusion

Using Rodgers' (1999) evolutionary method of concept analysis as a framework has enabled an investigation of the antecedents, attributes and consequences of the concept of hysteresis experienced by people of minority ethnic cultural heritage who are dying and their families. This paves the way for health care professionals working and researching in palliative care to take a more reflexive pathway to engaging in culturally appropriate and empowering research to enable difficult voices to be heard which will influence future directions of palliative care and societies approach to conversations about dying and ultimately enhance outcomes for a more diverse range of people facing death.

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4.5 In conclusion

This exploration of perceptions of engagement with palliative care of people of diverse ethnic heritage using Bourdieu's concept of practice as a lens was done using this concept analysis framework. The process of conducting this analysis was to help me explore these complex phenomena with the aid of related literature. It was done to provide a backdrop exploration of how a service like palliative care might be viewed and experienced by people who come from difficult cultures to the one more predominant in structuring modern palliative care prior to exploring in more depth people's experiences of family conversations about end-of-life care which is a core part of palliative care.

4..5.1 How this Lens of Bourdieu's concept of practice related to the study development

Bourdieu's theory helps to provide a way to envision how rules of engagement and ways of approaching many aspects of societal living including major life transitions such as birth and death operate in society. Bourdieu's ideas offer a way of considering how different communities within that society are impacted by those rules and norms. It also offers a way of considering how, for new people joining communities, things that are of value in the host community, will play a role in determining the social position of the newcomers and their ability to play a part in the rule making. It offers a macro or structural picture of society that is engaged with differently by different people due to differing sources and value of agency in the form of capitals.

This study of family conversations around end-of-life preferences has been conducted in a context where the way in which palliative care is conceptualised and delivered is influenced by a dominant philosophy that may not resonate equally in different communities, as explored through the concept analysis. Each community and cultural group are a dynamic entity with many intergroup dynamics impacting on the way everyone with the group or on the edge of the groups will experience and articulate their values and norms around any aspect of cultural practice. It is these more micro dynamics that are still to be explored and understood which is the aim of this study, this cannot be done without retaining an awareness of the overall dynamics of the societal contexts.

Secondly when exploring diverse cultural approaches, it is important to work on avoiding the taking of a deficit approach when considering any of the different groups involved. When conducting this research, although my underlying world view of how society operates is informed by Bourdieu's concept of practice, it was essential to be always vigilant to explore these elements of passivity and to be conscious of the gender roles being spoken about and how they are considered generated and moulded.

As a PhD student and reflexive researcher, I used the opportunities that came with being enrolled in a PhD program to how to investigate and understand my own underpinning ontology and epistemology. Using a concept analysis, I have been able to explore and make sense of Bourdieu's concepts of hysteresis aligned with the experiences of people from diverse ethnic heritage as I can ascertain it from the literature available. This chapter of exploration has resulted in my gaining a better understanding of my own worldview as one that is based in relativism where the social world is constructed by those within it. I have also developed an understanding that the knowledge we have is built on by what we know and find out and this construction is related to who we are in society, our grasp of social rules and sense of power within that society.

4.6 Moving from theoretical underpinnings to the methodology

Bourdieu's work is helpful in offering a perspective around how community knowledge and experiences is shaped by external and internal forces, his theory offers a macro view of society construction. It does not explore the more micro elements such as development of intra-family dynamics and conversations. Whilst the work of Bourdieu is a useful epistemological lens to understand some of the dynamics of cultural development in places where there is a multiplicity of cultures in one society, in this study, a more nuanced, understanding of the micro culture within families is being explored and developed. Exploring the literature to date, as outlined in chapter 3, elements of this microculture has been described but not theoretically constructed to provide a more in depth understanding of what it is and how it is shaped. My exploration of different methodologies centred around trying to find a methodology that would help me to do this.

Although this exploration offers some underlying potential illustration of why people make different choices around the way they die, embrace palliative care and discuss end of life preferences within their families, there are still things that need to be explored in more depth to be understood. There is still a gap in understanding what the perspectives are of people of African and Caribbean heritage living in the UK of these things, and particularly that of adult children in these communities. How do their life experiences, traditional values and positionality in society impact their perspectives about end-of-life family conversations and their value in improving dying of people within their communities? It feels like a deeper theoretical exploration will be helpful to give more insight. This led me to use a more qualitative theory building research approach to conduct my study into this area. This is discussed in the next section in chapter 5.

Chapter 5: Methodological approach

5.1 Introduction

Using as a basis the storylines constructed in the meta-ethnography in Paper 1 and the theoretical underpinnings in Chapter 4 and Paper 2, the methodological approach of constructivist grounded theory (Charmaz, 2014) was used to undertake this piece of research to answer the study research question is explored in this chapter. After the methodology has been outlined, the final section is a reflexive consideration of the steps undertaken based on Charmaz and Thornberg (2021)'s guiding principles for conducting a robust study to ensure a quality approach to theory construction.

5.2 Choosing an approach

The relativist ontology and social constructivist philosophy underpinning this research was discussed in Chapter 4. The next step involved determining the most effective methodologies for answering the research question and selecting appropriate data analysis techniques (Miles and Huberman, 1994). Although popular opinion suggests that the research question and study objectives are major factors driving methodology in research studies (Braun & Clarke, 2013). Study design is often a dynamic process, allowing for entry points beyond the initial research question as the study progresses (Staller & Chen, 2022). In part this is due to the learning that results from embedding oneself in an area, developing new insights and becoming aware of previously unrecognised assumptions and preconceptions (Palaganas et al., 2017). Qualitative research is designed to probe beneath the surface of phenomena, providing a nuanced understanding. The methodology employed shapes the type of knowledge generated, which can be instrumental in addressing specific research objectives.

The earlier chapters in this thesis illustrate that there are different views about the value of advance care planning or family conversations about future care, but it is often promoted by health and social systems as ways of encouraging people to think about preferences before they are in a crisis situation where decisions need to made quickly and people may not be in a position to contribute to the decision-making discussion (Carr, 2011). Whilst there is some understanding of why engagement with advance care planning and other palliative care services varies across communities (Ladd, 2014; Sanders et al., 2016), the reasons behind these variations and the specific factors that influence experiences within African and Caribbean heritage communities remain less clear. Qualitative research methods can help us explore these questions by examining people's perceptions, values and personal experiences (Starks & Brown Trinidad, 2007). They can also help to develop explanatory theories that can help to understand what other communities who have experienced similar things may also experience. This wider understanding can hopefully help professionals to have a deeper and more insightful understanding of people's experiences which may help communication, but also it gives insight to people about their own experiences.

As well as providing leverage to theory development, qualitative methods can ensure that the experiences of groups who may be underrepresented in tradition surveys or mass volunteer type approaches is heard (Koffman et al., 2023; Kopec, 2023). This is important when exploring structural societal issues. Qualitative research, in the form of phenomenology, can give voice to the specific lived experiences of people, or through discourse analysis and narrative methodologies, it can capture how it is being described by different voices, giving more community level perspectives (Starks & Brown Trinidad, 2007). Qualitative methodologies such as critical interpretivist methodologies highlight different aspects of people's experiences of social phenomena by capturing the sociopolitical influences. From a more constructivist standpoint, grounded theory can lead to more nuanced understandings of complex phenomena such as cultural values and perspectives but can still capture the hidden or unheard voices (Charmaz & Belgrave, 2018).

Initially when starting this research project, I was keen to use an asset-based community development approach (Matthiesen et al., 2014). However, having conducted the meta-ethnography and explored the underlying culture or field that exists in palliative care, it felt important to better understand the processes that were occurring here for families before moving into a type of research that is about generating interventions. This process allows detailed reflections to take place on the existing biases and assumptions of myself as a researcher and others promoting this work against what people in these communities' report for themselves.

5.3 Exploring theory generating methodologies

Exploring questions around people's experiences and perceptions of talking about and preparing for dying revealed that within every community there are nuances as to how these conversations are undertaken and received. There are commonalities across different communities; for example, there is some reluctance in most communities to contemplate and speak about a future death. The intention was to construct a picture of a community understanding of what happened around family conversations and why that might be, rather than of the experiences of individuals of a particular community, which could have been gathered using a more phenomenological approach (Ozuem et al., 2022). Through engaging in an in-depth analytical process using group constructed conversations, the intention of this study was to abstract the findings to a level that could be used to develop generalisable explanations and insights across communities (Starks & Brown Trinidad, 2007).

This led to an exploration of theory generating methodologies. In the area of advance care planning or family conversations around dying within health disciplines little theory seemed to exist and be utilised. Grounded theory is an appropriate approach for this research because it allows for the creation of theory through an inductive process, directly grounded in the data collected from participants (Glaser & Strauss, 2017; Poonamallee, 2009). In areas where little formal theory exists, grounded theory enables the researcher to build a conceptual framework based on participants' real-life experiences, rather than imposing pre-existing theories. By allowing theory to come from the data, this approach amplifies participants' voices, ensuring that the resulting insights are deeply rooted in their perspectives and lived experiences, which is important in underexplored fields.

Much qualitative research explores the what and how questions around social processes; however, social constructivist grounded theory engages with the why of these processes whilst preserving the complexity of social life (Bryant & Charmaz, 2010). To be able to develop effective interventions and just stop ‘admiring the issue’ (Meier et al., 2017) or describing the status quo, a deeper understanding of the underlying preferences, social processes and preferred modes of action of people from ethnically diverse heritage communities is needed.

Historical development of grounded theory

Grounded theory methods came out of a social interactionist paradigm and began with 'classical grounded theory' devised by Glaser and Strauss in 1967 (Groen et al., 2017). Glaser and Strauss sought to develop methods for understanding social behaviours by exploring individuals' perceptions of their actions, thoughts and interactions. Rather than imposing predetermined hypotheses, their goal was to explore the breadth of these experiences and generate theories grounded in qualitative research (Glaser & Strauss, 2017).

Grounded theory underpinned a more developed approach to qualitative research with qualitative research outputs regarded as valid knowledge where previously, only positivist or naturalistic research generated knowledge was valued. Glaser and Strauss' grounded theory approach emphasises data-driven research. They use comparative analysis to compare different data points, coding to label key phrases and categorisation to group similar codes. Throughout the process, memo writing helps researchers document their thoughts and insights. This approach allows researchers to discover theories directly from the data rather than imposing preconceived ideas (Glaser & Strauss, 2017). In time it became clear that Glaser and Strauss had slightly different views on how to conduct grounded theory (Heath & Cowley, 2004). Glaser wanted to limit the influences of the ideas of others onto the induction process that the researcher undertakes when working with and coding the empirical data collected from study participants. Only once categories are devised does Glaser recommend viewing existing literature to expand on and clarify the elements of theory being generated. Glaser suggests starting with a tabula rasa or clean slate, ensuring that subsequent influences are captured in memos and that efforts are taken to limit their influence. This allows the participant's words to be used to create the theory in an almost purist inductive way. This approach suggests a type of objectivity can be achieved in the inductions made. Because of this Glaser would argue that his model of research has a neutral epistemology (Breckenridge et al., 2012). Strauss, whilst still on board with most of the original theory, believes that at times an understanding of some of the preexisting theory could be useful, although there are limitations in which situations this would be appropriate (Strauss & Corbin, 1998). Alongside these debates between Glaser and Strauss, Charmaz (2006) and later Charmaz and Bryant (Bryant, 2007) developed their own approach to grounded theory informed by a more constructivist epistemology (Crotty, 1998).

5.4 Constructivist grounded theory

Social constructionists recognise not only the complexities of social life but also the researcher's role in constructing knowledge. By questioning, exploring and trying to understand the conversations observed, whilst acknowledging the influence of their own perspectives, researchers can engage in a more inductive and reflective process of knowledge construction (Palaganas et al., 2017). Qualitative data analysis is by its nature subjective and influenced by the perspectives of the researchers involved. Rather than seeing this as a limitation that needs to be removed, it is an integral and acknowledged part of constructivist grounded theory. Constructivist grounded theory appears to be a good approach to explore phenomena that are socially constructed like family conversations around dying and trying to understand the dynamics that exist a little better.

Constructivist grounded theory research places emphasis on uncovering contextual social processes to build theory that explains what is happening in the social interactions being studied (Bryant & Charmaz, 2010). In this study there are complex social processes to uncover that will have shaped both people’s experiences to date but also how they might envision the future (Charmaz & Belgrave, 2018). The exploration in Chapters 3 and 4 in this thesis of the experience of hysteresis experienced by many people of African and Caribbean heritage (most of whom have recent migration histories and will have family in more than one country in the world) provides some background exploration of the field of practice of palliative care in which this enquiry about end-of-life planning conversations has arisen.

The data collected and subsequent theory that has been generated is grounded in the experiences of the participants of the research. Rather than being an objective process, as the researcher I am a co-creator of the data in this study through my interactions with the participants both during data collection and afterwards through the analysis process (Charmaz, 2006). The theory that has been built is based on my own observations of the data and my understanding of the social processes described in the data.

Constructivist grounded theory is an emergent method that involves working with the data collected in an inductive, indeterminate and open-ended manner. Although I have tried to maintain an open mind during the analysis and theory creation process, it has been important to be conscious of firstly my own precognitions, which I have tried to lay out in my writing as I go. It has also been important to use regular fieldwork memos and a reflective diary to retain an understanding of what experiences and thinking processes have influenced me in the constructive process (Bryant & Charmaz, 2010). The introduction chapter of this thesis, the meta-ethnographic construction and the concept analysis in Chapter 4 helped develop an understanding of any previous discourses relating to the social processes under study.

In constructivist grounded theory (Charmaz, 2014) the researcher presupposes that everything is in context. This approach highlights the impact of the researcher and does not seek to reduce it. It allows and encourages an understanding of other contemporary views when interpreting the data collected from participants. The process of constructivist grounded theory involves the process of theorising as the research progresses; this theorising considers the participant voices but also frames them within their contexts. Additionally, constructivist grounded theory draws upon other knowledge relating to both the impact of context and societal constructs. In the conduct of this study, I have explored the experiences of people from other communities where particular social processes have highly influenced perspectives, such as filial piety in Chinese and other Southeast Asian heritage communities (Chan et al., 2012) and whānau in Māori communities in New Zealand (Gott et al., 2017). However, through this research, theory will be created using data grounded in the unique experiences of African and Caribbean heritage communities living in south London. It is therefore important to be cognisant of recent literature detailing the racism related experiences that are prevalent and understand how these play a part in the construction of social perceptions (Bajwah et al., 2024; Chukwusa et al.).

As this constructivist grounded theory is constructed, it is important to engage in several guiding principles (Charmaz & Thornberg, 2021).

1. It is important to engage in a reflexive review of all the experiences and decision making throughout the research process. Conducting this piece of research as a PhD student

offers me an opportunity to do this in a formal way at monthly meetings with my supervisors. They bring wide research experience and Dr Salifu also has lived experience of living within an African family and community. This allowed us to interrogate both the coding and the way in which ideas were constructed; this was particularly helpful around the development of categories into constructs and that process of abstraction.

2. For the theory that is generated to be considered valid, it is important for researchers to be transparent about their standpoints, starting points and the steps, they take whilst carrying out the research. To try and be transparent about this, time was taken to work on this in the first couple of years of doing this PhD. However, in a deviation from the processes of classical grounded theory, researchers should research and make themselves familiar with the contemporary literature in the area to aid the level of critical enquiry they can subject their data abstraction to (Charmaz, 2017; Charmaz & Thornberg, 2021). They warn against seeing this literature as the only way of viewing things and remind researchers to recognise that all methodological approaches, including grounded theory, have an epistemology, regardless of whether it is recognised or acknowledged in the work.

5.5 Research design

Aim

The aim of this study was to develop a theoretically constructed understanding of the dynamics that underpin end-of-life conversations within families of African and Caribbean heritage.

Objectives

To explore the perceptions of older adults and their adult children about having family conversations around end-of-life preferences.

Using constructivist grounded theory methodology to develop a theoretical understanding of these experiences drawing on Bourdieu's concept of practice as a philosophical lens.

To develop ways of enabling healthcare practitioners to connect with this theory when working with families.

To consider strategies to engage communities in the significance of this theory and how it can be used to influence the development of culturally sensitive approaches to having end-of-life family conversations.

Participant selection

This study was set in two boroughs in south London, UK where people of African and Caribbean heritage are the largest ethnically diverse heritage group. They form 15.6% of the population of London.

Recruitment

There were several planned participant recruitment strategies, some of which were used but others had to be abandoned as lockdown and social distancing came in with the development of the COVID 19 pandemic.

An early plan was for me as primary researcher (JDS) to approach group convenors of existing community groups that had high numbers of people of African and Caribbean heritage; for example, an Age UK group which held a luncheon once a week in a tenant's hall on a council estate in south London, and two local church groups which met on a social basis. Study posters (Appendix 3) were placed on noticeboards where the groups convened. The poster contained my contact details so people who were interested could make direct contact via the study mobile phone number or my Lancaster university email address. Alternatively potential participants could speak with a named community group facilitator (written on the poster). The plan was that participant information packs were to be provided to facilitators to be distributed to interested parties. They would take the names and contact details of interested potential participants and with their permission pass them back to me to contact them to discuss the study further and arrange for them to participate.

Although the group convenors were approached, only one of the church groups and one luncheon club was visited and information circulated. No participants volunteered initially; however, after a follow-up visit to the church group and informal conversations, some participants were recruited. Participant information packs (Appendix 3) were given to people expressing an interest and their contact details taken. No less than 48 hours after, I contacted them to discuss the study further to give time for them to read the information. Arrangements were made with participants who remained interested to participate in a focus group, most of these joined focus groups 2 and 3.

The Lambeth coalition for advance care planning (a coalition of local government and community groups with an interest in encouraging open conversations about dying) also ran a dying awareness tent during a two-day summer county show in Lambeth. I briefed volunteers running the stall about the study and the study poster was put on display in the tent. An expression of interest form was available for people to complete if they were interested in receiving further details from myself. However, although the volunteers at the tent were interested in the study, no participants were recruited. One volunteer was a local GP of Caribbean heritage herself. She felt this would be a very useful exercise as it was an area of her practice that she found complex as patients and families were often unrealistic about health outcomes and very reluctant to discuss the future. Other recruitment plans such as adverts in local newspapers were not pursued as the COVID pandemic resulted in a halt to participant recruitment.

Following the pandemic, when recruitment could be wider due to the use of online focus groups, the study was advertised on the international observatory for end-of-life care Facebook site of Lancaster University. Interested parties were advised to contact me via private message or by email. Twitter was also used to attempt to recruit volunteers. However, again there were no participants recruited via these methods. Research volunteer bulletins at both Lancaster University and King’s College London were also used. Two volunteers were recruited via the King’s College London bulletin method and one through a message that went out on a Yammer group in another health organisation. These participants joined groups 3 and 4.

Most of the successful recruitment for the study was through snowball sampling via direct contacts, participants or people who heard about the study and were unable to take part themselves due to eligibility but who contacted others they knew. They were requested to contact me to receive more information and involvement details. Potential participants were given a period of no less than 48 hours to read the information and decide if they wanted to participate.

Participant information packs (PIP)

The participant information packs (PIP) contained a letter of invitation, study information sheet and a stamped addressed envelope to return forms to the community group organisers. A phone number and email address were also provided if they wished to indicate their interest in the study in that way.

5.6 Data collection method: focus groups

This study sought to understand participants' perceptions about current cultural norms and practices as well as their own personal experiences. Although interviews are a common method used in constructivist grounded theory data collection, data collected via interviews gives a more individual perspective on the phenomenon under study. As we sought a more community held view, we were interested in how a more collective view could be elucidated. The method chosen to collect the data for this study was focus groups. Focus groups can be a useful form of data generation with which to understand things from the point of view of both one and of others in society. Focus groups are a commonly used method in constructivist grounded theory (Howitt & Cramer, 2010). Focus groups can allow participants to co-construct a picture of the social process they perceive to exist within their communities. The interaction of focus group members often produces data and particular insights that might be less likely to occur when interviewing one person at a time (Ott, 2008).

From a social constructivism viewpoint, the interests of the research are to observe how the group constructs shared meaning and a world view that comes from the individual's experiences. The purpose of a focus group in this instance was to provide an in-depth exploration of this topic of end-of-life planning family conversations in African and Caribbean heritage communities, about which little is known. Another reason for choosing focus groups as a data collection method was because in cultural research participants have reported feeling safer in a focus group than when voicing options in a one-to-one interview (Kieffer et al., 2013; Liamputtong, 2010). Focus groups can empower people, particularly those from marginalised communities whose voice is not always heard (Green & Thorogood, 2018).

Generating data using focus groups allows participants relatively more influence in the data generation process than exists in a traditional interviewer/interviewee situation with one-to-one research interviews, as participants outnumber the facilitators and this can have an influence on the power balance of the interaction (Acocella & Cataldi, 2021). Focus groups can be helpful when discussing difficult topics; group discussions can present themselves as less threatening and result in better recruitment (Clarke & Seymour, 2010).

Recruitment was through natural meeting groups as this has been found to be the most effective way of getting participation from people of ethnic minorities where recruitment of participants into research studies is known to be challenging (Liamputtong 2010). Where a study is seeking to get a sense of cultural patterns and societal doxas about end-of-life conversations, focus groups conducted in groups who are already known to one another can be helpful. People who already have some sort of group identity can offer more sense of where shared ideas have developed from (Stewart & Shamdasani, 2014). Issues such as inter-group power relations, particularly where group members are known to each other, can reduce the ability of those lower in the group hierarchy from having a voice in this group situation (Green, 2013). This limitation was acknowledged, and careful consideration was given to ensuring group facilitators were skilled in helping to facilitate all group members to be part of the conversation. Interaction questionnaires were also used to explore the interactions and to look for what influences participants had on each other (Stevens, 1996). This is explored in more detail in Paper 3 in Chapter 6.

As the study is a constructivist grounded theory, ethical approval was sought and granted to include some individual interviews using theoretical sampling at a later stage of the project if it appeared to be a helpful strategy to develop understanding around aspects of the concepts being constructed. The use of focus groups can risk missing negative or personal experiences which may be only accessible through individual interviews. However, follow-up interviewing was not employed in the end as the group conversations generated a wealth of elements that were useful to generate the theory.

Each focus group was facilitated by two experienced researchers. I led the groups and the second (KG) observed and took notes. The notes were used as study memos to help guide subsequent groups and to provide material for reflection by the research team. Initially we convened two focus groups, one with adult children and one of elders, and then using a process of coding outlined by Charmaz (2014) and Saldaña (2013), we started the process of data analysis. This initial analysis was helpful in identifying what codes were appearing important to the group. It also allowed us to see what areas had been mentioned but perhaps not explored. This iterant data collection and coding allow the researcher to adapt the questions in the next group to ensure in-depth exploration of ideas. This is how the process of construction works. The researcher plays a role in this with the participants, rather than collecting data that is only generated by participants. This also allows the researcher to use purposeful and theoretical sampling in subsequent focus groups to clarify concepts further. Further detail about the process of analysis is discussed in the findings in Chapter 6, and in Paper 4 in Chapter 7.

5.7 Axiology – ethical issues

It is important that due regard is given to ensure all research projects are safe, legal and ethical (HRA, 2023). The framework provided by the Economic and Social Research Council (ESRC, 2019) based on six key principles for ethical research was used to guide the exploration of the ethical, and potentially legal issues, that were raised through this piece of social research. Areas addressed included informed consent; confidentiality; data protection, and right to withdraw; and potential benefits and harms. These elements were incorporated into the framework.

Potential benefits and harms

The background section of this thesis has identified the rationale behind the value of exploring this area of family conversations around dying and using this study to start a process of community collaboration to work on reducing death taboos and to encourage family dialogue around difficult health matters including end-of-life wishes.

Discussion about death and dying, however, can be frightening and people often have high levels of death anxiety (Depaola et al., 2003) and discussions of this nature can conflict with strongly held beliefs and cultural mores. Care needs to be taken to protect the participants and their families from harm. To minimise any harm or distress that may be caused by engaging in discussions about death and dying, firstly it was important to ensure that the nature of these discussions was known to participants before attending. This was covered in the participant information that was given to anyone who might potentially participate in the project, and a period of at least 48 hours was set before approaching them for a second time to see if they would be willing to participate (Appendix 3).

Secondly, the focus groups moderators are experienced in the field of palliative care (JDS & KG). Both moderators are familiar with preparing groups for challenging conversations and working with participants who find themselves upset or disturbed by such conversations. Alongside the written information, participants received a clear briefing at the start of each focus group session and were offered an opportunity to stay behind and share any difficult aspects with us afterwards. Having two moderators in the room meant that if a participant had become distressed during the focus group, one moderator could take them out of the group and talk with them whilst the other managed the other participants. This was not needed but it was important to have that provision available. Further follow-up support was offered in the participant information follow up.

Several studies on attitudes to advance care planning amongst ethnic communities have revealed a lack of awareness of the process; however, once participants have become aware, they express a desire to engage in some advance care planning (Sanders et al., 2016). Provision of an information booklet about culturally sensitive advance care planning was made available to anyone requesting it after the focus group sessions.

It is also important to consider the wellbeing of the facilitators (Gilbert & Stoneman, 2015). In this study the facilitators are experienced nursing lecturers who have extensive experience of managing groups and discussing difficult topics. They are also known to each other and could draw on each other for support with any emotions brought up by the research or any group facilitation issues whilst still maintaining participant confidentiality. A time of debriefing was held between them after each focus group. Further debriefing was held during monthly PhD supervision with the two supervisors, people also skilled in both of these types of research techniques but also as palliative care healthcare professionals.

Respecting the rights and dignity of individuals and groups

In a focus group, participants outnumber the facilitators, and this can help to even out the power balance of the interaction (Acocella & Cataldi, 2021). The use of focus groups can empower people, particularly from marginalised communities whose voice is not always heard, by putting the group participants in the majority (Green & Thorogood, 2018). Inter-group power relations, particularly where group members know each other can reduce the ability of those lower in the group hierarchy from having a voice in this group situation. Some negative or personal experiences may only have been accessible through individual interviews. It was made clear in the study information and at the start of the group that members could be offered follow-up interviews (Appendix 3). The observing facilitators took note of whether members did not contribute much or if something sensitive was alluded to but not discussed. There was the potential to offer such individuals a follow-up phone interview so their perspectives could be explored. The same was offered to any individuals who may have liked to have the opportunity to follow up on something that came up in the group. No follow-up interviews were considered necessary, and no participants requested follow-up calls. These dynamics are discussed in more detail in Paper 3 in Chapter 6.

Anonymity/confidentiality – All data collected was kept carefully and securely. The audio recordings were downloaded into the NVivo software where they were transcribed. The recordings were kept in my university secure account so they could be relistened to. They will be destroyed when this study is complete. The transcripts were anonymised so that they are not personally identifiable. When the groups were discussed with the supervisors and any other forum, only the anonymised scripts were referred to. Anonymisation keys were established with secured access to the keys on my computer in a secure drive.

Data/sample use and destruction – As part of the participant information (Appendix 3) participants were informed that the data in the form of recordings, transcripts and notes would be retained for a period of 10 years to allow completion of the study and any subsequent research papers written. All of these will be deleted in a secure digital deletion process.

Informed consent

Informed consent is an important concept in the conduct of research (Silverman, 2016). Informed consent can give the study participant a sense of control over their personal information and aims to alleviate the fear that their information will be retained or used in any other unintended manner.

The study protocol was informed by the Royal College of Nursing (RCN, 2011) guidance which included key information to provide people entering research studies. These include the aims of the study; duration of the study; risks involved; benefits of the research; how their data would be used; and the importance of consent being given without the individual feeling coerced or influenced. It is important to ensure information is transparent, easy to understand, clearly communicated using non jargon words and checks are put in place to ensure potential participants' comprehension (Polit & Beck, 2012).

It is important that any information pages and consent forms are clear, comprehensive and reflect current practice. Careful briefing at the start of the focus groups included an option to leave the room if the research was not comfortable for them. Discussions were held with members of both African and Caribbean heritage communities about the most appropriate and honest way to introduce the topic and word the focus group and individual interview work.

Participants were also offered the opportunity to withdraw from the study at any time without a need to give reasons; however, in the participant information it was explained that we would not be able to remove their contributions to the focus group conversations as they are part of something co-constructed. Part of giving consent meant giving consent for us to use that co-created data even if they chose to withdraw from the study (Appendix 3) ("Data Protection Act 2018," 2018).

The right of participants to withdraw from the study and have their contributions excluded is a complicated issue in the collection of material through focus groups. Generally, if a participant has been interviewed, they can ask afterwards that their interview data is not used; however, as discussions are integrated in a focus group it is difficult to exclude a particular individual's contribution. This is partly because it is not always clear all the time who said what and as it would impact on making sense of what is said by others. Participants were given the option of a particular section of the group discussion being excluded for personal reasons, if they had requested it. None of the participants made this request or appeared distressed at what they had disclosed to the others.

Signing consent forms can be a real barrier to people taking part in studies due to a general distrust of signing official forms (Silverman, 2013); this has been found to be a particular issue amongst people of ethnically diverse communities. However, due to the sensitive nature of the discussions that may take place, written consent was taken from all the participants, often after some discussion of this when arranging their focus group with them.

Responsibility and accountability

I was the primary research investigator and was both responsible and accountable for the entire project. This was made clear to all stakeholders and potential participants both verbally when explaining the project and in the participant information. Some explanation in the participant information and in the discussion when signing people up for their focus group was given to assure only data necessary and proportionate to the research objectives would be collected.

Careful consideration was needed throughout the study to decide how many focus groups were required to offer a useful amount of data that could be used to inform the creation of this theory. This was regularly discussed with both the project supervisors (CW & YS) and with KG the critical friend. These conversations were captured in the supervision meeting records and in memos around aspects of the data.

5.8 Impact: Dissemination plans

Previous work in this area has highlighted issues of unequal access to palliative care and to a gap in understanding the perspectives of people of African and Caribbean heritage on having family conversations about end-of-life care planning (De Souza et al., 2020). This study sought to capture some of those views and through theory construction to provide an informative picture of those views for consideration, both by people in those communities but also by healthcare professionals. As a result, it was important to consider dissemination to different types of communities.

I decided to undertake this PhD as an alternative format PhD. I was aware that much PhD research is never published, and I was keen to try and ensure this did not happen with this work (Merga et al., 2020). Initially the work has been disseminated via publishing in academic journals and using social media tools such as ‘X’, ‘LinkedIn’ and other social media platforms to widen its impact. As the study progressed, different elements were presented at conferences (Appendix 1 & 5). The plan is to continue this after the PhD is completed. The findings will be used in the teaching of pre-registration and post-registration education. It is also hoped that an educational resource will be created following the PhD to make teaching these types of subjects easier.

The findings will also be used more locally to inform the strategy for public engagement that is an ongoing project in both the Lambeth and Southwark advance care planning consortiums where they are working with large populations of people of African and Caribbean heritage. Results of the study will also be shared with community groups from whom participants are recruited to explore how the results may be used to precipitate codesign work on culturally appropriate further interventions. The entire study will be written up and published as a thesis which will be submitted for the award of PhD to Lancaster University.

5.9 Guiding principles for creating a robust study

In this section I have undertaken a reflexive exploration of the processes I undertook in my study guided by Charmaz and Thornburg’s (2021) guiding principles (Table 4). This starts with a summary and is followed by a more discursive critical reflection.

Table 4: Guiding principles for creating a robust study

	Quality Indicator
1 & 2	Strive to achieve methodological self-consciousness (Charmaz, 2017)
3	Take an open, non-committal, critical, analytic view of the existing literature in the field
4	Gather rich data
5	Be transparent
6	Go back and forth between data and your developing analysis to focus your subsequent data collection and to fill out your emerging analytic categories

7	Tolerate ambiguity
8	Ask progressively focused questions
9	Look for all possible theoretical explanations of the data and check them
10	Collect sufficient data
11	Ask questions about your categories
12	Treat your codes, categories and theoretical outlines as provisional and open for revision
13	After completing analysis, compare with relevant material from the literature not addressed during earlier review

As I progressed through my study, learning more about the techniques of constructing grounded theory, I developed an understanding of the process and the importance of abstracting when moving from focused codes to category and concept formation and more so when moving to constructs (Conlon et al., 2020; Groen et al., 2017). This was a useful way of really engaging with the theory forming element of this mode of research.

Principle 3. Take an open, non-committal, critical, analytic view of the existing literature in the field

The relationship of literature searching and constructing grounded theories is a complex one (Charmaz & Thornberg, 2021; Deering & Williams, 2024). Charmaz has a more open view on literature searching than those who engaged in classical grounded theory methods. This has been explored further in section 5.4.

Searching the literature was both illuminating and frustrating. There is a wide range of terminology used that makes it hard to find the literature using standard keyword searches. Much of the literature that seemed most relevant to the question was work done in the USA. Chapters 2 and 3 discuss the approach I took to both initially scope and then more systematically search the literature. A meta-ethnography felt an appropriate approach as discussed in Chapter 3; however, a realist review may also have been helpful as sources were limited at the time, and I could have included some further sources such as reports. Some strong work had been done in my area by the organisation Compassion in Dying (CID, 2016) and by David Smith in Kent (Smith, 2012); however, none of these were written up as studies in an academic journal so were difficult to include in the meta-ethnography as the reports lacked detail. They were considered in my introduction.

As the study progressed, the phenomenon of how cultural differences impact on people's experiences of palliative care was an area that started to receive much more interest. A wide range of studies were completed around advance care planning and around issues such as racism in palliative care in the past 10 years. It was necessary at times to take a more purposeful approach to gathering the literature that was most relevant and built on the themes under exploration for this piece (Benoot et al., 2016; Booth et al., 2016). In both the concept analysis and in the integrated discussion chapter I have attempted to offer a critical discussion of this literature and the different perspectives that exist on some of the elements of this research.

Principle 4. Gather rich data

This, as with so many qualitative studies, almost become a limitation. The data that can be gathered is so rich. In Chapter 4, the methodology chapter, I discuss why I decided on focus groups to collect this data. That discursive interaction really generated reflective thought in the participants, and a wide range of topics ensued. Whilst this was impacted by the change to online focus groups, the conversations remained rich. Initially, coding these resulted in my data feeling 'flat'. We undertook much discussion as a research group around this. Charmaz's (2014) recommendation to use some NVivo data as codes and to use gerunds as we moved to categories really helped turn this corner.

Principle 5. Be transparent

For me, this raised an issue when doing an alternative format PhD. Traditional PhDs are more descriptive than an alternative format presentation of a PhD. Academic journal articles are required to be succinct. However, again they need to offer a clear picture of the research steps taken. Often methods sections are so brief; some of the salient points are missed. Care was taken in all four of the papers to offer a clear picture not only of the methodologies used but also the way in which the results were generated. These have been further expanded in this thesis. However, thought is needed on how to disseminate this to a wider audience than the academic world.

Principle 6. Go back and forth between data and your developing analysis to focus your subsequent data collection and to fill out your emerging analytic categories

This is a particular feature of constructivist grounded theory that differs from some other qualitative research methodologies. It was one of the more interesting aspects of this type of research. I used memos and my research diary to do this. I found it helpful, once line-by-line coding was done and in the process of moving to categories and constructs, to relisten to the focus groups rather than look at the transcripts. Charmaz and Keller (2016) talk about how she found this helpful for remembering how things were said and not just what was said. Since analysis occurs as you collect data, analysis of focus group 1 and then 2 and bringing those together before moving onto focus group 3 allowed some consideration and discussion with my supervisors and critical friend about elements to explore in the next group. This is discussed in chapter 6.

Principle 7. Tolerate ambiguity

Doing a PhD is a journey in tolerating ambiguity. From the start, I was amazed I had to spend a year understanding what an ontology, epistemology and a methodology was before I could finalise my research question and go on to what method I would use for my study. On each new step of the journey there were new things to learn and new depths of understanding to develop by considering lots of different approaches. Alongside this, you also need to make progress with what you are doing to progress your study.

As I abstracted in my study, I found it hard to differentiate between the categories that I had constructed from my codes into my constructs. Choosing the words that accurately describe the concept you are trying to express is a challenge. I imagine this is something that you develop as you learn the doxa of your trade. The resultant model is one of ambiguity. The hysteresis effect that comes with living between two worlds is a core aspect of the theory created (De Souza et al., 2024b). I feel as a lecturer in higher education I had the advantage of being able to teach from my study from an early stage and then finally after the theory constructs were formed.

Holding ambiguity for me has continued. I felt conflicted when participants were not keen to be in the study, about the worth of the research being done. Why should I try to speak for people when they perhaps did not want that story told. As I started to publish, that feeling of tolerating ambiguity was heightened. Would the papers be accepted, first by the journal and then by reviewers, and once published by anyone at all? The process of publication is outlined in Appendix 4. Life is ambiguous and constantly changing. I found Bourdieu's insightful detection of this experience of habitus and its influences such a useful way of understanding the almost constant life of change and influence we live and how it makes us all of what we are.

Principle 8. Ask progressively focused questions

Learning to do research through a PhD gives a student the opportunity to not only learn as they go from the data they are gathering and what they are reading, but also the ongoing Socratic process of PhD supervision. These three elements were helpful in developing the progression of the work. Having both my supervisors and my critical friend to talk through some of the codes that were coming through was useful. During those early days of research, I also had some particularly helpful meetings with experienced researchers looking at elements that I was exploring; this also helped to think about aspects I may not have been considering. This helped me to return to my data and explore things further in the next meeting.

As the focus groups progressed and we became more in tune with the topics being discussed, we were able to explore certain ones that seemed important in more depth. Having the freedom to use purposeful sampling and the more theoretical sampling was helpful in being able to follow up more focused questions like how this experience changes across generations. This is explored in Chapter 6 in the presentation of the results.

Principle 9. Look for all possible theoretical explanations of the data and check them

Whilst I was doing my research, I read widely and was able to consider things from different theoretical perspectives. In addition, there was an upsurge of interest into understanding a broader view of how elements around dying, not only in terms of the conversations being had but also people's experiences of palliative care, were experienced by people from different communities. This resulted in rich opportunities to engage in lectures, discussion and debates about these topics which has played a part in helping me to develop my own theorising from my data.

As I started to explore the impact of migration on people's experiences, I explored the idea of temporal dissonance and the work done in this area, particularly in the USA and mainly in the education field around children who have moved from one culture to another or had parents who had not been socialised through the US school systems. This was insightful and helped me to think about this in a health context. This also worked well with using Bourdieu's concepts of habitus and hysteresis. This led to spending an extended amount of time on the concept analysis presented in Chapter 4. This was complex as there were new ideas emerging in the areas being explored in the practice of palliative care and advance care planning. That paper took three years to work through to its completion but was helpful in informing both the theory and the questions that came afterwards in Chapters 7 and 8.

Principle 10. Collect sufficient data

This is a continuing area of debate in qualitative research (Braun & Clarke, 2021). Having moved from the idea of data saturation to recognising that with each participant or group of participants more experiences or perspectives can be shared, in constructivist grounded theory the concern is more about reaching a point of theoretical saturation. This is reaching a point where you have sufficient data to fully abstract your concepts to evidenced constructs and use these to draw conclusions to develop the theory.

Principles 11. and 12. Ask questions about your categories treat your codes, categories and theoretical outlines as provisional and open for revision, and even rejection

This process was an iterative one. Developing ideas, returning to the transcripts and recordings to listen again to how things were said, allowed me to adapt the categories being formed (Groen et al., 2017). Then finally relistening to the all the recordings to see if there were themes that had not been picked up.

Principle 13. After completing analysis, compare with relevant material from the literature not addressed during earlier review

The process of writing Paper 4 – the whole study paper, completing the concept analysis paper (Paper 2 but completed last) and the final integrated discussion chapter were reflective episodes where I reconnected not only with my original literature but also some of the newer literature to see how the concepts being created were reflecting both what was and what things are today. In line with Bourdieu's concepts of practice, field and habitus, these are always evolving and changing. I experienced a sense of hysteresis as my own ideas changed and evolved over the process of doing this PhD. How do you reflect that in a piece that is written in stages over a period of times, particularly when it is a topic in which new insights are becoming much clearer and currently debated. It was because of this I decided to explore the set of questions I did in the second part of Chapter 7. It is also important to note this is not a closed and finished book but more a topic that will continue to evolve.

Attendance and presentation of the work at a series of conferences where others were also looking at the issues of marginalisation of groups in palliative care have increased my methodological self-consciousness. Sanders et al. (2018) and Gunaratnam's (2012) work has been particularly helpful in trying to reduce the way in which difference is problematised.

5.10 Conclusion

This chapter contains an outline of the methodology chosen and the methods employed to carry out this study. In the following chapter the process of analysis and synthesis of the focus group data and then abduction will be detailed, including a discussion of the impact of modifying the methods when external circumstances changed.

Chapter 6: Findings

6.1 Introduction

This chapter consists of the findings of the empirical work and is divided into several sections. The first sections explore the process of conducting the focus groups and how concurrent data coding processes evolved over the study. The process of induction, abstraction of the theoretical constructs and theory creation is explored. The purpose of constructing a theory is to provide an explanation of a phenomenon that has not been explored in depth before. The theory needs to provide understanding of the nature of the phenomenon, causes, and potential consequences. It is hoped that having a better understanding of why people approach elements in palliative care differently, will help to reduce anxieties both for health care professionals, but also for families contemplating end of life family conversations.

The last section includes Paper 3 and explores the impact on the data generated through the conversational dynamics within the focus groups. The paper, as well as exploring how these types of dynamics can be captured and analysed, includes a reflection on these dynamics in both in-person and online data collection focus groups.

> Paper 3. De Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024a). Changes in Participant Interactions. Using Focus Group Analysis Methodology to Explore the Impact on Participant Interactions of Face-to-Face Versus Online Video Data Collection Methods. *International Journal of Qualitative Methods*, *23*, https://doi.org/10.1177/16094069241241151

The following chapter, Chapter 7, contains the final paper of the study (Paper 4) which details a summary of the full study, the constructed theory and the implications this new knowledge has for practice and society.

6.2 Conducting the focus groups

The data collection stage of the study took place over a period of three years between 2020 and 2023. A total of 21 participants were recruited, and five focus groups were held. The process of reaching that final paper (Paper 4) is discussed in more detail in this chapter through a discussion of how the focus groups were convened and the data analysed and abstracted.

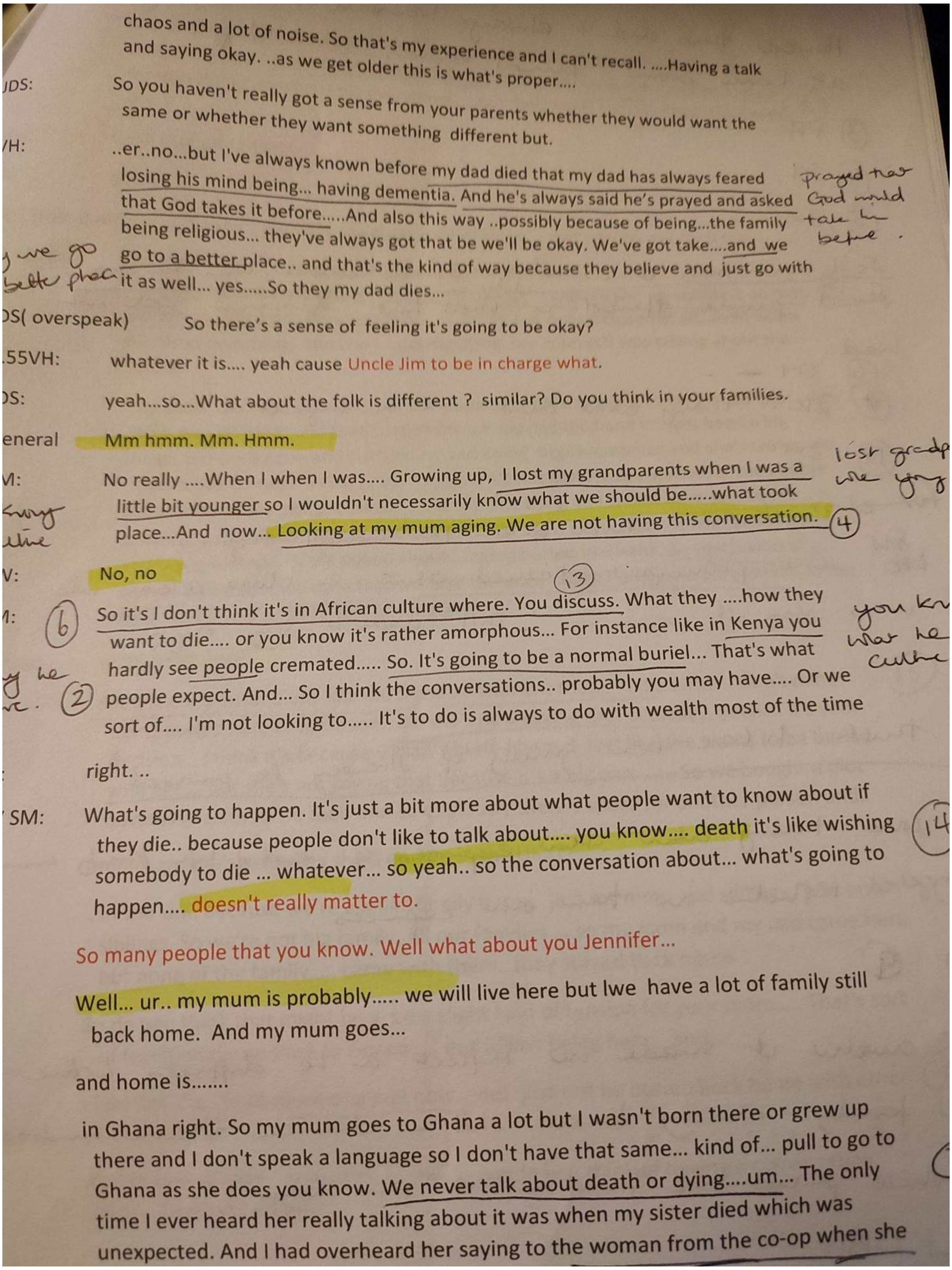
Focus group 1: Adult children

The participants in the first focus group were recruited from the same higher education institution. They worked in different areas of the institution and were not all known to each other. The focus group was held in a room in the institution in which they worked. A light lunch was provided, in part to provide a space for some initial introductions and rapport building between participants. The focus groups were led by me as the primary researcher (JDS) and a secondary researcher (KG) sat in on the groups as an observer. KG made notes of what was said and the interactions she saw taking place. Each focus group started with introductions and an ice-breaking discussion.

All these participants had a parent, aunt or uncle who lived in the UK. One participant reflected on the death of her mother who lived abroad; however, her account resonated with the group as they also contemplated deaths of older people where family were both in the UK and abroad. This first focus group flowed well and easily moved from topic to topic. The participants were close in age, all female and appeared to converse freely with each other. Often what was said by one resonated with another and that prompted them to discuss their relative experiences. This group produced a rich discussion. Whilst there is some discussion of the analysis process in Papers 3 and 4, some further discussion of the coding process is explored in more detail here than was possible in Paper 4.

6.3 Concurrent data analysis 1: Initial data coding

Initially following transcription, manual line-by-line coding was undertaken, generating codes using the printed-out copies of transcribed transcripts of the focus group discussion (Figure 5). This process of line-by-line coding involves questioning what is being observed in the data and describing it as an analytic code that is perceived to align with that observation (Charmaz, 2014; Saldaña, 2013). Following this manual process of coding, NVivo was also used to do line-by-line coding; codes were numbered, and some comparative work was done between the two sets of coding. Increasingly Nvivo (computerised coding system) was used for coding through subsequent focus group data analysis, however the paper transcripts were used when clarification was needed by going back manually to the transcripts (Table 5).



chaos and a lot of noise. So that's my experience and I can't recall. ....Having a talk and saying okay. ..as we get older this is what's proper....

JDS: So you haven't really got a sense from your parents whether they would want the same or whether they want something different but.

/H: ..er..no...but I've always known before my dad died that my dad has always feared losing his mind being... having dementia. And he's always said he's prayed and asked that God takes it before.....And also this way ..possibly because of being...the family being religious... they've always got that be we'll be okay. We've got take....and we go to a better place.. and that's the kind of way because they believe and just go with it as well... yes.....So they my dad dies...

prayed that God would take him before.

we go better place

DS(overspeak) So there's a sense of feeling it's going to be okay?

.55VH: whatever it is.... yeah cause Uncle Jim to be in charge what.

DS: yeah...so...What about the folk is different ? similar? Do you think in your families.

eneral Mm hmm. Mm. Hmm.

M: No really ....When I when I was.... Growing up, I lost my grandparents when I was a little bit younger so I wouldn't necessarily know what we should be.....what took place...And now... Looking at my mum aging. We are not having this conversation. ④

lost grandp when young

V: No, no

⑬

1: ⑥ So it's I don't think it's in African culture where. You discuss. What they ....how they want to die.... or you know it's rather amorphous... For instance like in Kenya you hardly see people cremated..... So. It's going to be a normal buriel... That's what people expect. And... So I think the conversations.. probably you may have.... Or we sort of.... I'm not looking to..... It's to do is always to do with wealth most of the time

②

you kn what the culture

: right. ..

SM: What's going to happen. It's just a bit more about what people want to know about if they die.. because people don't like to talk about.... you know.... death it's like wishing somebody to die ... whatever... so yeah.. so the conversation about... what's going to happen.... doesn't really matter to. 14

So many people that you know. Well what about you Jennifer...

Well... ur.. my mum is probably..... we will live here but lwe have a lot of family still back home. And my mum goes...

and home is.......

in Ghana right. So my mum goes to Ghana a lot but I wasn't born there or grew up there and I don't speak a language so I don't have that same... kind of... pull to go to Ghana as she does you know. We never talk about death or dying....um... The only time I ever heard her really talking about it was when my sister died which was unexpected. And I had overheard her saying to the woman from the co-op when she

Figure 5: Example of manual line-by-line coding in focus group 1

Table 5: Examples of initial coding in focus group 1 using NVIVO

Focused codes	NODES	Codes
2	can you give me a card with your qualifications on it? Yeah dad I've got enough time for that	legitimacy
2	and he goes yes you will	trusting
2	at times when Mom might want to talk about those things and I'll be saying.. ah … you're right, there's nothing wrong with you, simply because I think that's what she wants me to say.	assuming
5	because I remember when my brother died in America… My mum said she is going back home, you know well buried him there…	Experiencing the death of another
6	because I remember when my brother died in America… My mum said she is going back home, you know well buried him there…	Happening at a distance
7	because I've seen the opposite where a close relative of mine who was very, very ill but didn't say anything and kept it to themselves	Not sharing
2	Because like you said, shutting it down, like it happened with dad and me.	Closing down conversations
8	before his dad died. He was in his sixties but he was 90 when he died. His mom had gone through all the photos and each set of boys had all the photos of everything. It was horrible for me I felt it was horrible They liked it.	**Not talked about it** religious influences
9	before his dad died. He was in his sixties but he was 90 when he died. His mom had gone through all the photos and each set of boys had all the photos of everything. It was horrible for me I felt it was horrible They liked it.	Different to others
10	But I think it's because probably the expectation is that if you fall ill then you get taken to the hospital. I mean what else can you do with a sick person or what.	Hospital is the expected thing
1	but in most cases where they are… they've got their capacity. People don't talk about them.	cultural rituals
1	but she's never actually discussed it with me…	**I've got time for that**

For many participants, thinking about their parents and conversations they did or did not have made them reflect on the conversations they were having with their own children; this became a recurrent theme.

Focus group 2

The second focus group was convened through purposeful sampling looking to recruit older adults to the study. Ways of recruiting participants was a constant theme in my supervision meetings with a wide variety of potential strategies proposed and attempted, as discussed earlier in this chapter. The main successful strategy for this was an advertisement to older adults in a church congregation which had a large population of people from African or Caribbean heritage communities. Most people approached indicated it was not a topic they wanted to talk about. About 15 people did express some interest in the study and took away the study information; however, few of these older adults signed up to the study. Much later in the study, a couple did say they would not want to discuss these kinds of things as a group. This is further discussed in the limitation section of the discussion in Chapter 9.

Initially six older adults responded and were invited to the second focus group, sadly one lady had a stroke between volunteering and participating and remained unwell to the end of the study so was not able to participate; another woman was unwell on the day and when contacted subsequently, did not want to participate in a later group. Four older adults gathered after a church service for a light lunch and then participated in a recorded in-person focus group.

The conversation dynamics in this group were different. This group had one married couple in it. The participants in this group gave longer monologues and spoke a little more to me as facilitator than to each other. The husband of the couple spoke most, and his wife spoke less, although they both acknowledged how the wife found it more difficult to talk about these kinds of difficult topics and she seemed comfortable with her husband taking the lead. After the group, myself as moderator and KG as observer discussed the conversation and wrote memos about our initial observations. The recordings were transcribed, and the data was coded as with focus group 1.

The conversational dynamics in this focus group are discussed in the third published paper in this thesis later in this chapter (de Souza et al., 2024a). The dynamics of conversations when they are about one's own contemplation of the future rather than that of another's (such as when people are contemplating the death of a parent) are interesting to consider. This is further discussed in Chapter 9.

6.4 Concurrent data analysis 2: Focused coding

Focused coding is a process whereby the initial codes are synthesised and redefined to build explanations for larger activities that are seen across elements of data (Table 6) (Groen et al., 2017; Saldaña, 2013). As time progressed and more data was examined, new insights were gained which resulted in revisiting the codes that had been formed. My skills as a coding researcher also developed over time giving rise to more perceptive focus coding and moving up into creating categories. I used my research diary and coding memos to work with this process. I called these tentative categories axial codes, but I use this term lightly and not wholly in the way Strauss would suggest i.e. to specify the properties and dimensions of the categories; they were more to provide an extra level of abstraction as I moved towards determining the categories (Charmaz, 2014; Saldaña, 2013; Strauss & Corbin, 1998).

Table 6: Example of focus coding in focus group 1 and 2

Axial codes	**Focused codes**
PERCEPTIONS ON END-OF-LIFE CONVERSATIONS	Remembering previous experiences
	Having open conversations
	Shaping of expectations from 1st experiences
	Cultural patterns
	Dying is not something talked about
	Being unfamiliar with home
IT'S THE CULTURAL WAY	It's the cultural way
	It's what you do
	Planning is all about the wealth
GIVING RESPONSIBILITY TO GOD	Leaving it in God's hands
	Praying for God to take
LOOKING AFTER YOUR OWN	Looking after your own
	Default is to go to hospital
	Family spread worldwide
	Thinking about role of culture
	Cultural thinking
	Protecting self and others
	Upsetting people
	Parents not burdening children
SILENCING THE CONVERSATION	Shutting down conversations
	Children protecting parents
	Guilty awareness

Alongside this coding process, I also started developing a narrative synthesis around the coding that was being constructed (Figure 6).

Several of the codes that arose from the analytical process came about as a result of the direction taken by the participants. This findings section follows course of that conversation.

1.0 Perceptions on end-of-life family conversations

1.1 Shaping of expectations

The focus group started with participants discussing their familiarity with the process of funerals. Some had clergy fathers or uncles and going to funerals as part of their wider communities was a common experience for all. This gave them a sense of awareness of the cultural norms around these events.

> *'My dad's a pastor so we went to loads of funerals' P2*

For most participants, this led into a conversation around how their first death experiences were of the illness and funerals of their grandparents, generally when they were still children. Memories were hazy but seeping in exposure to cultural patterns to which they were unfamiliar.

> *My first experience of somebody dying was when I went to xxxx to see my grandma. It was my first experience of seeing her. Met my grandma and then…. I think it might have been two weeks later she died. I'm going to somewhere I've never been before. And the culture's completely different to what I know… P2*
>
> *When I was…. Growing up, I lost my grandparents when I was a little bit younger so I wouldn't necessarily know what should be…..what took place…And now… looking at my mum aging… it makes me wonder what she wants but we don't have that conversation P3*
>
> *So, my mum goes to xxx a lot, but I wasn't born there or grew up there and I don't speak a language, so I don't have that same… kind of… pull to go to xxx as she does you know. P4*

Figure 6; Adding narrative to code

Focus group 3

Following the second focus group in February 2020, the Covid pandemic was declared in March 2020 by the WHO. This resulted in a change to guidance for any in-person gatherings and all working processes such as university teaching were moved online. There was a period of intense activity for many including healthcare professionals and university lecturers such as myself and the research team. For a period of six months, work on this study stopped. When work restarted on the project, most older people and many others were still living in semi-isolation. During the lockdowns, many studies had started to make more use of online data generation in the form of both interviews and focus groups (de Souza et al., 2024a). Ethical clearance to conduct focus groups online was obtained. This time using university and social media research volunteer recruitment flyers generated more interest. All the respondents were female, and the first online focus group was convened. This was the group with the most diverse experiences. One of the participants had Muslim parents although she did not practice the religion herself. One of the other participants worked in a family funeral business interestingly this had not resulted in family planning conversations, and her mother was in fact very distrustful of palliative care.

The themes discussed in this group started with an animated discussion of funeral traditions in their countries of heritage. The participants were interested in the similarities there were in these traditions around the world. As the group progressed there were some illuminative discussions both around the fear of dying and how that often results in a distrust of palliative care in their parent's generation, and a growing realisation that holding quite different views from your parents may result in some difficult decision making when they are very ill. There was also a good discussion of how the wishes of one parent may not reflect the wishes of the other, particularly when there has been migration in the family with the hysteresis that occurs when balancing traditional and newer ideas about traditions. So many of these linked in with previous groups; however, it did make me aware of the richness of each person's journey. Following the group and transcription, coding was completed and the process of integrating the coding with the coding from groups 1 and 2 took place. This process was discussed with KG and with my two PhD supervisors CW and YS with discussion around the conceptual categories that I was constructing. Speaking on a podcast (Charmaz & Keller, 2016) Charmaz highlights the helpfulness of relistening to the recording as you code and categorise to really feel how the conversation is being crafted and developed by the participants, something that is not always easy to glean from a flat transcription.

6.5 Purposeful sampling

Whilst recruiting focus group 4 the research team had a discussion. As a result of the data that had been collected and the codes and categories that were being developed, we were interested to see how this may be seen in communities that were of different cultures to the Christian one that had been discussed so far. We were also keen to interview more older adults and hear more male perspectives. Recruitment of the male voice was a challenge (Bamidele et al., 2019; Graham et al., 2018). Strategies suggested in the literature were to use snowball sampling and to build rapport with potential participants to develop trust and also to employ flexible data collection. Through a local contact I approached a local Caribbean Hindu temple which had an active older people's lunch club. They were very welcoming and suggested I come along and join them for a session now they had started meeting again post the Covid lockdowns. Having visited once, I arranged to return and was able to speak about my project during the notices. I was also able to distribute some research information packs to people. I had a small group of men who were interested to take part, they were mainly ex nurses and social workers with some from Mauritius and some from Trinidad and Guyana. They were keen only to convene a group in person and on the premises after their luncheon. Just when we were coming to be able to host the group after the next luncheon, there was an unexpected death of one of their congregations which resulted in the plan being cancelled, then further lockdowns ensued, and the group stopped meeting again. Although I did return to make enquires post pandemic, the new person running the club was less keen for me to recruit and hold a session there.

Focus group 4

Focus group 4 was recruited via personal contacts in university and lay networks. One participant volunteered having responded to the research volunteer flyer in a health trust internal social media Yammer group. One person in this group was visually impaired and preferred to join the group by phone rather than on screen. The impact of the person not being visible is discussed in Paper 3.

This group had an animated discussion building on themes of family dynamics and decision making but also introducing the theme of how their parents' fear of cancer impacted on their experiences. At times it was hard to hear them talk about their experiences; for example, when they had a diagnosis or had a sibling who did, the parents found it very hard to discuss this with any of their children. As much of this group was made up of academics, they shared features like being families who communicated by WhatsApp so when there was bad news it got around quicky and that contact can be supportive even if someone is not physically present. The coding process following this focus group was completed and these codes were integrated into the body of conceptual categories (Saldaña, 2013). Alongside this I continued to read new literature that was being published on topics around ethnic diversity and aspects of palliative care like advance care planning and end-of-life decision making, particularly post Covid where such matters had become much more at the forefront of the news. It was important to ensure we remained grounded in what we were finding in the data but also that we explored how these findings were appearing alongside that growing body of literature (Charmaz, 2017; Charmaz & Belgrave, 2018).

6.6 Abduction and Theoretical Sampling

Following the analysis of the data collected in the third and fourth focus groups, categories of intersectionality around family decision making were appearing, such as the role of gender, age and proximity. Around the category of things changing over time, what influences remain from heritage cultures and what changes, were surfacing. How did geographical proximity impact on how discussions took place and decisions were made.

An area of interest was that appearing through the coding process was around building death literacy (Noonan et al., 2016), as some participants had parents who had died already. Codes and then a category on how familiarity with death and death processes may influence family members to have early conversations was being developed. It seemed useful to explore how people from different generations thought about this.

Abduction, Theoretical sampling and Recruitment

When coding these prior experiences of family deaths and thinking about what was significant about them, how they shaped the perspectives of talking with the family, as a research team, we had a discussion around the process of abduction and theoretical sampling (Charmaz, 2014; Charmaz, 2020; Conlon et al., 2020). Abductive thinking is useful when faced with puzzling findings, it is helpful to think about all possible theoretical explanations and sometimes to take a creative imaginative leap which fosters making links between subjective experiences and social structures. Recognising how these experiences of observing dying were reduced for people who grow up and live in a different country to their grandparent generation, I decided this was an interesting new direction to explore.

In grounded theory research, when using a process of coding and memoing, as you develop analytical categories, sometimes ideas for categories are emerging, but the data collected so far only alludes to the developing category, but it would be useful to know more to really develop the category. Theoretical sampling is a method that allows recruitment of targeted participants who may be able to help develop the properties of this developing category (Charmaz, 2014). Using this approach, I thought it would be good to capture the voice of younger people who may be more open to having earlier conversations or may be overhearing conversations in their families around grandparents.

As a team, we also thought it would be good to hear more male voices in the discussion, particularly men who were sons and brothers, how did they see their roles in end-of-life decision making and speaking to their parents beforehand about this? I wanted to explore with the next group more about how these dynamics played out in different families and what the collective narrative was about this in their communities (Charmaz, 2017).

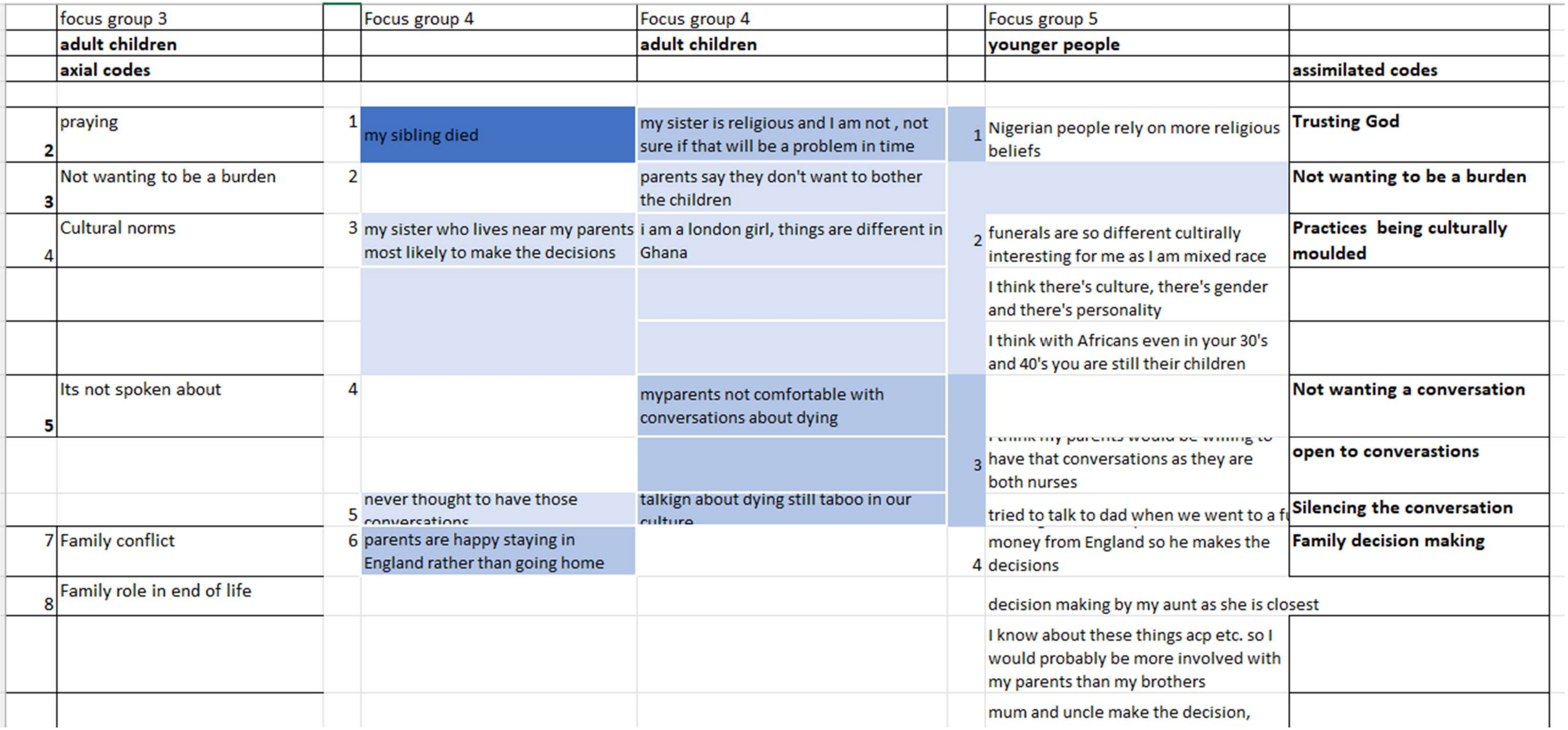
So, with an aim to recruit more young people and male voices I did a more targeted social media recruitment drive. Different forms of social media were used like Facebook and X (formerly Twitter) and university research volunteer circulars for participant recruitment. Using suggested recruitment strategies, personal and professionals contacts were approached to share information about the study with male friends and family members (Graham et al., 2018). My attendance at a university held research participation community event in a hall in a shopping area in south London popular with African and Caribbean heritage communities turned out to be a successful endeavour. Whilst take up of opportunities to be involved in the various projects on display by passing members of the public was very low, one of the other researchers at the event fitted the criteria and having had an opportunity to explore the participant information, decided to volunteer. He tried to recruit others from his friends' network and then to encourage his brothers to join a group. However, none of them decided to participate.

Focus group 5

Focus group 5 was the smallest group. Four participants were recruited. They were all in their 20s and had parents living in the UK who are or had been involved in caring for their own parents at the end of life. All these participants expressed a preference to have this focus group online. In the end, one of the women was unable to make the agreed date due to an unexpected commitment near the time of the focus group. Two women and one male participant met with me and observer for an online focus group. This group was fruitful in discussing some themes that had not been explored in previous groups; these are discussed in section 6.9 under the construct of watching the death of another prompt's conversations. One participant was of mixed heritage, and they reflected on some of the differences they had experienced observing matters in two very different cultural families.

As coding progressed, I created coding frames (Figure 6). These enabled me to construct codes across the data from the five groups and adjust the focus codes and categories I had already created as new data shaped them.

Prior to moving to consideration of this study as a whole, as presented in the next chapter as a published paper (Paper 4, Chapter 7), and the subsequent discussion of the knowledge this adds to the field in Chapter 9, this next section focuses on offering a more detailed picture of the data that was used to ground the eventual theoretical categories and constructs of the theory constructed through this research study.



	focus group 3		Focus group 4	Focus group 4		Focus group 5	
	adult children			**adult children**		**younger people**	
	axial codes						**assimilated codes**
2	praying	1	my sibling died	my sister is religious and I am not , not sure if that will be a problem in time	1	Nigerian people rely on more religious beliefs	**Trusting God**
3	Not wanting to be a burden	2		parents say they don't want to bother the children			**Not wanting to be a burden**
4	Cultural norms	3	my sister who lives near my parents most likely to make the decisions	i am a london girl, things are different in Ghana	2	funerals are so different cultirally interesting for me as I am mixed race	**Practices being culturally moulded**
						I think there's culture, there's gender and there's personality	
						I think with Africans even in your 30's and 40's you are still their children	
5	Its not spoken about	4		myparents not comfortable with conversations about dying			**Not wanting a conversation**
					3	I think my parents would be willing to have that conversations as they are both nurses	**open to converastions**
		5	never thought to have those conversations	talkign about dying still taboo in our culture		tried to talk to dad when we went to a f	**Silencing the conversation**
7	Family conflict	6	parents are happy staying in England rather than going home		4	money from England so he makes the decisions	**Family decision making**
8	Family role in end of life					decision making by my aunt as she is closest	
						I know about these things acp etc. so I would probably be more involved with my parents than my brothers	
						mum and uncle make the decision,	

Figure 7: Coding frame

6.7 Concurrent data analysis 3: developing theoretical categories, concepts and constructs

During the collection and coding process of the data from the five focus groups, alongside the reading I was doing in the area, I started to develop conceptual categories. Keeping a research diary helped to record these and to interrogate them not only through discussion and returning to the data already collected but also by delving into these aspects as the focus groups continued. As I raised my axial/focused codes to conceptual categories, I needed to make decisions as to which were major categories, and which were minor ones. This was done in discussion with the rest of the team. This helped me to move to defining the final concepts and constructs that really tell the story of the theory and provide the important abstracted explanations of what we see happening (Charmaz, 2014). As I progressed with this coding process, I found moving to the more abstract categories felt like I was losing the authentic voice of the participants. I started to integrate some in vivo codes into this process (Saldaña, 2013). My final concepts contained some of these in vivo elements (Table7.) As I started to piece together the final theory, I also needed to think about the order of the layering by thinking about the links between the constructs and how they build on each other or support each other.

During the process of moving from the tentative categories to the theoretical categories, it was important to engage both with the conceptual framework of the work of Bourdieu, that has provided a lens through which to understand the experiences of people moving between different world views and finding a path which is laden with layers of different types of capital which influence people’s individual journeys. As I analysed my data, I continued to develop the concept analysis in Chapter 3. This took a period of three years, evolving as my own understanding of these competing fields of practice or growing awareness of different people’s experiences developed.

As I moved from iterative analysis of codes identified in the data collected from the focus groups to the construction of five core theoretical categories that were abstracted into the constructs of the theory outlined in the model (Table 7), I used a variety of techniques including concept mapping looking at linkages (Ligita et al., 2022) (Figures 7, 8 and 9) and the experiences of other areas of migrant experiences (Gunaratnam, 2013; Zontini, 2015).

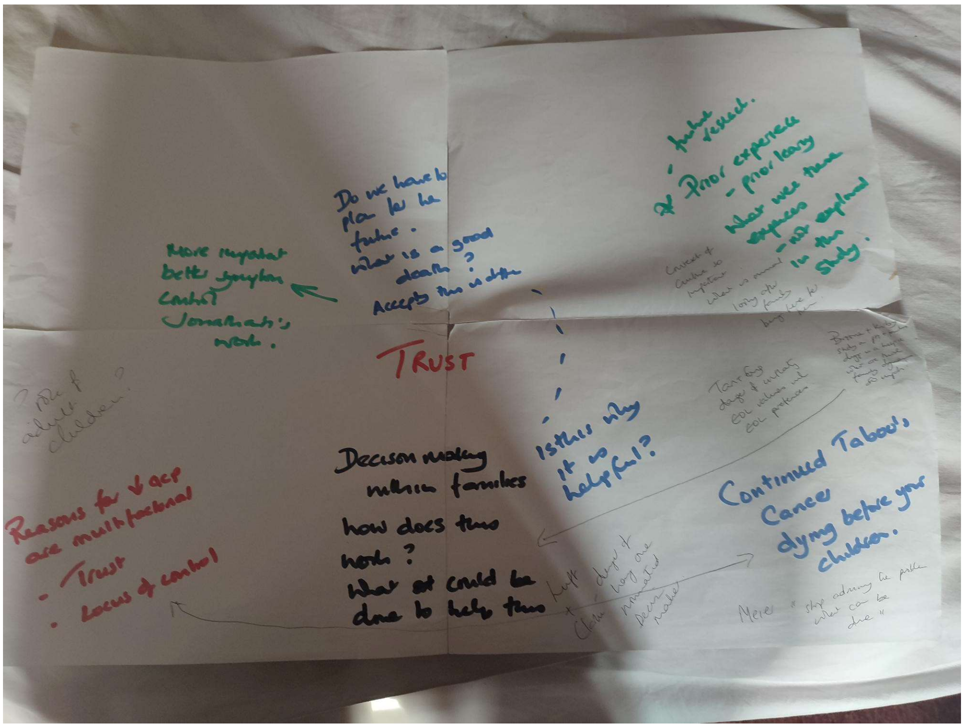


Figure 8: Starting to develop categories

I used these written posters and whiteboards to both explore the concepts as I constructed them from my data but also as a way of discussing them with others. In meetings with my PhD supervisors and critical friend, this enabled us to look at the categories and work on them in line with the data in the original scripts and from the coding frames.

As we constructed, we were drawn to how the experiences people discussed and the perspectives they had were entwined between their current and heritage cultures. Even when older people were living in the UK, there are many experiences of returning to heritage countries for other funerals and dying processes. This enhanced the sense of hysteresis than ran through all of these experiences. Some of this hysteresis was fracturing but some of it provided a frame for understanding what was important in their current experiences of experiencing or anticipating the experience of loss. This is illustrated in more detail using quotes in section 6.9.

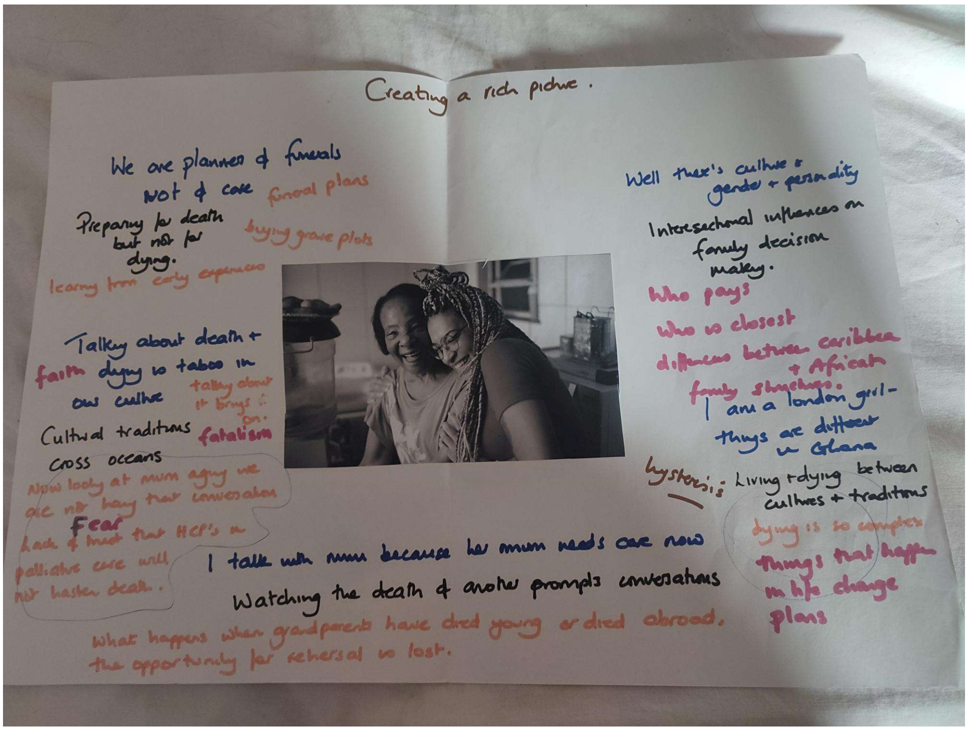


Figure 9: Layering concepts in theory construction

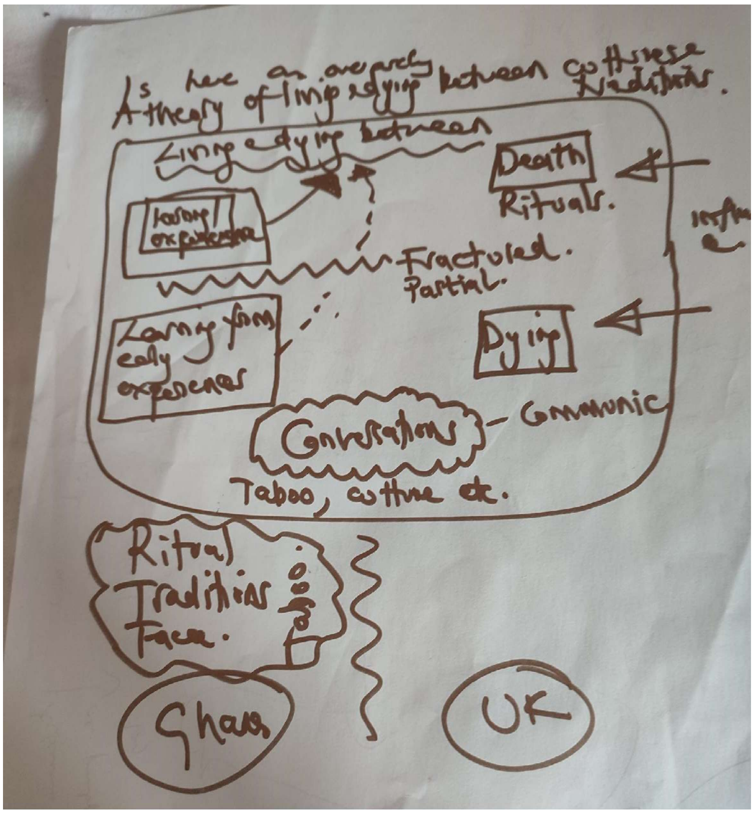


Figure 10: Exploring linkages and relationships in the developing theory

Table 7: Constructs and related categories

	Theoretical Constructs	Theoretical Concepts
1	Preparing for death but not for dying	We are planners of funerals but not of care
2	Complexity in traditions crosses oceans	Talking about cancer and dying is taboo
3	Living and dying between cultures and traditions	I am a London girl; things are different in Ghana
4	There is culture, gender and there is personality	Intersectional influences on negotiating family decision making, who speaks to whom about what and when
5	Watching the death of another prompt's conversations	I talk with mum because her mum needs care now
6	Hysteresis	Inertia and change

6.8 Theory formation

The final theory that was constructed in this study as a result of the data collection and the constructive coding processes, is a theory of living and dying between cultural traditions. This theory has been developed to illustrate the nature, causes and potentially the potential outcomes of this experience of having family conversations within the family about end-of-life preferences. To understand this theory that has been constructed during this research process, it is helpful to briefly explore the layering of the empirical data through the consecutive focus groups from which the categories were developed and extrapolated into the theoretical constructs of this theory. The model that I have constructed to illustrate the model (Figure 11) offers a picture of the phenomenon.

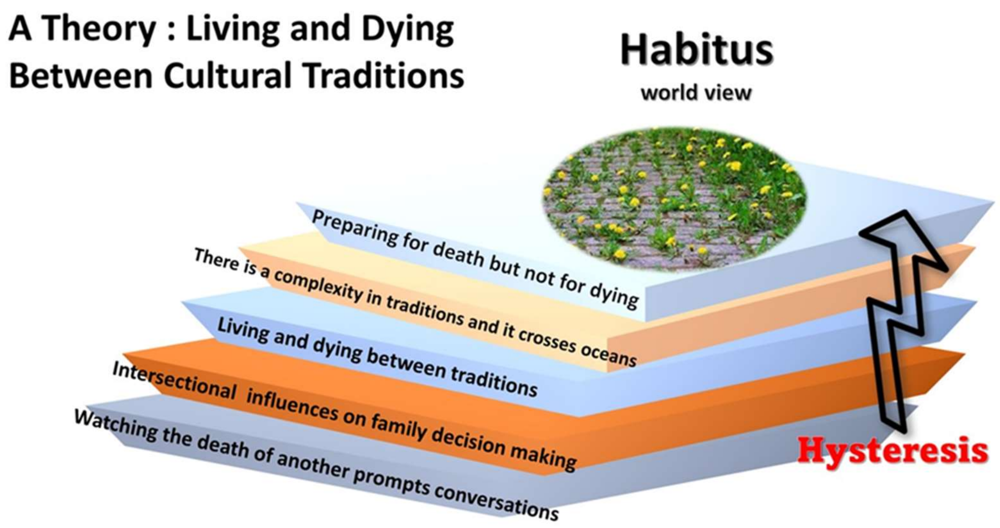


Figure 11: A conceptual model of the theory of living and dying between cultural traditions

6.8.1. Explaining the theory - nature, causes and consequences of the phenomenon

On the surface, the observed habitus by others is a regular field that may look similar to that of another person's field (figure 12)

Figure 12 Habitus

Underneath that surface, a person's habitus is a wealth of life experiences that create it. In this study, the values of heritage cultures remained strong and resulted in both a sense of hysteresis of being pulled between the heritage culture and the new host cultural norms, but also a creation of a new hybrid culture where new norms are created and shaped by the new geographies of families. This new culture of living and dying between cultural traditions is shaped by these families forging a new direction. This is in part shaped by this generation of families experiencing this phenomenon of dying without having had the experience of watching the deaths of the previous generation in any detail. Families are creating this hybrid culture as they go through the experience of someone dying.

6.8.2. Grounding the theory in the data

The causes of the phenomenon are illustrated through the constructs of the theory which have been generated from the data. The following section offers a little more detail about the way in which these final theoretical concepts and constructs were grounded in data from the focus groups.

Construct 1. We are planners of funerals but not of care: preparing for death but not for dying

Several of the focus groups started with a discussion of funerals and funeral planning. Through the discussions in the groups there was a recognition that there was a shared sense of death being something that was spoken about in public and planned for across African and Caribbean communities particularly back 'home'.

> ***Quote 1***
>
> *It feels different in Ghana it seems so public there, there are posters about funerals coming up, people talk about it, funerals and memorials are more about celebrating the life lived than mourning. (adult child, African)*
>
> ***Quote 2***
>
> *Yes it is the same in Nigeria, funerals are a large celebration of life for older people... (adult child, African)*
>
> *In Grenada, ... they have big billboards up ... it has a photo of the person and all the family… (adult child, Caribbean)*
>
> ***Quote 3***
>
> *In Jamaica obituaries are read out on the radio every day... (adult child, Caribbean)*

Several participants spoke of their parents having financial funeral plans.

> ***Quote 4***
>
> *Just to say also that she had four insurance policies written on her life because she wanted not to, she didn't want us to have the expense. She even had insurance policy back home in Grenada. So all those insurance policies just covered everything. (adult child, Caribbean)*

The only group who were not sure about their parents' plans were the group of grandchildren. For them it was something they talked about with friends but not yet with parents.

> ***Quote 5***
>
> *I would speak about it with friends and kind of not in a morbid way, just in a like, Oh, what do you think about this or that? And as ... grandparents are getting older and dying. Then there's more friends talking about going to their grandparents' cremations or burials and stuff, and that's coming up more now that we're getting older. (adult grandchild, Caribbean)*

> ***Quote 6***
>
> *I know that she's put something in place, some sort of insurance in place that will pay for a funeral as she doesn't want us to be worrying about that… (adult grandchild, African)*

However, as the groups discussed this there was a developing awareness that much of this conversation centres around funerals and after-death planning. When it comes to the process of dying there was an agreement that this was an aspect that was rarely discussed.

> ***Quote 7***
>
> *And we've certainly talked about death and funeral plans and all that sort of thing. I'm, I'm very open to having these discussions because I feel, certainly in our culture, you know, celebrating someone's life after death is a huge thing in our culture. But I feel talking about death and dying is still very much taboo and not really spoken about. It is something I would like to visit with mum. (adult child, African)*
>
> ***Quote 8***
>
> *So I don't, I really don't know what my parents' wishes are, believe it or not, I'm in the process of doing POA [power of attorney] for my kids, but with mum and dad … (adult child, African)*
>
> ***Quote 9***
>
> *…if, if Ma became ill, you know, what would she want… I don't know. It's never crossed my mind to ask. (adult child, Caribbean)*

And from an older adult*:*

> ***Quote 10***
>
> *I'm like my dad … I don't like to talk about my health… (older adult, African)*

And from another older adult*:*

> ***Quote 11***
>
> *When I do talk to my daughter, I start to say, when I am dying … she says, no mum don't talk like that… I feel they are all frightened of losing me… so I don't talk about it because I don't want to upset them, but I make my own plans… (older adult, African)*

Construct 2. Talking about cancer and dying is taboo in our culture: there is complexity in traditions, and it crosses oceans

Part of this lack of discussion about dying and illness may be associated with this second construct. Participants discussed how a continued fear and taboo around serious illnesses and particularly cancer persisted in their families resulting in a lack of open family disclosure.

> ***Quote 12***

> *So it's interesting that you're saying that because a close relative of mine who was very ill but didn't say anything and kept it to themselves, I don't know if it's a Caribbean thing but literally did not actually outline how ill they were until it was like ... When you kind of think to yourself, why did I not know, why is it that I'm here in the UK you're over there in Jamaica. Why am I hearing now, right now. Because it's like if I had known I would have been able to go over. (adult child, Caribbean)*

Listening to the experiences of several participants, this sense of fear and taboo remains strong even when families have been living in the UK for a while.

> ***Quote 13***
>
> *When I was diagnosed, I remember having a discussion with my mother about it. And, you know, the kind of distress it caused meant that I was never, ever able to have a conversation with her again, it was because it was cancer and she was petrified. It was a real shame because, you know…, your mom's your confidant… (adult child, Caribbean)*
>
> ***Quote 14***
>
> *My brother has cancer, he and I talk… but we don't talk about it with Mum and Dad. Dad had the same cancer and now ... So there's a bit of self-preservation with that. But I yeah, yeah, I'm not entirely sure, you know, he's… I feel like it's part of men, they don't want to be vulnerable and so on. (adult child, African)*
>
> ***Quote 15***
>
> *…sorry to interrupt but that's really kind of surprised me, because I'm now realising that's more of a cultural thing we've had in my family, my husband's you know his brothers and sisters are actually talking to their mom and she's saying I want to have this. I want this, you know, this song at my funeral… She talks about it which is, which is fine but I know with my own family, they are in the Caribbean, it was more like ... They kept it to themselves, no-none really knew they were ill until suddenly they wanted us to come… (adult child, Caribbean)*

Similarly, speaking about palliative care was a taboo subject. One participant, whose family worked in the funeral industry, described her experience. Her mother had been unwell for some time; however, her mother became distraught when she was seriously ill in hospital, and the doctor started to talk about palliative care.

> ***Quote 16***
>
> *I said, what's, what is this? Even though I've been in the funeral business, I have never really known the terminology, I've never really come across it. ...she said that's what it is for people who are dying, they try to kill you off. ...said she felt that she is, she took the help that was offered from the team that, you know, her life would end it sooner rather than later. She managed to get some bags packed because she wanted to fly back home to the Caribbean because she just felt that she needed the care that was going to be offered to her there. (adult child, Caribbean)*

Her mother died soon after and never made it back home.

Another topic that was raised in several groups was the funeral tradition of parents not attending the funerals of their children. This was interesting from two aspects. Firstly, the number in the group that had experienced serious illness or the death of a younger person within the family, but also how this tradition again was one that continues within some families, even though they were living in countries where this would be quite counter cultural.

> ***Quote 17***
>
> *And traditionally, a parent doesn't bury a child because that's not the natural order of things. So your parents would not be at your funeral. (adult child, African)*
>
> ***Quote 18***
>
> *That's right, yeah… you know my nephew who died recently, he died over here and it was sudden so although we took him home, his parents never saw him, they did not came to the funeral. (adult child, African)*
>
> ***Quote 19***
>
> *Yes I had an older sister who passed but they never saw her and they weren't at the funeral because it is not done. (adult child, Caribbean)*

This construct overlaps with construct 3. How much and what things do change, both for whole families or between generations, and how does that impact on family conversations?

Construct 3. I am a London girl; things are different in Ghana: living and dying between traditions

As they talked about these taboo subjects, participants reflected on how there continued to be cultural differences either between them and their parents, or between their parents and their parents' siblings who were perhaps still living abroad. Sometimes these cultural differences were experiences of the older people themselves.

> ***Quote 18***
>
> *I'm very much westernised, a London girl. And in Ghana, things happen differently, there would be many traditions like painting the house and I don't think mum would want that, she'd prefer it painted now while she can enjoy it. (adult child, African)*
>
> ***Quote 19***
>
> *But the one thing ... is… previously she always said that when she died she… she's talked about… being buried in Ghana. So that's kind of a cultural thing that we do is that we take the body ... back home and bury them ... there's a family plot or whatever...(adult child, African)*
>
> *(Others: umm, yeah, yeah)*
>
> *But when my sister died, she did make a comment that… if I die either I don't mind being buried here or in Ghana. ... So she's now saying that actually… yeah… it's your decision… I*

> *think it's because she's buried here. I feel like she wants to be buried with her… (adult child, African)*

This sense of living between cultures seems to be shared by both the adult children and the older adults. Having a sense of tradition and wanting to return to the place of their birth when dying was a strong pull for several parents, however their children living and also for some dying and being buried in this new home was a source of tension, or hysteresis, for these parents. Working out what a parent really wanted is difficult for these adult children, particularly if these tensions are never discussed openly. Sometimes one aspect is discussed with one family member and another with another family member which can also lead to tensions. This is discussed under the next construct.

> ***Quote 20***
>
> *Yeah. My mom passed ... it was very sudden. So there was no conversation with regards to what was going to happen. The one thing she really said if she passed was that she wanted to be taken back to Ghana. And we didn't know what conversation she had with the family there, because obviously we wanted her back in Nigeria, but we all knew she wanted to be buried in Ghana and, but she wasn't because there was a compromise, the compromise being she was buried with my dad who lived in Nigeria. I still kind of feel bad about it because that was her wish and it wasn't actually done. (adult child, African)*
>
> ***Quote 21***
>
> *My mother bought a house, she had always planned to go back to retire ... you know… but my dad he didn't want to leave the grandchildren and everything… (adult child, Caribbean)*
>
> ***Quote 22***
>
> *And yeah, it's like that, that's in my family. That has been the dilemma. One parent wanting to go back and one parent just not wanting to go back ever… (adult child, Caribbean)*

Construct 4. Who discusses what with whom: intersectional influences on family decision making

In general, participants acknowledged that conversations about future care preferences were rare between generations. There was generally an expectation that as adult children they would make future care decisions as best they could, without having discussed preferences, and that this is what was expected of them.

> ***Quote 23***
>
> *I remember from a young age, my mom doesn't say so much now… You're the youngest and it's your job to look after us when we're old ... (adult child, African)*
>
> ***Quote 24***

> *So if she becomes less well… what do you think she will want … Well that's going to be my decision. She's… She's not going to discuss it. I don't think it's something we would discuss. It's just whatever I decide. That's how it is. Like almost like the um, the parent becomes a child at a certain age… it flips and then they do whatever you do, you think… (adult child, African)*

Although for some, things were not said as parents tried to protect their children from having to feel responsible for them

> ***Quote 25***
>
> *We don't want to bother them. If we can do something for ourselves, we will do it. Sometimes we need help with this and that, but we don't want to bother them. (older adult, African)*

Sometimes people felt they only heard preferences accidently.

> ***Quote 26***
>
> *The only time I ever heard her really talking about it was when my sister died which was unexpected. And I had overheard her saying to the woman from the Co-op when she was in the living room in my sister's house… and I went to the kitchen to do something and I could overhear and talking, saying 'Oh yeah I've paid, I've paid up for everything so when I die everything … but she's never actually discussed it with me… (adult child, African)*

When family members are unwell, care decisions and treatment decision making can be particularly complex when family members are living in different countries. Having established that conversations around end-of-life care planning are rare, we asked the groups to discuss what does happen about end-of-life care decision making in their families. Initially we expected to see reference to a patriarchal approach as to who may be considered the best person to make decisions, particularly when the older person was unwell and had limited cognition. Some participants spoke about this

> ***Quote 27***
>
> *My experience of that was … you have a brother who comes in like the person on a white horse and he knows everything. And because … gains… through, I feel a level of coercion…. That's my fear. And I know it … gains power of attorney and starts making these decisions, which, which frustrates you, because if you haven't got the finance to fight that, then things have to go along with it. (adult child, Caribbean)*
>
> ***Quote 28***
>
> *Yeah, when my aunt died, her brother just wanted everything possible to be done, even though it was clear that nothing could be done. He just wanted her to have intravenous fluids or some fluids or anything that would just keep her going because he, they don't really understand the term end of life. So they just want to have that person kept alive, whatever. It was just really difficult trying to get across to him, you know, this is the end. There is nothing to be done apart from settling him… (adult child, Caribbean)*

> ***Quote 29***
>
> *Yeah. And I think it's a culture thing, because I remember when I lost my brother and he was in the States. We had to take his body back home. And we were having a conversation about where he was going to get buried and you know… my uncles were at the forefront… we, it's like we have no say….(adult child, Caribbean)*
>
> ***Quote 30***
>
> *But it's still very patriarchal. If anything happens, it will be the men that will take the lead. (adult grandchild, Caribbean)*

So, although patriarchy existed, as the discussions developed it became clear it is much more complex than that.

> ***Quote 31***
>
> *... when my dad died, he was living in the US with my half-sister, she made, she made all the decisions ... kind of you know, he was over there. We were over here. Oh, my goodness me, it was, it was very, very, very, very, very, very tricky. (adult child, Caribbean)*
>
> ***Quote 32***
>
> *And I think there is a, there is a power dynamic going on because frankly, my dad or the siblings who live in the UK they send back money quite often. So I think probably he usually doesn't look after my grandma… But in terms of making decisions, I think he probably has quite a lot of say because it seems like she needs to go to the hospital and he gets informed ... And I think it was the same for my mom as well whilst her dad was still alive, even though she was not looking after him physically, but she was sort of involved in those decisions because she was the one who was sending the money. (adult grandchild, African)*

Factors such as proximity and also who was providing funding when there were care costs involved played a big role in who made what decisions. Negotiating and planning and funding when families live in different countries adds layers of complexity to an already emotional and difficult process. Several of the participants spoke of the value of modern communication aids like WhatsApp in helping to negotiate in these difficult times.

> ***Quote 33***
>
> *Oh, my God, it's amazing. A revolution. It really has. You can make decisions on WhatsApp . You know, ... We were deciding when the headstone for my brother actually will be put in place this week and the decisions, the discussions were so smooth on WhatsApp. So it really has helped. (adult child, Caribbean)*

Lastly, for several participants being part of these focus groups highlighted for them conversations they perhaps had not had but either wished they had had or would like to be moving forwards.

> ***Quote 34***

> *Yeah. My, my mom passed quite a while now, 18 years ago, and it was very sudden. So there was no conversation with regards to what was going to happen. And we didn't know what conversation she had with the family there..., that she wanted to be buried in Ghana. So it was a compromise, she was buried in Nigeria so she could be beside my dad, I still kind of feel bad about it because that was her wish and it wasn't actually done. (adult child, African)*

> ***Quote 35***
>
> *It concerns me now that we're talking about it, that I hadn't had that conversation with my sister myself. (adult child, Caribbean)*

Regrets over conversations that had not taken place was common in the focus group discussions with adult children showing an indication that they were open to having more preparative conversations themselves. Getting that timing right with one's own children was seen to be a complex one, some felt their children were young to be thinking about these things. In the final focus group with grandchildren, some grandchildren saw having early conversations as helpful which led onto the development of the next construct of the theory.

Construct 5. I talk with mum because her mum needs care now: watching the death of another prompt's conversations

As part of the theoretical sampling the final focus group was with younger people who had living grandparents. Analysis of their reflections along with the previous conversations with adult children and older people resulted in this final Construct: as you watch the process of someone dying it stimulates thoughts about what you may want and sometimes this results in conversations with others about it.

> ***Quote 36***
>
> *I think you don't realise just how much care someone elderly can need unless you're in the scenario of caring for them … So mum and I … we have had that conversation recently, but before my grandma needed so much care, we'd never had that conversation… (adult grandchild, Caribbean)*

Many of the older people and adult children in this study had been living in another country when their parents or grandparents had died. The impact of this is that they saw only a glimpse of what went on, resulting in a loss of opportunity to reflect on how it may be for them when they are dying.

> ***Quote 37***
>
> *My first experience of somebody dying was when I went to Jamaica to see my grandma. My dad lived over here and his mom was writing him and saying I don't think I'm going to see*

you again and he goes yes you will. So we ended up going over to see her. It was my first experience of seeing her… I think it might have been two weeks later she died… (adult child, Caribbean)

Quote 38

Yes Mum was often in Ghana, she went to look after him … But I didn't go… (adult child, African)

Picking up on the fragmentation of these communities' experiences of being with and watching loved ones dying, how much do we learn from that of what we want, can expect; what happens when that experience is fractured?

Data collection and interpretive synthesis of the data collected led to the development of constructs of a substantive grounded theory of living and dying between cultural traditions in African & Caribbean heritage families. In this theory, the constructs, and related categories of how individuals and family's habitus regarding end-of-life conversations are shaped is presented. Being part of multigenerational families who have experienced migration in recent generations shape many of the core elements reflected in this theory.

Analysis of the conversations between the participants suggests that their visible habitus was shaped by a complex set of life experiences. All the participants had lived in the UK for a significant period; some were born in the UK. However, their views and experiences of conversations about dying within their families was very connected to both their current life situations but also to the practices, values and beliefs of their heritage countries. They all also experienced a sense of hysteresis (Bourdieu, 2000) or pull between familial cultural norms and practices and the cultural norms of the normative populations in the country in which they now lived (Figure 10).

These Constructs and the process of creating the constructed theory is summarised in Paper 4 in Chapter 7. This is followed by an integrated discussion chapter in Chapter 9. However, prior to moving to that space, another aspect of the data analysis of the data of this study was to consider the shape of the discussions that took place in the focus groups. These conversation dynamics will be discussed next, followed by the 3rd published paper of this thesis.

6.9 Exploring the conversation dynamics

An important aspect of collecting data through focus groups is to maintain an awareness of the dynamics of the conversations that go on in a focus group to see how the resultant conversation is created (Morgan, 2010). In this study, having to convene focus groups online instead of face to face raised new issues that potentially could impact the interactions within the group. Firstly, as we could not meet in person, we had to change the way groups first met each other. In the face-to-face groups introductory conversations were initiated over some light refreshments that we provided. In the online groups this was more difficult to engineer. When the first online focus group started, I became quite conscious of a few new dynamics. Much of the conversation seemed to be directed at me as the facilitator rather than between participants. Some people started to raise their hand when wanting to speak and then it seemed to be in the moderator's control what order people would speak.

As a result of these experiences, during this group and the next ones I wrote Paper 3 exploring how convening online may have changed some of the conversation dynamics. Together with advisory support from the research team we developed the paper to publication. The paper details the systems I used to analyse conversation dynamics and offers an analytical discussion of how moving online does run the risk of becoming a series of group interviews influenced and controlled by the moderator, rather than a focus group conversation, orchestrated more by the group. In this study, the nature of the participants also seemed to influence these dynamics so only ambiguous conclusions can be drawn. It does highlight, however, the importance of taking some measures to consider participant interactions when using group data collection techniques.

6.10 Paper 3: Changes in participant interactions. Using focus group analysis methodology to explore the impact on participant interactions of face-to-face versus online video data collection methods

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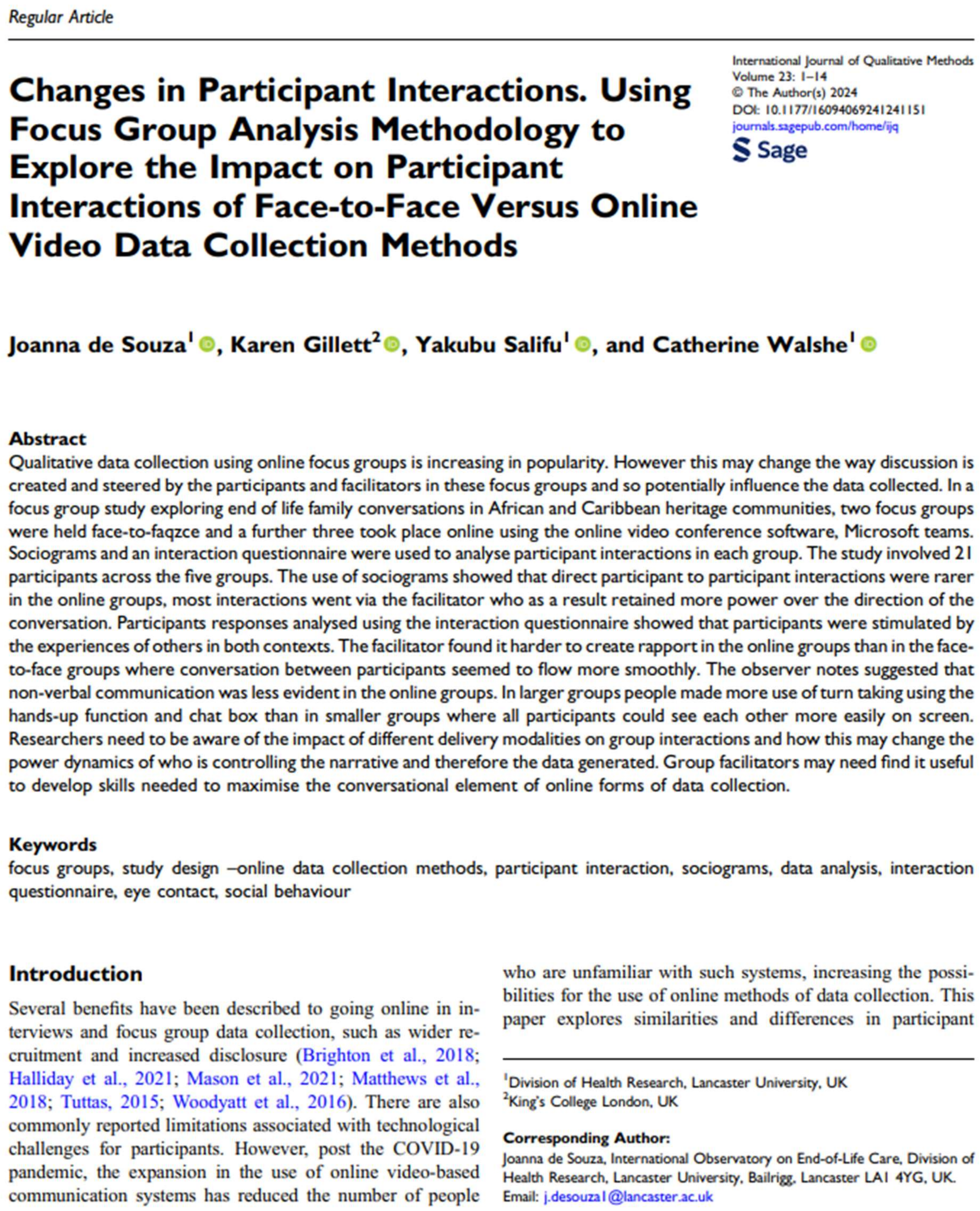

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Changes in Participant Interactions. Using Focus Group Analysis Methodology to Explore the Impact on Participant Interactions of Face-to-Face Versus Online Video Data Collection Methods

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Abstract

Qualitative data collection using online focus groups is increasing in popularity. However this may change the way discussion is created and steered by the participants and facilitators in these focus groups and so potentially influence the data collected. In a focus group study exploring end of life family conversations in African and Caribbean heritage communities, two focus groups were held face-to-faqzce and a further three took place online using the online video conference software, Microsoft teams. Sociograms and an interaction questionnaire were used to analyse participant interactions in each group. The study involved 21 participants across the five groups. The use of sociograms showed that direct participant to participant interactions were rarer in the online groups, most interactions went via the facilitator who as a result retained more power over the direction of the conversation. Participants responses analysed using the interaction questionnaire showed that participants were stimulated by the experiences of others in both contexts. The facilitator found it harder to create rapport in the online groups than in the face-to-face groups where conversation between participants seemed to flow more smoothly. The observer notes suggested that non-verbal communication was less evident in the online groups. In larger groups people made more use of turn taking using the hands-up function and chat box than in smaller groups where all participants could see each other more easily on screen. Researchers need to be aware of the impact of different delivery modalities on group interactions and how this may change the power dynamics of who is controlling the narrative and therefore the data generated. Group facilitators may need find it useful to develop skills needed to maximise the conversational element of online forms of data collection.

Keywords
focus groups, study design –online data collection methods, participant interaction, sociograms, data analysis, interaction questionnaire, eye contact, social behaviour

Introduction

Several benefits have been described to going online in interviews and focus group data collection, such as wider recruitment and increased disclosure (Brighton et al., 2018; Halliday et al., 2021; Mason et al., 2021; Matthews et al., 2018; Tuttas, 2015; Woodyatt et al., 2016). There are also commonly reported limitations associated with technological challenges for participants. However, post the COVID-19 pandemic, the expansion in the use of online video-based communication systems has reduced the number of people who are unfamiliar with such systems, increasing the possibilities for the use of online methods of data collection. This paper explores similarities and differences in participant

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interaction between online and in person focus groups using data from our qualitative study.

Focus groups were selected as the approach to data collection in a constructivist grounded theory study exploring end-of-life conversations in families from African or Caribbean heritage communities. Focus groups enabled us to capture a shared picture of this phenomenon as experienced by people from these communities living in the United Kingdom. Five focus groups of 4–6 participants were conducted with older adults, adult children and adult grandchildren. The results of this study are in the process of being published by the same authors elsewhere. Two out of a planned six focus groups had been completed face-to-face just before March 2020. As the COVID lockdown persisted, research ethics committee approval was sought to recruit participants and run focus groups online using video capture on Microsoft Teams to enable the study to continue (Table 1).

There is a growing literature exploring how solutions can be found to ensuring a smooth technological experience online (Brighton et al., 2018; Menary et al., 2021). It is likely that online data collection will increase so it is important to understand more fully the impact this may have on data collected.

Influence of Interaction on Generation of Focus Group Data

Focus groups are a popular mode of qualitative data collection as their interactive nature can stimulate discussions and recollections by participants of experiences and events (Synnot et al., 2014). Much of the existing focus group literature reports on the generation of codes and themes from individual participant contributions in the focus group. However, proponents of focus group data collection suggest that the interactions within groups are important and analysis should consider their impact on the data generated (Acocella & Cataldi, 2021; Kitzinger, 1994; Kook et al., 2019; Krueger, 2014; Liamputtong, 2011; Morgan, 2010; Wilkinson, 1998). Morgan (2010) argues that even if the aim of using a focus group is to produce conversations, and the ideas generated are what is of interest rather than how they were created, it is important to take some note of the interactions in the group to determine whether ideas have been dominated by individuals or influenced in particular ways.

Focus groups are typically chosen when the purpose of the research is to gain understanding of how a community perceives a phenomenon, through discussion of divergent or similar views (Krueger, 2014). Focus groups also allow the study of how people engage in collective sense making (Kitzinger, 1994; Wilkinson, 1998), with a focus on co-created knowledge by the group rather than a 'singular truth' about the research question and the debates that arise around it (Rodriguez et al., 2011).

A focus group lies somewhere between a meeting, which has been preorganised and has some element of planned structure, and a conversation, where, with a degree of spontaneity, individuals pick up on one another's contributions (Agar & MacDonald, 1995). Participants can be called by other participants to justify their views about a subject particularly when it is different to that held by others in the group who have also shared an experience (Liamputtong, 2011). Being asked to explain a viewpoint, can result in a deeper sense of processing of that view than perhaps is needed when describing one's view or experience in a single person interview. As individuals present their experiences and perceptions, other participants become more conscious of their own perceptions and of the way in which that fits with collective elements of their experiences (Morgan & Hoffman,

Table 1. Exemplar Research Study Design: Exploring End of Life Family Conversations in Families of African or Caribbean Heritage.

Design: Constructivist Grounded Theory Approach (Charmaz, 2014).
Setting: Participants were recruited from communities in London, UK
Population: 21 participants were recruited using a variety of methods.
Data collection: 5 Focus groups- 2 face-to-face before the start of the COVID 19 pandemic in March 2020. 3 online using MS teams video conferencing.

	Age	Gender	Heritage	Relationships	Type
FG1	48-56	5F	Kenya, Ghana,	Adult children	Face to face
FG2	63-69	3F 1M	Nigeria, Liberia,	Older adults	Face to face
FG3	45-59	6F	Ghana, Nigeria,	Adult children	Online Video
FG4	48-58	4F	Trinidad, Jamaica	Adult children	Online Video
FG5	27-30	2F1M	Jamaica, Nigeria, Ghana	Adult Grandchildren	Online Video

Data Analysis: Alongside traditional coding techniques on the data (reported in another paper), sociograms were created to explore group dynamics and a list of analytical questions were asked adapted from Stevens (1996).

2018). Group discussion often produces data and particular insights that might not occur when interviewing one person at a time (Ott, 2008; Synnot et al., 2014). Analysis of focus group data can capture the group's constructed ideas about the phenomenon, when consensus and divergent views exist, how they are dealt with by the group and can raise possible solutions to a presented problem (Acocella & Cataldi, 2021; Lobe et al., 2022).

Moderator and Observer - The Role of the Researchers

The researcher/moderator's role in a focus group is to be catalytic to encourage group discussion (Acocella & Cataldi, 2021). The success of the moderator role can have an impact on how much this interaction is facilitated and how safe participants feel to engage in this type of dialogue (Kitzinger, 1994, 2013). Interactive focus groups should enable people within the group to have more control of the agenda than in a traditional interview and if moderated well reduces the power of the researcher/moderator to drive the direction of the conversation. The second researcher takes the role of observer and makes notes during the process, noting down both non-verbal interactions and particular interactions between participants or perhaps the way a particular participant reacts to the ongoing conversation. This additional data becomes part of the interpretation of the data collected (Acocella & Cataldi, 2021).

Creating Rapport in Focus Groups to Promote Wider Discussion

Creating rapport within a focus group to enable interactive discussion to take place may need different skills dependant on the composition of the groups and the environment in which they are conducted (Acocella & Cataldi, 2021; Kitzinger, 1994). Whether it is useful for participants to be known to each or not is also debated (Brighton et al., 2018; Tates, 2009; Tates et al., 2009; Watson et al., 2006). People may be guarded in what they express dependant on their experiences and perceptions of the focus group and other participants. Dominance of one participant or subgroup in face-to-face groups is a common issue noted by focus group researchers (Kook et al., 2019; Schneider et al., 2002; Tates et al., 2009). Analysis of focus group interaction processes can pick up how the participants have influenced each other and where disparate views may have been silenced.

In conversations that may be of a sensitive nature, some groups may disclose more thoughts and feelings about personal things in individual interviews rather than in focus groups, such as like women talking about their body image (Kruger et al., 2019). Consideration of particular ethical issues relating to focus groups is important, including consent and confidentiality, if people perhaps reveal more than they expected to within the conversation (Sim & Waterfield, 2019). However peer support of others who have shared experiences has been found to be an enabling factor to encourage discussion about difficult issues (Kook et al., 2019; Seymour et al., 2002). Moving to online methods of data collection may make self-disclosure easier for some participants because they are less visible (Tates et al., 2009; Woodyatt et al., 2016).

Participation in Online Focus Groups

For some rural populations, geographically dispersed professionals, populations of unwell younger people, and vulnerable adults, online focus groups can offer more opportunities to participate than having to travel to a particular destination at a specific time (Brighton et al., 2018; Tates, 2009; Tuttas, 2015). The relative anonymity of online groups can also offer more opportunity for access, noticeable in groups such as young people discussing sensitive topics (Woodyatt et al., 2016). For focus groups to be culturally effective the environment must be intentionally designed to affirm participants (Foley & Timonen, 2015; Kook et al., 2019; Rodriguez et al., 2011).

Being online allows for different formats such as asynchronous online focus groups. Asynchronous discussions can be a particularly helpful format for some people to join a conversation and explore their experiences particularly around sensitive topics (Brüggen & Willems, 2009; Reisner et al., 2018; Synnot et al., 2014). This is illustrated by the popularity of online forum discussions.

Contributions people make in focus groups also seem to differ when conducted online. Over time as technological confidence increases, participants in synchronous online focus groups appear to contribute longer and more varied accounts. What has been less studied is how the interactions between the participants in the groups that are convened online alters and impacts on how the group functions and the data are produced (Morgan & Hoffman, 2018; Shaw et al., 2021). The following analysis is an attempt to explore this using our exemplar qualitative study.

Methods

Analysis of Interaction of Focus Groups

While conducting a research study exploring end of life family conversations in African and Caribbean heritage communities using focus groups, the research team had to transfer from face-to-face data gathering to using online video-based approaches during the covid 19 pandemic in 2020–2022 (Table 1). This experience offered the opportunity to explore the similarities and differences in the interactions in the focus group where the moderating team remained the same, but the delivery modality changed.

Different methods have been used to capture the interactional elements of focus group data (Morgan, 2010). Conversational or discourse analysis techniques have been used to explore the processes of the conversation that takes place such as using sociograms and word counts to explore the dynamics of interaction (Drahota & Dewey, 2008). Some researchers are interested less in the process of conversation that takes place and more in the co creation of meaning and so use a process of questions to explore what types of conversations took place (Kook et al., 2019; Stevens, 1996; Watson et al., 2006; Wilkinson, 1998).

Qualitative Focus Group Interaction Tool

Goffman inspired interactional analysis and positioning theory offers a more in-depth analysis of the construction of a social event within the focus group interaction (Halkier, 2010; Morgan & Hoffman, 2018). Many things impact on what a person may say in a group and how they may defend their point of view, much of which is influenced by their perception of self and their positioning within the power dynamics of the group. Capturing these dynamics using both what is said verbally but also the nonverbal behaviours helps the helps the researcher in their analysis and interpretation of how what is said relates to the experiences of the people in the group. Some of this is captured using a researcher observer and using their field notes, and by analysing the transcripts and the audio and video recordings of the groups to capture dynamics (Greenwood et al., 2017). Steven's (1996) interaction questionnaire was designed to interrogate these aspects.

To explore how in group interactions may alter by moving data collection from in person to online contexts, data from our study was analysed using both sociograms (Figures 2 and 3) and an adapted form of Steven's (1996) questions (Table 2).

Quantitative Focus Group Interaction Tool - Sociograms

Although every focus group is unique, conversational analysis patterns can emerge which can be visualised using a sociogram (Drahota & Dewey, 2008). Generally, arrows between participants illustrate flows of conversations with the weight of the arrow growing with the number of conversational interactions there are between people. The more heavily weighted the arrows are between participants the more interactive the discussion is between them. If the arrows are more heavily weighted between the moderator and each participant, it indicates that the discussion is more like a series of interviews with each group member than an interactive focus group discussion (Figures 1 and 2).

Analysis of the Nature of the Interactions

Using Steven's (1996) questions, each focus group transcript and audio tape were analysed for the types of interactions that took place using a coding system related to the constructs of the table, i.e., topic changes, conflict, consensus, elements of dominance, common experiences, emotional disclosure and support, inclusion, and exclusion of participants in the group and how they made their final conclusions (Table 3). This was completed via analysis of the verbatim transcripts and the notes from the observer researcher.

Findings

Developing and Maintaining Rapport

The two face-to-face focus groups had 5 and 4 participants respectively. These groups occurred in places in which participants were familiar, the first at a shared place of work and the second in the church at which all the participants attended. The groups were started with the provision of a light lunch and a drink during which participants could briefly interact. Formal introductions of Group 1 occurred at the start of the group as they were not all known to each other. The second group knew everyone except the second facilitator who was introduced during the meal. In general, rapport developed easily in the face-to-face groups and a lively discussion ensued up to the allotted time of 1.5 hours and continued after the groups had finished.

The next three focus groups were conducted online, involving 6, 4 and 3 participants. The online focus groups

Table 2. Focus Group Interaction- Qualitative Analysis Tool (Stevens, 1996).

1	How closely did the group adhere to the issues presented for discussion?
2	Why, how, and when were related issues brought up?
3	What statements seemed to evoke conflict?
4	What were the contradictions in the discussion?
5	What common experiences were expressed?
6	Were alliances formed among group members?
7	Was a particular member or viewpoint silenced?
8	Was a particular view dominant?
9	How did the group resolve disagreements?
10	What topics produced consensus?
11	Whose interests were being represented in the group?
12	How were emotions handled?

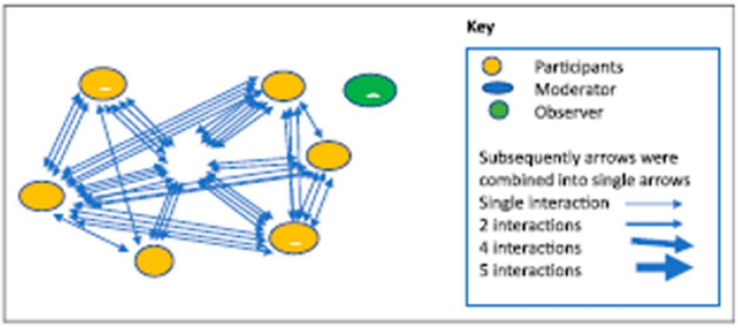

Figure 1. Initial stages in creating sociograms.

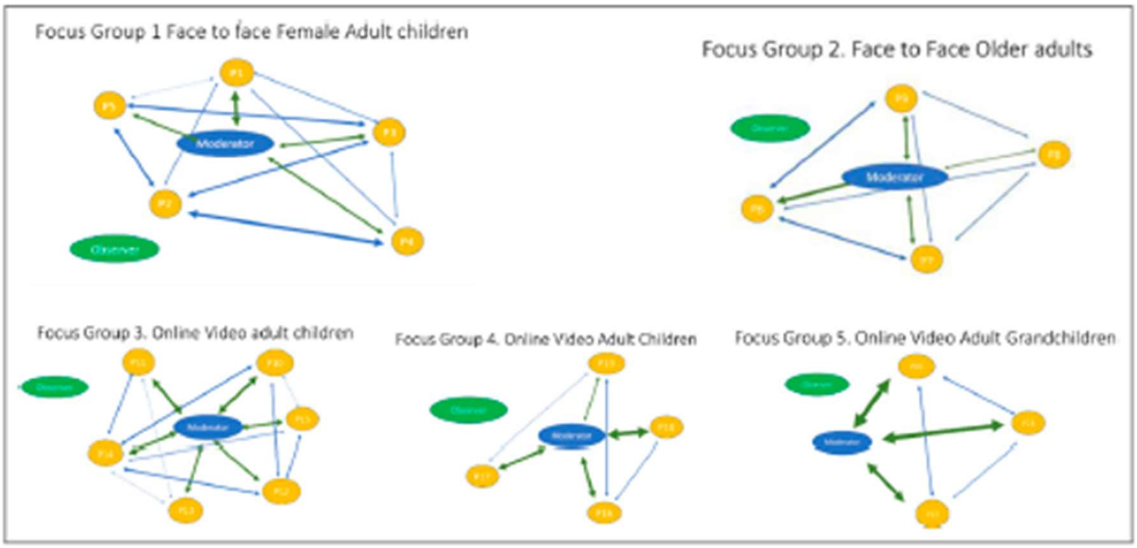

Figure 2. Sociograms of the 5 focus groups (face to face and online video groups).

started more quickly as were did not have a pre sessional meal. Rapport was encouraged as they arrived in the virtual space by trying to ensure that all participants had cameras on. The moderator then engaged the group in informal conversation before the formal focus group began but little participant to participant interaction occurred until the more formal introductions at the start of the focus group discussion when everyone in the group had successfully logged on.

Group Discussions – Face-To-Face Focus Groups

The sociograms and qualitative interactions (Figure 1 and Table 2) illustrate that conversation flowed between participants as well as with the moderator, with interactions in Group 1 more prolific than in Group 2. There were several interactions where the participants of the group built on each other's comments often to shape the direction of discourse (Fragment 1, 2 and 3).

Fragment 1: Face-to-Face Interaction Focus Group 1. Moderator: *Well .is he older than you or something .?*

Adult child (P4FG1): *There's the thing...no he is not older, you know he's much younger than me.*

Adult child (P3FG1): *Is it that's he's the only boy.?*

Adult child (P4FG1): *No he isn't. I've got an older brother.*

Adult child (P3FG1): *Okay sometimes i understand it can be a cultural thing...*

Others: *Yeah. Yeah…Let's talk to the main man.*

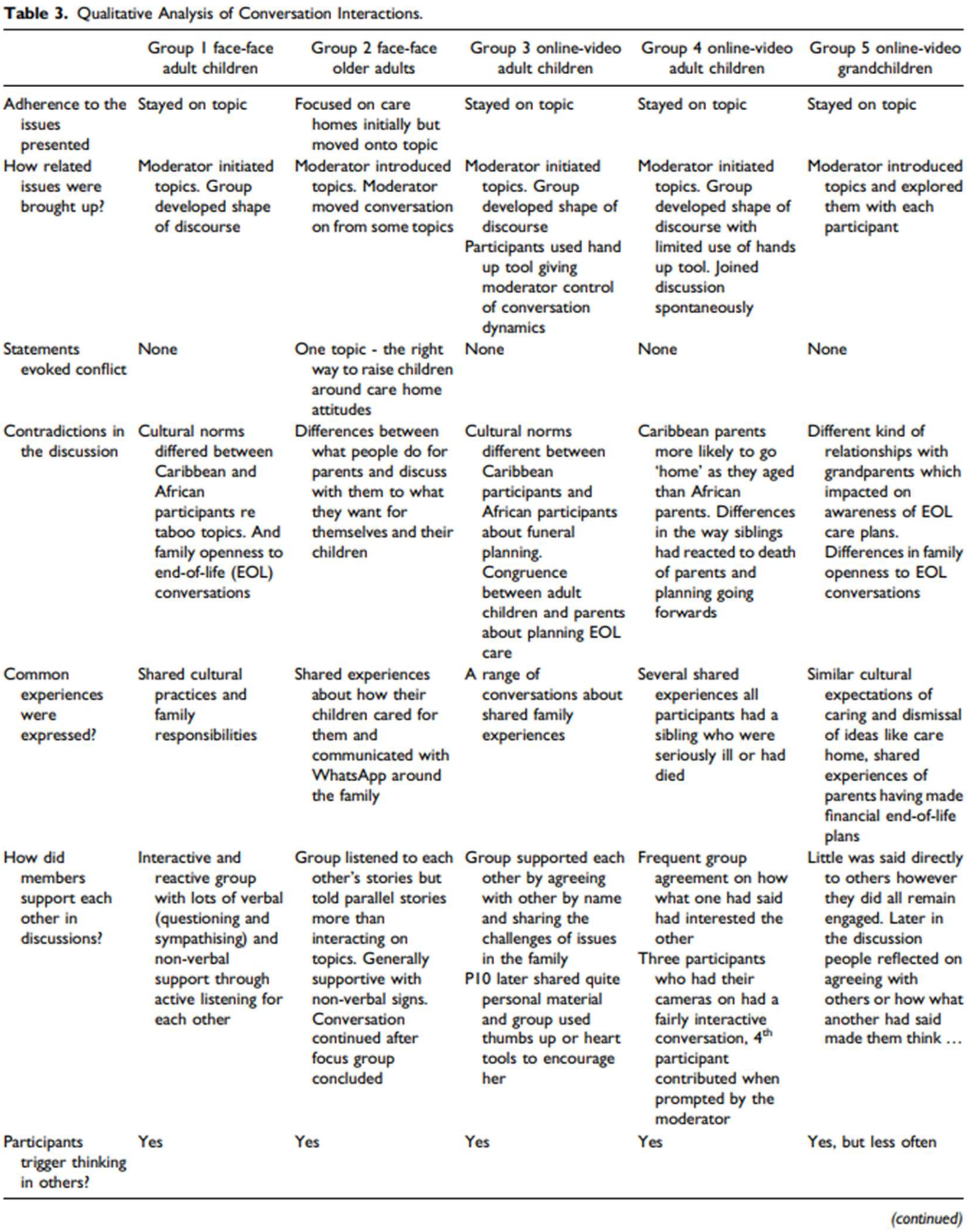

Table 3. Qualitative Analysis of Conversation Interactions.

	Group 1 face-face adult children	Group 2 face-face older adults	Group 3 online-video adult children	Group 4 online-video adult children	Group 5 online-video grandchildren
Adherence to the issues presented	Stayed on topic	Focused on care homes initially but moved onto topic	Stayed on topic	Stayed on topic	Stayed on topic
How related issues were brought up?	Moderator initiated topics. Group developed shape of discourse	Moderator introduced topics. Moderator moved conversation on from some topics	Moderator initiated topics. Group developed shape of discourse Participants used hand up tool giving moderator control of conversation dynamics	Moderator initiated topics. Group developed shape of discourse with limited use of hands up tool. Joined discussion spontaneously	Moderator introduced topics and explored them with each participant
Statements evoked conflict	None	One topic - the right way to raise children around care home attitudes	None	None	None
Contradictions in the discussion	Cultural norms differed between Caribbean and African participants re taboo topics. And family openness to end-of-life (EOL) conversations	Differences between what people do for parents and discuss with them to what they want for themselves and their children	Cultural norms different between Caribbean and African participants about funeral planning. Congruence between adult children and parents about planning EOL care	Caribbean parents more likely to go 'home' as they aged than African parents. Differences in the way siblings had reacted to death of parents and planning going forwards	Different kind of relationships with grandparents which impacted on awareness of EOL care plans. Differences in family openness to EOL conversations
Common experiences were expressed?	Shared cultural practices and family responsibilities	Shared experiences about how their children cared for them and communicated with WhatsApp around the family	A range of conversations about shared family experiences	Several shared experiences all participants had a sibling who were seriously ill or had died	Similar cultural expectations of caring and dismissal of ideas like care home, shared experiences of parents having made financial end-of-life plans
How did members support each other in discussions?	Interactive and reactive group with lots of verbal (questioning and sympathising) and non-verbal support through active listening for each other	Group listened to each other's stories but told parallel stories more than interacting on topics. Generally supportive with non-verbal signs. Conversation continued after focus group concluded	Group supported each other by agreeing with other by name and sharing the challenges of issues in the family P10 later shared quite personal material and group used thumbs up or heart tools to encourage her	Frequent group agreement on how what one had said had interested the other Three participants who had their cameras on had a fairly interactive conversation, 4th participant contributed when prompted by the moderator	Little was said directly to others however they did all remain engaged. Later in the discussion people reflected on agreeing with others or how what another had said made them think …
Participants trigger thinking in others?	Yes	Yes	Yes	Yes	Yes, but less often

(continued)

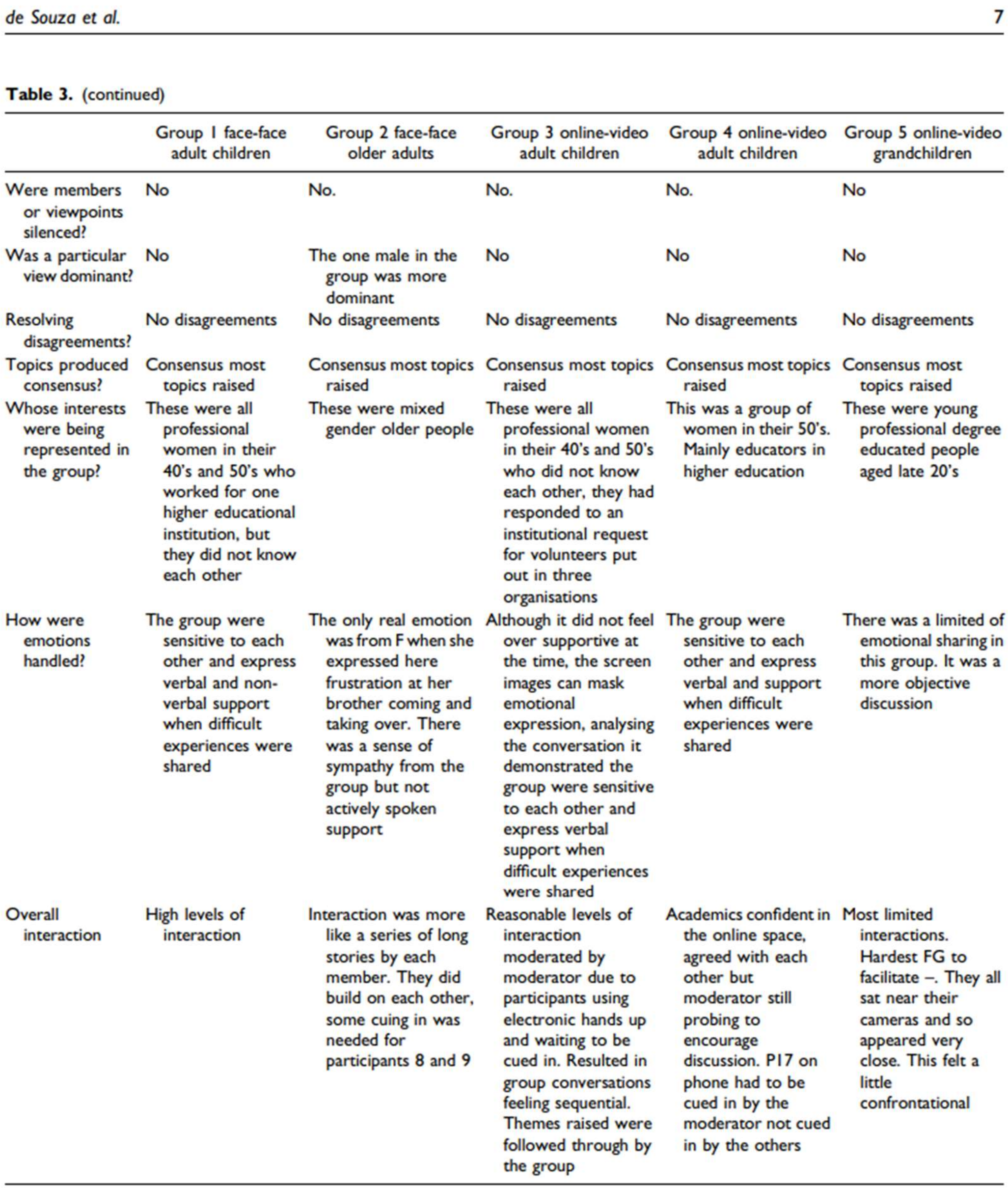

Table 3. (continued)

	Group 1 face-face adult children	Group 2 face-face older adults	Group 3 online-video adult children	Group 4 online-video adult children	Group 5 online-video grandchildren
Were members or viewpoints silenced?	No	No.	No.	No.	No
Was a particular view dominant?	No	The one male in the group was more dominant	No	No	No
Resolving disagreements?	No disagreements	No disagreements	No disagreements	No disagreements	No disagreements
Topics produced consensus?	Consensus most topics raised	Consensus most topics raised	Consensus most topics raised	Consensus most topics raised	Consensus most topics raised
Whose interests were being represented in the group?	These were all professional women in their 40's and 50's who worked for one higher educational institution, but they did not know each other	These were mixed gender older people	These were all professional women in their 40's and 50's who did not know each other, they had responded to an institutional request for volunteers put out in three organisations	This was a group of women in their 50's. Mainly educators in higher education	These were young professional degree educated people aged late 20's
How were emotions handled?	The group were sensitive to each other and express verbal and non-verbal support when difficult experiences were shared	The only real emotion was from F when she expressed here frustration at her brother coming and taking over. There was a sense of sympathy from the group but not actively spoken support	Although it did not feel over supportive at the time, the screen images can mask emotional expression, analysing the conversation it demonstrated the group were sensitive to each other and express verbal support when difficult experiences were shared	The group were sensitive to each other and express verbal and support when difficult experiences were shared	There was a limited of emotional sharing in this group. It was a more objective discussion
Overall interaction	High levels of interaction	Interaction was more like a series of long stories by each member. They did build on each other, some cuing in was needed for participants 8 and 9	Reasonable levels of interaction moderated by moderator due to participants using electronic hands up and waiting to be cued in. Resulted in group conversations feeling sequential. Themes raised were followed through by the group	Academics confident in the online space, agreed with each other but moderator still probing to encourage discussion. P17 on phone had to be cued in by the moderator not cued in by the others	Most limited interactions. Hardest FG to facilitate –. They all sat near their cameras and so appeared very close. This felt a little confrontational

Fragment 2: Face-to-Face Interaction Focus Group 1. Discussing who benefits from advance planning conversations:

> Adult child (P1FG1): *So I'm just saying that's our generation and I'm thinking. Who benefits from having that conversation? Is it for my own benefit or for my relatives benefit? To kind of have that.*
>
> Moderator: *So you've done a donor card. If you died… assumingly your husband would be asked.*
>
> Adult child (P1FG1): *No not any more…I've taken out of his hands because he would probably say no for me where I'm saying yes…*
>
> Adult child (P3FG1): *Yeah. Because they've taken that away from your relatives now. Yes because relatives were saying that.*
>
> Adult child (P1FG1): *Exactly. But I'm just saying that end of life conversation you're talking about. Do we think it's beneficial to have it? My question is whose benefit, is it? Is it for their benefit or my benefit. because it would be beneficial for me to have that conversation, but I know that family members would find it…*
>
> Adult child (P3FG1): *or confirm that they're going to die.*

The same happened in the second focus group. Group 2 was a group of older people who attended the same church.

Fragment 3: Face-To-Face Interaction Focus Group 2. Older adult (P9FG2): *I think it's the thought of losing me, that's what they're afraid about. You know that mom wouldn't be here. You know, they don't want to accept that. That's it, they don't want to accept.*

> Older adult (P6FG2): *because I think I'd agree with you because I don't think my children really thought their Nan would go. Yeah. And I think because she's always been there.*

In these focus groups, it was clear from the observer researcher's memo, all the participants were engaging in active listening to the person speaking using non-verbal facial interactions or body posture to verify this for the speaker. Although there was still a need for the moderator to steer conversations and get them started, participants would enter discussion with other participants.

The participants in the older people's group told longer stories and spoke more of how they were preparing their children to play a caring role for them. Slight interjections 'yah' and mummering's encouraged the story telling and gave participants a sense of shared experiences. There was mainly consensus in the conversations. There did not appear to be any active silencing of any participants by the others.

In the second group there was an older couple, the male partner, P7, whilst not dominant of the group, did speak more than the others in the group and occasionally made a comment about what he thought his wife thought. In contrast his wife, P8, spoke very little. She admitted that the topic was not something she particularly liked to talk about.

Group Discussions – Online Focus Groups

In all the online focus groups the group dynamics changed with more interactions being initiated by the moderator and most conversations being between the moderator and a particular participant (Figure 2).

In the online focus groups, initially conversation started serially with conversations between the facilitator and individual participants (fragment 4).

Fragment 4 Online Interaction Focus Group 3. Adult child (P11FG3): *What I find from my mother's generation is that they've made provisions for their funeral arrangements who's going to play the organ, what hymns are going to be sung …*

> Moderator: *ummmm… silence … and what sort of age were they when they did that?*
>
> Adult child (P11FG3) *..:oh when I was still in school….. (fairly long descriptive conversation of several things)*
>
> Moderator: *maybe if we first of all, just talk about funeral planning and that kind of thing, what's it like in other people's families? Is it similar or different?... silence*
>
> Moderator' participant 12? *(by name)*
>
> Adult child (P12FG3): *I was going to say it's .. quite interesting to hear P11's (by name) explanation. I can relate to a lot of that when I think back for my mom and dad…..(again a fairly lengthy conversation)*
>
> While this took place two other participants used the raised hand feature, so the moderator called them into speak in turn after participant 12 had finished.

This was followed by quite an active conversation, all participants had interactions with other participants however the arrows to the moderator are noticeably bigger than in the face-to-face groups and the moderator choose who to invite to speak next from those who had raised their electronic hands. This resulted in quite a serial conversation. P11 (FG3) said the least but did have some interactions directly with other participants.

Focus Group 4 ran quite differently. One successful recruitment strategy for the focus groups during the pandemic was via internal communication bulletins in two academic institutions. This resulted in focus group four involving four academic participants and one lay person. The academic participants demonstrated both a real understanding of the research and a keen interest in it, they also had confidence speaking in this type of online space. However serial interviewing was still apparent and P17 (FG4) had to be cued in each time by the moderator. She had joined the group by phone and her lack of camera seemed to reduce her presence in the discussion and the ability of the others to develop a rapport with her.

Focus Group 5 was the smallest group and was with a group of the youngest participants who were reflecting on conversations with and about both their parents and grandparents. The two women knew each other but the male participant was unknown to them both. This group felt the most intense, with participants seated close to their camera's and facing directly forward. It was not easy to avoid direct eye contact through much of the focus group.

Changes in Group Interactions Between Face-to-Face and Online Groups

From the experience of the researchers, moving online resulted in group dynamic changes. The focus groups became more intense. Rather than having discussions with each other, participants waited to be cued in to engage in conversation. In focus Group 3 and 5 participants used the hands up function and so gave control to the moderator about when and in what order to call people into the conversation. What was noticeable was that some participants interacted very little with each other or not at all. On a screen it is possible to forget that other participants are in the space if they did not have their camera on or if using a screen or device that only shows a certain number of people. It is harder to forget other participants in a face-to-face group (Figure 3 and fragment 5).

Fragment 5 Online Participant Interaction Focus Group. Adult Child (P11fg3): *I don't think mother would care either way. It's just whether she's getting the care that she needs at that stage of her life or she's probably written it down to, but she just hasn't told me, my family's very practical about whatever they need. And it also depends on what her ailment is*

Moderator: *Yeah, so for some things, you think she would seek some treatment and for others not all, ...*

Adult Child (P11 fg3) : *Oh she would seek treatment for anything because she's made provisions for that, because my mother retired early, so she made provisions for the rest of her life financially. And as I said, she wrote everything down and the same for my father. They have everything planned for whoever has to take care of them, will take care of them and whatever setup is fit....*

Pause

Moderator: *Mm hmm. And what about you others ?*

Adult Child (P14 fg3) *....(put her electronic hand up) There we go. Yeah, I think similar to P11, my.. my parents would seek treatment for whatever…...*

Similarly to the face-to-face groups, there did not seem to be any topics that caused conflict, however with participants being on mute there was a lack of murmured encouragements. There was recognition that cultural norms were different particularly between Caribbean and African heritage cultures, although there were also a number of shared experiences between participants of both cultures. Participants did comment on how the stories of other participants stimulated new thinking for them and they went on to build on the conversation of the others.

Ending the Focus Groups

The online focus groups were brought to a close after an average of an hour. This felt a long enough time to be having this rather intense type of conversation and new topics of conversation were not being generated. None of the participants made use of the chat facility although all had contributed some demographic information in the chat so were aware of its presence. Much like the start of the online groups, the ending seemed more abrupt than face-to-face groups and no further conversation took place in the online chat areas.

Discussion

In this qualitative study exploring family conversations about end-of-life preferences, focus groups were initially conducted face-to-face, this changed to online focus groups due to the need for social isolation procedures during the COVID-19 pandemic. The focus groups were lead and moderated by two researchers who used transcripts, videos, observation memos, a qualitative group discussion analysis tool and sociograms to analyse the construction of the conversations that took place

Image Credit (Microsoft) IICD from The Hague, The Netherlands during the groups and the interpersonal dynamics of the conversations. Two themes that arose from that analytic process were associated with the context in which the groups occurred, face to face versus online: 1. Developing and maintaining rapport in the groups and 2. Interactions between participants.

Analysing the interactions in the data it appears that focus groups that take place online risk becoming group interviews where the moderator controls the narrative more than in focus groups that take place face to face.

Developing and Maintaining Rapport in the Groups

For groups of participants who do not know each other, initially rapport is created as people arrive in the research space (Weller, 2017). When meeting in person, people present their whole person and exercises like sharing food and drink allow participants to mingle tentatively, speak to one or two others and appraise one another before the focus groups starts. If these experiences are positive this builds rapport. People joining the online meeting space, if people have cameras on, present with just a head and shoulder image and so participants gain little non-verbal contextual information of their fellow participants as the group convenes. There is little discussion of this phenomenon in the current focus group literature.

Where online rapport has been studied in health care, is mainly with health care professionals holding online patient consultations. Professionals are surprised by how much they rely on non-verbal elements like watching someone walk or how their handshake feels to make judgements about people's health and engage in conversation about alongside what is said verbally (Primholdt Christensen et al., 2021). In our study, the rapport created in the initial two face-to -face focus groups was more visible to the researchers than that created in the online groups, by how participants interacted with each other directly during the focus group (Figure 2 and Table 3).

Initial conversations in online focus groups can be focused on the technicalities of establishing good internet connections and whether participants can hear and see each other, difficulties with these can result in focus on that individual leaving the others in a position where it is not easy to engage with anyone in the space (Daniels et al., 2019; Foley, 2021; Menary et al., 2021; Shaw et al., 2021; Tuttas, 2015). One benefit of the covid pandemic has been people across societies rapidly becoming more familiar with using web based online platforms for meetings, so these technological problems are diminishing. However presentation of self, prolonged eye contact, engaging in conversations where non-verbal cues are much harder to use to evaluate engagement in the discussion, are all factors that need to be considered when moving data collection online (Bailenson, 2021; Weller, 2017).

An observation of the researchers in our study was how eye contact in the online groups is almost forced. Each person looks straight ahead at the other participants who appear on their screens. They are unaware of their physical position to other participants as viewed by the rest of the group on their screens. Any conversations need to be made to the whole group rather than just the person closest to them. In a face-to-face group people sit further part and when talking to one participant an individual is usually not facing everyone else (Figure 3).

The importance of eye contact and the role it plays in regulating and directing conversation is extensive and detailed (Degutyte & Astell, 2021) with discourse focusing on disrupted conversations when eye contact is not made. During an online focus group conversation, eye contact becomes more intense as each group member is in close eye contact with the others (Figure 3).

This type of eye contact can be normal when people are in close relationships, however engaging in this way with strangers can result in fatigue and a rise in self-consciousness as one can also see one's own image (Bailenson, 2021; Kaiser et al., 2022). This may explain why the online focus groups finished more quickly and had less of a sense of unfinished conversations than the face-to-face groups, both of which had some ongoing conversations on topic between participants even after the focus group was concluded. This ease and informality of conversation may be lost in the online groups.

In an online group, people can join with their cameras off, so they can present unseen. For some this relative anonymity, increased if cameras are not required, can enhance a sense of safety in expressing personal experiences and thoughts (Gazit et al., 2018; Tates et al., 2009). However, the growing academic literature on making conversation or conducting interactive online education with unseen participants suggests creating and maintaining rapport in these situations is difficult. Participant 17, an adult child, in focus Group 4 was unable to join the focus group using a camera, this impacted on their ability to be seen in the space and be included in the discussion, this may have been a factor in her limited contributions to the conversation. Eye contact available via video conference has been found to enhance rapport in comparison to groups with just audio contact between participants (Bohannon et al., 2013).

More consideration and preparation of introductory exercises, consideration of visibility and more understanding of the impact of multifocal eye contact when facilitating online groups may result in creating better rapport between participants and in the resultant focus group conversations.

Nature of Interactive Conversations - Group Discussion versus Group Interviewing

The depth of what individuals shared was similar in the two groups. In the face-to-face groups this became a deeper shared conversation developed by group members, however in the online groups, it required the moderator to pick up the themes to generate more conversation around them (Fragment 4). Where participants were fairly unknown to each other synchronous online focus groups are shorter, with less in-depth conversations even though more unique codes can be generated (Schneider et al., 2002; Woodyatt et al., 2016). Small conversation prompts, verbal and non-verbal from fellow participants, more prolific in face-to face encounters perhaps promotes deeper and more extended discussions (Weller, 2017). When permission (by raising hands or asking to speak) is needed and non-verbal prompts are lost, the group loses some of its power to control and develop the narrative and a core aim of focus group methodology (Acocella & Cataldi, 2021; Kitzinger, 2013) to reduce the power and control of the moderator by giving is lost.

The pattern was different in focus Group 4 where the participants were academics used to facilitating online group discussions themselves, here similarly to the face-face groups, the conversations were more fluent. Increased fluency is a phenomenon documented by others when focus groups are conversations between experts or professionals used to team communication situations (Brüggen & Willems, 2009; Tuttas, 2015). Itis important to consider when designing studies that include different types of populations, facilitation for one type of group may require different techniques than that of others.

As participants spoke, shared experiences triggered memories and a sense of connection between the participants, this was similar in both types of focus groups and has been noted before (Kook et al., 2019; Seymour et al., 2002). As individual narratives captured in focus groups can result in conflict and disagreement in the group, this is important to note as it impacts on how much the data generated is a shared or negotiated narrative (Onwuegbuzie et al., 2009; Stevens, 1996). The lack of conflict in any of the focus groups, high degree of consensus and recognition of shared experiences indicates that the mode of delivery of the groups did not seem to influence consensus around the topic in question.

Impact of Group Size on Group Dynamics

Group size is a topic well debated in the literature and depends on many different variables like topic, context, and cultural variations. Participants in smaller group sizes feel more comfortable when they have more expertise or things to say on a topic (Krueger & Casey, 2014). In a comparison of 2 person online dyads and 4 person groups, conversation seemed easier in smaller groups on line, however larger groups generated more themes (Lobe & Morgan, 2021). The influence of group size may be heightened by the visibility differences in online focus groups. Verbal and non-verbal cues can be less evident, such as when a participant may want to join in the conversation, groups sizes above 5 can raise difficulties for the moderator and others to facilitate an inclusive discussion (Lobe et al., 2022). The groups in the study were between 3 and 6 participants.

The two face-to-face focus groups had 5 and 4 participants respectively. Both flowed well and appeared similarly comfortable and facilitative of a free-flowing discussions between the participants and moderator. Focus groups 3 and 4 online had 6 and 4 participants, the former felt more formal and longer was needed to facilitate all participants to contribute things. The role of the moderator in determining order and negotiating the conservation was greater. Focus Group 4 with its 4 participants flowed easier between the three more dominant participants, all these participants were academics and so had a practiced online video presence and sat back from their screens. Focus Group 5, the smallest group of three younger participants who all sat quite close to their screens, was different to what has been observed in Lobe and Morgan's study, where smaller groups resulted in more discussion, for this group discussions were more limited and the sense of looking directly at all the participants felt the most intense.

A larger group discussion may have diluted this sense of unease, in part because the screen contains more faces and the sense of speaking directly to one or two people is lessened. The original group was designed to be 4 participants, but one was unable to attend on the day. Commitment to attending a focus group can be unpredictable, and going online may not reduce this, over recruitment has been suggested to try and ensure a suitable group size (Tuttas, 2015). This may be easier to do when recruiting to online groups where people may not mind being on 'standby' if you are not wanting to exceed optimum group sizes (Lobe et al., 2022).

Innovative research exploring lurkers and active participants in online forums, revealed strong links between personality types and online contributions (Gazit et al., 2018). Focus group discussions suggested that unless actively facilitated, lurkers choose to remain passive associated with not feeling a need to contribute or feeling everything they could contribute has already been offered. An adult child, P17 in Fg4 introduced herself by suggesting she was only invited to make up the numbers, as she was the only non-academic in the group, she chose to lurk, and only spoke when cued in by the moderator… P17 who did not have a video on was almost ignored by the rest of the group who could see each other on the screen. The experiences of many lecturers during the pandemic is that students have become increasingly quiet in online spaces and there has been a developing fatigue in engaging in online small group discussions.

Control of the Direction of the Narrative

What is especially noticeable from the sociograms (Figure 2) is how the role of the moderator in raising topics and encouraging conversation flow was quite different in the online groups in comparison to the face-to-face groups. Much of the discussion is initiated by the moderator and interactions go through the moderator (Figure 1 and fragment 4). This can result in group interviewing (Acocella & Cataldi, 2021; Munday, 2006) and reduce the richness that can come from participant to participant negotiation over experiences. This can also happen in face-to-face groups where a dominant participant can interject comments that result in them acting as the study monitor. It is important to ensure skilful moderation

Table 4. Recommendations for Running Focus Groups Online.

1 Make it clear about whether the focus group is being used as a tool to do multiple interviews to gain a range of perspectives or whether it is the shared meaning of experiences that is being sought. If it is the latter, think about how to enable groups to feel in control of the space and comfortable to interact with each other whether it is in a face-to-face situation or online

2 Physical positioning is important whether it is a face-to-face or online group. Making sure participants are comfortable, in a good light so their faces can be seen but perhaps not too close to the screen. Encouraging participants to join the online group in a pair or small group where there is then less intensity of eye contact maybe something to explore going forwards

3 Starting an online group with a discussion about how interactions are different online to in a face-to-face situation may be helpful. Explaining that participants do not need permission to speak and make it clear the raised hand function will not be monitored by the moderator, but instead participants can use it to indicate to fellow participants that they have a point to make or that they wish to respond, and then they should do so when they feel it is an appropriate time to come into the conversation

4 Using an effective introductory exercise to develop rapport between participants may be helpful. This can allow participants to become familiar with each other, learn some contextual information about each other and increase confidence in communicating using both the video functions and the chat function which can help illustrate consensus or conflict

to ensure that it is not only the loud voices that are heard in the online group discussion.

Recommendations for Online Focus Group Moderation

Moving forwards, it is important for researchers to be conscious of the dynamics of their focus groups. Using online spaces has proven to have many advantages in terms of accessibility so it is likely their use will continue to gain popularity. To gain the best outcomes several factors need to be considered, these are outlined in Table 4.

Conclusion

Qualitative researchers are increasingly using online data collection as it reduces complexity of gathering participants, can be less costly in time and traveling costs, and can provide a space in which some participants feel more comfortable to disclose information. Focus groups are used as a data collection method where ideas offered by participants generate thoughts and opinions for other study participants in the group, and the discussion that ensues offers insight into the positionality of different group members on the phenomenon under study. Analysis of the interaction in the focus group is also important in situating the data gathered using the process. Through this discussion, questions have been raised about whether the interaction in focus groups changes when data is collected online and how this can be analysed, considered and perhaps mitigated. It is important to be clear about the rationale for using focus groups as a method of data collection and to ensure these aims are achieved when using this method online.

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Ethical Statement

Ethical Approval

Research ethics committee approval to conduct the study was obtained by the research ethics committee at Lancaster University FHMREC18 (August 2019) and amended to allow online focus groups (July 2020). The study was considered low risk at King's College London and allowed to proceed.

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6.11 Conclusion

This chapter contains an outline of the methodology chosen and the methods employed to carry out this study. It also contains a discussion in the form of a published article of the impact of modifying the methods when external circumstances change and an awareness that the data generated in focus groups is potentially vulnerable to the way in which the groups are conducted. It is therefore important to measure and observe the group dynamics alongside analysing the codes of what is actually said to ensure you continue to get a co-constructed discussion by participants, rather than a discussion that is more like a group interview where the construction of conversation is driven more strongly by the moderator. These are important aspects of methodology to be conscious of when conducting this type of research. The chapter concluded with a more detailed dive into the data collected to demonstrate the process of grounding the abstracted constructs of the theory of living and dying between cultural traditions in the data from the focus groups.

In the following chapter, Paper 4 is presented. This offers a full summary of the study that has been undertaken and lays out this new theory with some discussion around its potential impacts. This is followed by the integrated discussion in Chapter 9 in which this theory is discussed in more detail and how it relates to current knowledge in this area.

Chapter 7: Paper 4: Living and dying between cultural traditions in African and Caribbean heritage families: a constructivist grounded theory

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This study was also presented as an oral presentation at the European Association of Palliative Care in 2023 prior to the completion of this paper (appendix 5), this will be discussed following the presentation of the paper.

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Living and dying between cultural traditions in African & Caribbean Heritage families: a constructivist grounded theory

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Abstract

Background Ethnic differences influence end-of-life health behaviours and use of palliative care services. Use of formal Advance care planning is not common in minority ethnic heritage communities. Older adults expect and trust their children to be their decision makers at the end of life. The study aim was to construct a theory of the dynamics that underpin end-of-life conversations within families of African and Caribbean heritage. This is a voice not well represented in the current debate on improving end-of-life outcomes.

Methods Using Charmaz's constructivist grounded theory approach, a purposive sample of elders, adult-children, and grandchildren of African and Caribbean Heritage were recruited. In-person and online focus groups were conducted and analysed using an inductive, reflexive comparative analysis process. Initial and axial coding facilitated the creation of categories, these categories were abstracted to constructs and used in theory construction.

Results Elders ($n=4$), adult-children ($n=14$), and adult grandchildren ($n=3$) took part in 5 focus groups. A grounded theory of living and dying between cultural traditions in African and Caribbean heritage families was created. The constructs are (a) Preparing for death but not for dying (b) Complexity in traditions crosses oceans (c) Living and dying between cultures and traditions (d) There is culture, gender and there is personality (e) Watching the death of another prompts conversations. (f) An experience of Hysteresis.

Discussion African and Caribbean cultures celebrate preparation for after-death processes resulting in early exposure to and opportunities for discussion of these processes. Migration results in reforming of people's habitus/ world views shaped by a mixing of cultures. Being in different geographical places impacts generational learning-by-watching of the dying process and related decision making.

Conclusions Recognising the impact of migration on the roles of different family members and the exposure of those family members to previous dying experiences is important. This can provide a more empathetic and insightful approach to partnership working between health care professionals and patients and families of minority ethic heritage facing serious illness. A public health approach focusing on enabling adult-children to have better end of life conversations with their parents can inform the development of culturally competent palliative care.

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Keywords Advance care planning*, Communication, Minority groups*, Ethnicity, Black or African/ethnology, Palliative care, Terminal care*, Adult-children/ethnology

Background

Ethnic and cultural differences influence patterns of health behaviours around end of life and in particular the take up of current palliative care services [1, 2]. There are a range of factors at play including cultural approaches to advance care planning, end-of-life values, care preferences at the end of life and inequalities in the provision and accessibility of services [3–10].

Despite an increasing take up of palliative care from people of ethnic minorities, advance care planning remains unpopular [11, 12]. Concerns remain about how to honour individual end-of-life preferences and reduce distress and confusion among surrogate decision makers [12, 13]. Fearing causing distress, coupled with a religious view that 'it is in God's hands', and a desire for a collective family based system of decision making, result in fewer conversations about end of life being reported in families of Black and minority ethnic heritage migrant communities [12, 14–16].

In a range of minority ethnic heritage migrant communities, adult-children often play a key role as end-of-life decision makers for their parents [14, 17, 18]. However, few of these children have conversations with their parents about their end-of-life preferences, and there is often poor congruency between elders and children about preferences of care at end of life [13, 19]. In addition, when surveying the relatives of family members of people who have died, having a documented advance care plan resulted in a higher level of unmet mental health needs for people who identify as black [20]. Though the cause remains unknown, Luth & Prigerson recommend caution and further research since advance care planning might differ in effectiveness for different communities. The benefits of such plans may be based on an assumption that control of future care is a good thing and that choice will be available to people equally [21]. Zivkovic's discussion of temporal dissonance and the risk of advance care planning not only forecasting futures but also potentially foreclosing possible futures indicates the complexity of this practice when used by people of different cultures [21, 22]. A meta ethnographic approach was used to explore existing research on perspectives of older people from Black and minority ethnic heritage about having end-of-life family conversations [16]. Four storylines were constructed:

My family will carry out everything for me, it is trust; No mum, don't talk like that; I leave it in God's hands; Who's going to look after us? Older people acknowledged that while they do not find it comfortable talking about dying, they trusted their children to make the right decisions for them when needed. Some recognised these decisions may be different to the ones they might make for themselves but felt this was not important. However, several found that it was their children who closed down conversations. Children acknowledged they were frightened and found it distressing to contemplate the death of their parent. There continues to be a high level of religiosity in some ethnic minority heritage communities and those religions favoured a perspective of God having a direct influence on the timing of death of people. Lastly there was a growing concern, particularly in the South Asian communities, that family patterns were changing and that children would not be able to play the caring roles that had existed in the past. Recognising a need to change but also keen to maintain cultural traditions, these older people felt a sense of change and disquiet about their own futures [16].

A complex interplay was found between avoidance as protection [14], a world view that God will plan the time, place and nature of death and that children will make the right decisions for their parents when needed resulting in a silence instead of discussions of end-of-life preferences. Our current narrow approaches to the influences of culture in advance care planning could be widened by exploring the perspectives of a broader range of society [6].

More work is needed to explore how standard palliative care interventions work for different communities and the reasons why people's experiences may vary between different communities [12, 23]. To develop understanding of what helps and what hinders the reduction of distress at the end of life, the aim of this study was to explore what people from African and Caribbean heritage feel about end-of-life care planning conversations within their families and the role these conversations should play.

Definitions used in this study

Palliative and end of life care are defined differently in different contexts, however they both have at their heart, the alleviation of health related suffering in the face of serious illness [24]. For the sake of brevity, the term palliative care is used to encompass palliative and end of life care. To denote populations who have in their history migrated to become of a minority ethnicity heritage in countries such as the UK, the term minority ethnic will be used. It is acknowledged that this is complex and risks assuming a conformity that does not exist [25]. Care is needed to recognise these limitations.

The view of what constitutes a good death remains a 'contested space' [26]. Much of the expectation of good dying in the literature is informed by evidence gathered from predominantly white communities, rather than a more plural global perspective [26–28]. When facing a terminal diagnosis and seeking health care support, independence, individualism, autonomy, fear of relentless efforts extending poor quality life, choice and veracity are the values that shape the provision of palliative care [27]. These values take the shape of open discussions about prognosis and options, autonomous decision making in the form of formal advance care planning and acceptance of input from health care professionals focused on symptom management and comfort rather than cure. Rates of completion of formal advance care planning remain lower in all minority ethnic groups [29]. As with all cultural processes, advance care planning is a field that changes constantly due to prevailing influences. However, whilst completion of care plans amongst black minority populations is rising, they remain low and indicate a higher preference for continuing 'aggressive' care than white populations [15, 30]. Among most minority ethnic populations, choosing a collective family decision making model remains an expressed preference. This is a complex matter and it is important to explore preferences expressed in some detail as there can be a translation gap due to different health literacies, they may not reflect the values of the person expressing them, but more disguise concerns they have regarding treatment choices [8].

Methods

Research aim

To construct a theory of the dynamics that underpin end-of-life conversations within families of African and Caribbean heritage.

Study objectives:

1. To explore the perceptions of older adults and their adult-children about having family conversations around end-of-life preferences.
2. Using constructivist grounded theory methodology to develop a theoretical understanding of these experiences.
3. To develop ways of enabling health care practitioners to connect with this theory when working with families.
4. To consider strategies to engage communities to consider the significance of this theory and how it can be used to influence the development of culturally sensitive approaches to having end-of-life family conversations.

Design

A subjective and interpretivist approach of constructivist grounded theory using the model developed by Charmaz [31] was chosen to construct a theoretical understanding of people's experiences and perceptions in the form of a descriptive theory. Grounded theory relies on the gathering of rich thick data [32]. Focus groups are the data collection approach for this study because capturing a group discussion provides co-created knowledge by the group than a 'singular truth' about the research question [33].

Population

The study population was people of African or Caribbean heritage living in the UK. The inclusion criteria for the study were:

> *Adults aged over 60 years who identify as of African or Caribbean heritage, live in the UK, and have children or next generation family members over 18 years old.*
>
> *OR*
>
> *Adults over 18 years of age who have a parent or other family member over 60 years old, who identify as of African or Caribbean heritage and live or have lived in the UK.*

Sampling

A purposive approach to sampling was deployed, with potential participants given the opportunity to respond to a call for participants via various means. The research team discussed theoretical sampling following the analysis of data from the third and fourth focus groups. Emerging data indicated there might be gendered influences on perceptions and experiences and some of the older adult child participant's parents who had already died. The decision was taken to capture the voice of younger people who potentially might be having earlier conversations with their parents and to include male voices in focus group 5.

Recruitment

Study recruitment was mainly targeted at communities in South London where there is a high proportion of people from an African or Caribbean heritage. We did not actively recruit people with an established illness, however nor were they participants excluded on that basis. The study was advertised in community settings with posters displayed in churches, a university, a primary school, a shop, and pub in areas with high populations of people from African and Caribbean heritage and a Caribbean Hindu temple. Social media (twitter, Instagram,

Table 1 Types of initial coding

Initial line by line coding using in-vivo coding	he's always said he's prayed and asked that God takes him before
Sensitizing concepts	*Umm no we've not talked about end of life or anything like that*
FG1 process coding	Process code - Trusting *God*

Table 2 The process of coding from initial codes to constructs

Initial codes	Process/ Focused codes	Constructs
friends' parents are dying so we talk about things I talk with mum because her mum needs a lot of care now	Learning by watching	Watching the dying of another prompts conversations

Facebook) were also used to inform people of the study, together with a university research volunteer recruitment circular and an internal organisational Yammer group.

Data collection

The first two focus groups were face-to-face and the last three were online due to the need for social distancing during the COVID- 19 global pandemic [34]. The primary researcher moderated all the focus groups, but a second researcher sat in on the groups as an observer who made notes of what was said and the interactions taking place. Each started with an introductory time of informal socialising to allow participants to meet prior to the focus group. This was more successful in the face-to-face groups than those run online [34].

Participants in the groups discussed the following questions:

1. What do older people from African or Caribbean heritage want to plan for at the end of life?
2. What role do they think their children should play in the decisions about their health care at this stage?
3. How do older people and adult-children within families find talking to each other about end-of-life care planning?

Data analysis

The focus group sessions were recorded and transcribed using data analysis software NVIVO version 12 [35]. Each script was coded using line by line initial coding in-vivo coding using the direct words of the participants which retained the voice and language of the participants through the analytic process [31, 36, 37]. Following this initial coding, the codes were reconsidered using process coding where gerunds or action words are employed to capture the dynamics of the experiences being expressed (Table 1).

Conversation dynamics were also noted and analysed using sociograms [34, 38]. Care was taken to capture what is stressed by participants in the discussion. Wider discussion with the other research team members led to axial codes and category development (Table 2) [31, 37].

Once this was completed for the first two focus groups, initial coding was followed by focused coping where significant or frequent initial codes were considered by the primary researcher (JDS) and researcher observer (KG) along with both the research field notes to see what made most analytic sense for categorising data (Table 2). This process was documented using a Microsoft excel document. This was shared and verbally discussed with the wider research team (CW & YS) along with the initial group transcripts.

The constructs were derived from the categories that reflect the grounded data and a process of reflecting using the processing of memoing to reflect on the ideas as a research team, these are discussed in the results.

Ethical considerations

Careful consideration was given to psychological safety of participants being asked to share personal experiences and perspectives around emotive issues such as the future death of loved ones. All participants received information about the study and at least 48 h to consider whether they wanted to take part. Verbal and written informed consent was obtained. All responses were anonymised, and participant's heritage ethnicity was referred to as African or Caribbean when attached to in vivo quotations to minimise individual attribution. Research ethics committee approval to conduct the study was granted by the research ethics committee at Lancaster University FHMREC18 (August 2019). The study was considered low risk by King's College London and allowed to proceed. In July 2020 a modification request was approved to move data collection online.

Results

Twenty one participants were recruited into 5 focus groups between 2020 and 2023 (Tables 3 and 4). Each focus group lasted between 60 and 90 min.

Developing a theory

Data collection and interpretive synthesis of the data collected led to the development of constructs of a substantive grounded theory of Living and Dying between Cultural Traditions in African & Caribbean Heritage

Table 3 Sample characteristics

Characteristic	Participants ($n=21$)
Gender	M = 2 F = 19
Heritage	Ghana $n=3$ Nigeria $n=4$ Kenya $n=1$ Jamaica = 7 Trinidad = 1 Grenada = 1 Mixed Nigeria/Ghana) = 3 Mixed English/Caribbean = 1
Age – Adult Grandchildren	20–29 $n=3$
Adult-children	30–40 = 0
Elders	40–59 = 14 60–70 = 3 > 70 = 1
Recorded Religion	Christian = 14 Muslim = 1 None recorded = 6

Families. In this theory, the constructs, and related categories of how a family's habitus regarding end-of-life conversations are shaped are presented (Table 5). Being part of multigeneration families who are assimilating into a culture different to the one in which the older people may have been born experiences are a core element reflected.

Analysis of the conversations between the participants suggest that a complex set of life experiences shaped their visible habitus. All the participants had lived in the UK for a substantial period, some were born in the UK. However, their views and experiences of conversations about dying within their families was very connected to both their current life situations and to the practices, values, and beliefs of their heritage countries. They all also experienced a sense of hysteresis [39] or pull between familial cultural norms and practices and the cultural norms of the normative populations in the country in which they now lived (Fig. 1).

The constructs of the theory

Preparing for death but not for dying; We are planners of funerals but not of care

Across cultures many people in older generations prepared for their funerals. In this study several participants spoke of their parents having financial funeral plans, although the older adults did not disclose this. There was an openness around funerals and funeral planning. However, as the groups discussed these financial

Table 4 Focus group participants

Group	Range	Heritage	Context
1	Adult-children between 50-60y 5 women	Ghana, Nigeria, Kenya, Jamaican	Professional women working in one higher education institution but in different roles
2	Older adults, between 65-80y 3 women, 1 man	Ghana, Nigeria, Jamaican	All attending same church
3	Adult-children between 45-60y 6 women	Ghana, Nigeria, Jamaica Grenada	Professional women from a variety of backgrounds
4	Adult-children between 45-55y 4 women	Ghana, Nigeria, Trinidad	3 Professional women, one nonprofessional woman who lived independently but was visually impaired,
5	Adult grandchildren between 28-30y 2 women, 1 man	Ghana, Nigeria, and mixed-race Scotland/ Nigeria	Young professionals

Table 5 Constructs and related categories

	Constructs	Categories
1	Preparing for death but not for dying	We are planners of funerals but not of care
2	Complexity in traditions crosses oceans	Talking about cancer and dying is taboo
3	Living and dying between cultures and traditions	I am a London girl; things are different in Ghana
4	There is culture, gender and there is personality	Intersectional influences on negotiating family decision making, who speaks to whom about what and when
5	Watching the death of another prompts conversations	I talk with mum because her mum needs care now
6	Hysteresis	Inertia and change

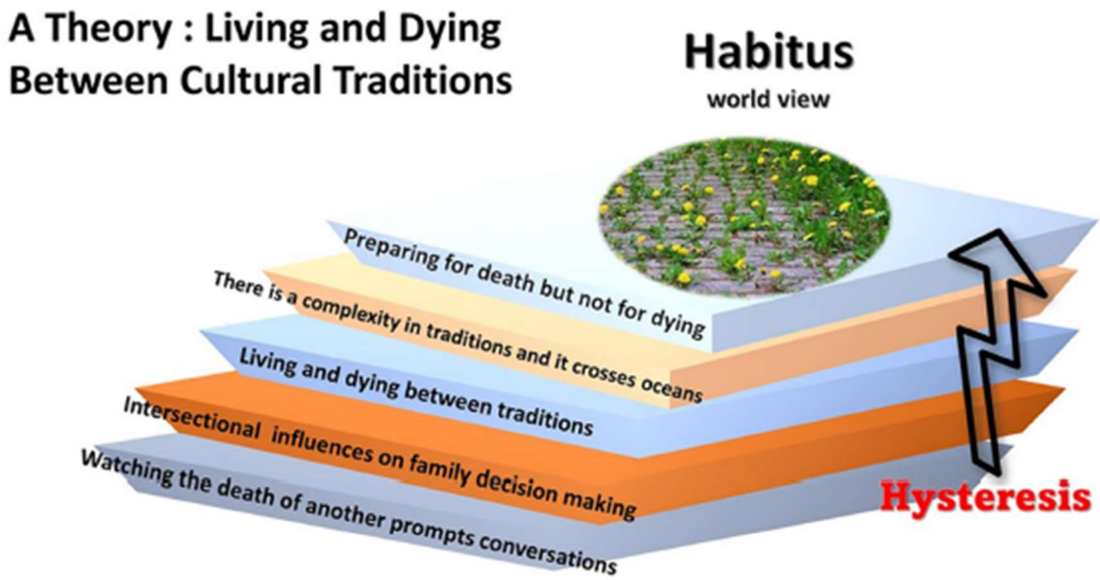

Fig. 1 A conceptual model of the theory of living and dying between cultural traditions

arrangements there was a developing awareness that much of the conversation centres around after death planning. There was agreement that the process of dying was rarely discussed:

> *It feels different in Ghana it seems so public there, there are posters about funerals coming up, people talk about it, funerals and memorials are more about celebrating the life lived than mourning. (Adult child, African)*

> *In Grenada, ... they have big billboards up .... it has a photo of the person and all the family (Adult child, Caribbean).*

> *And we've certainly talked about death and funeral plans and all that sort of thing. But I feel talking about death and dying is still very much taboo and not really spoken about. It is something I would like to visit with mum. (Adult child, African)*

The older adults in the study had great concern about having everything sorted out to reduce the stresses on their children. They spoke about how their children silence conversations:

> *When I do talk to my daughter, I start to say, when I am dying ...she says, no mum don't talk like that.... I feel they are all frightened of losing me...so I don't talk about it because I don't want to upset them, but I make my own plans... (Older Adult child, African).*

These are cultures who have strong open traditions around marking death, visible and shared with the whole community. People are now having to compromise these to fit in with new cultures where funerals are less visible and generally private. The conversational opportunities these intergenerational community funeral events presented are reduced and a fear of talking about the death of a parent results in a hiatus of conversation between one generation and the next.

Complexity in traditions crosses oceans: talking about cancer and dying is taboo in our culture

Part of this lack of discussion about dying and illness may be associated with fear and taboo around serious illnesses and particularly cancer. Many of the participants who shared their family stories, felt this resulted in a lack of open family disclosure:

> *When I was diagnosed, I remember having a discussion with my mother about it. And, you know, the kind of distress it caused meant that I was never, ever able to have a conversation with her again, it was because it was cancer and she was petrified, It was a real shame because, you know... your mom's your confidant (adult child, Caribbean).*

> *My brother has cancer, he and I talk... but we don't talk about it with mum and dad. Dad had the same cancer and now .... so there's a bit of self-preservation with that. (adult child, African)*

This sense of fear and taboo remains strong even when families have been living in the UK for a while. As one participant raised this, others recognised that this was a shared experience:

> *So it's interesting that you're saying that because a close relative of mine who was very ill but didn't say anything and kept it to themselves, I don't know if it's a Caribbean thing.... when you kind of think to yourself, why did I not know, why is it that I'm here in the UK you're over there in Jamaica. Why am I hearing now, right now. Because it's like if I had known I would have been able to go over (adult child, Caribbean).*

This concept has overlaps with the concept of living between traditions (concept 3) and the hysteresis or tension that exists when one cultural practice is very different to another (concept 6). We consider the impact of this on family conversations as we explore the next layers of this constructed theory.

Several participants had experienced serious illness or the death of a younger person within the family. In their discussions they discussed the prevailing funeral tradition of parents not attending the funerals of their children. Although participants discussed how difficult this might have been for the parents concerned there was also an acceptance that this was an important aspect of culture that needed to be respected:

> *That's right, yeah...you know my nephew who died recently, he died over here and it was sudden so although we took him home, his parents never saw him, they did not came to the funeral (Adult child, African).*

> *Yes, I had an older sister who passed but they never saw her and they weren't at the funeral because it is not done (Adult child, Caribbean).*

There were discussions about how experiences caused a change in what people wanted, that this was perhaps a tension for people, and so not openly discussed between family members. Participants, both the older adults and the adult-children spoke about situations where they felt they were *Living and dying between cultures and traditions*: The category of *I am a London girl, things are different in Ghana* indicated this changing perception of who they were and the challenge of what traditions to keep up with and what different ways of doing things may be more in tune with how they currently perceive themselves. Some of the adult-children could see that in their parents as well:

> *I'm very much westernized, a London girl. And in Ghana, things happen differently, there would be many traditions like painting the house and I don't think mum would want that, she'd prefer it painted now while she can enjoy it ...But the one thing ... is.... previously she always said that when she died she... she's talked about....being buried in Ghana. .... there's a family plot or whatever.... But when my sister died, she did make a comment that...if I die either I don't mind being buried here or in Ghana. . (Adult child, African)*

> *My mother bought a house, she had always planned to go back to retire . you know. but my dad he didn't want to leave the grandchildren and everything... (Adult child, African).*

> *And yeah, it's like that that's in my family. That has been the dilemma. One parent wanting to go back and one parent just not wanting to go back ever ... (Adult child, Caribbean).*

Finding themselves part of families with ties to more than one place, each with different sets of rituals and values made the universal experiences of generational change more complex. This is additionally complicated around death rituals which are tied to the marking of respect which is an important value in many cultures.

There is culture, gender and there is personality: who discusses what with whom

Participants acknowledged that conversations about future care preferences were rare in their families both between and within generations. There was an expectation that adult-children would make future care decisions as best they could, without having discussed preferences.

> *I remember from a young age, my mom doesn't say so much now.... You're the youngest and it's your job to look after us when we're old ... (Adult child, African).*

> *So if she becomes less well... what do you think she will want ... well that's going to be my decision. She's.... She's not going to discuss it. ... it's just whatever I decide. That's how it is. (Adult child, Caribbean)*

Parents tried to protect their children from having to feel responsible for them:

> *We don't want to bother them. If we can do something for ourselves, we will do it. sometimes we need*

> *help with this and that, but we don't want to bother them (Older Adult child, African).*

When family members are unwell, care decisions and treatment decision making can be particularly complex when family members are living in different countries, particularly when the older person was unwell and had limited cognition. Some participants spoke about this:

> *Yeah. And I think it's a culture thing, because I remember when I lost my brother and he was in the States. We had to take his body back home. And we were having a conversation about where he was going to get buried and you know... my uncles were at the forefront... we it's like we have no say. (Adult child, African)*

However, as the discussions developed it becomes clear it is much more complex than that, more about proximity and funding.

> *... when my dad died, he was living in the US with my half-sister, she made she made all the decisions ...kind of you know, he was over there. We were over here. oh, my goodness me. it was it was very, very, very, very, very, very tricky (Adult child, Caribbean).*

> *And I think there is a there is a power dynamic going on because frankly, my dad or the siblings who live in the UK they send back money quite often. So . usually they don't look after grandma.... But in terms of making decisions, I think they have a lot of say because it seems like if she... needs to go to the hospital, he(participant's father) gets informed .... (Adult grandchild, African)*

Negotiating and planning and funding when family live in different countries adds layers of complexity to an already emotional and difficult process. Participants spoke of the value of modern communication aids like WhatsApp in helping to negotiate in these challenging times. Participants indicated that WhatsApp allowed all parties to be part of the conversation, including the participant who was visually impaired:

> *Oh, my God, it's amazing. A revolution. It really has. You can make decisions on WhatsApp. You know, ... We were deciding when the headstone for my brother actually this week and the decisions, the discussions were so smooth on WhatsApp. So, it really has helped (Adult child, Caribbean).*

Lastly for several participants being part of these focus groups highlighted for them conversations they had not had but wished they had or would like to have in the future:

> *Yeah. My mom passed quite a while now, 18 years ago, and it was very sudden. So, there was no conversation with regards to what was going to happen. And we didn't know what conversation she had with the family there..., that she wanted to be buried in Ghana. So, it was a compromise, she was buried in Nigeria so she could be beside my dad, I still kind of feel bad about it because that was a wish and it wasn't actually done (Adult child, African).*

> *It concerns me now that we're talking about it, that I hadn't had that conversation with my sister myself (Adult child, Caribbean).*

As part of the theoretical sampling the final focus group was with younger people who had living grandparents. Analysis of their reflections along with the previous conversations with adult-children and older people resulted in this final concept: *Watching the death of another prompts conversations: I talk with mum because her mum needs care now.* So much of what individuals do is borne out of the way in which they have been culturally nurtured and develops from watching role models such as parents or other aspirational societal members. Watching a family member, a friend or a friend's parents go through life events like dying, often stimulated conversations about what went well, what was difficult and perhaps what they would want for themselves or their parents when they die.

> *I think you don't realise just how much care someone elderly can need unless you're in the scenario of caring for them ...So mum and I ... we have had that conversation recently, but before my grandma needed so much care, we'd never had that conversation (Adult grandchild, Caribbean).*

Many of the older people and adult-children in this study had been living in another country when their parents or grandparents had died. The impact of this was that they saw only a glimpse of what went on, resulting in a loss of an opportunity to reflect on how it may be for them when they were dying:

> *Yes, mum was often in Ghana, she went to look after him .... But I didn't go (Adult child, African).*

People of the generation who are now approaching the end of life themselves and their adult-children have often only had fragmented opportunities to be present at the deathbeds of the generations before them. This rehearsal and potential opportunity to consider what they may want for themselves if in a similar situation and to discuss this with other family members around the death bed has been lost.

Hysteresis; Inertia and change Threaded through all the concepts of this theory, is the concept of hysteresis [40]. Hysteresis describes the lag or a miss-alignment in cultural values as part of the process of cultural adaptation [41, 42]. As families assimilate into new cultures there is a tension between what holds, in terms of existing values, beliefs, and rituals and what changes. This tension is sometimes shaped by the power dynamics of both the heritage communities, the host culture or how cultural and symbolic capital is distributed [43].

Captured in the layers of cultural experiences was a sense of change, either between participants and their parents or children or even within their own experiences over time. When there are limited conversations between people and a lack of cultural curiosity into the perceptions of others [44], particularly amongst health care professionals, this cross cutting concept of hysteresis and differences in the way experiences are experienced and understood can be hidden.

Discussion

This study uses an inductive focus group approach to explore the perspectives of older adults and adult-children of African and Caribbean heritage on having family conversations about end-of-life preferences. A constructivist grounded theory approach was taken to analyse the empirical data collected and to construct a theory of living and dying between cultural traditions in African and Caribbean heritage communities. There is a focus on the perspectives of adult-children, as at the very end of life adult-children are often the end-of-life decision makers for their parents in these communities, and the use of advance care planning is low. The goal of this theory construction is to promote a deeper understanding for health and social care professionals, of the complex underpinnings of diverse cultural perspectives and how experiences of migration impact planning and discussing of key social processes such as aging and dying. Cultural practices become particularly important at significant times such as approaching the end of life (Fig. 1).

Oscillating values and preferences create tensions [21, 41, 42]. Norms and values of the cultures in which people are currently living sometimes jar with those of their heritage cultures. Families are forced to seek ways of living between these tensions. There is a sense of hysteresis or 'being pulled between' as families navigate illness and dying when family members live in different places in the world [8, 9]. Often it is simply who lives where that determines who makes the decisions. Geographical location influences the role family members play in making the healthcare decisions when an older family member is coming towards the end of life, for example being the provider of care or being the provider of the means with which to buy the care. Some traditions and cultural practices are cultural assets [6], such as the of openness experienced in both African and Caribbean cultures around funeral planning and celebration. Even for families where whole generations have been born in their country of residence, migration has an impact on cultural learning about death and dying which results in them choosing a different approach to engage in planning for the end of life.

An openness about families attending community funerals and so the exposure to burial rituals throughout the life course is a positive aspect and a cultural asset [6] of both African and Caribbean culture that was celebrated by the study participants. It is on such occasions people are exposed to cultural norms, values and rituals. These multigenerational events offer opportunities for conversations around family practices and plans. Funeral planning is one of these opportunities. More interventional research is needed to embrace the opportunities to think and plan around people's own values and end-of-life preferences when attending the funerals of others. Co-produced research with both funeral directors and faith leaders who conduct funerals maybe helpful to consider how both discussing care preferences with family could be part of funeral planning [6, 45, 46].

A new concept constructed from the findings of this study is 'watching the death of another prompts conversations'. A younger participant in the study spoke of how watching her mother care for her grandmother provided an opportunity to discuss her mother's own preferences. Both the participant and her mother had not realised how complex end-of-life care decision making can be before this experience. Many participants in the study talked of grandparents who died abroad, making that process 'invisible ' [47]. Both the older adults living in the UK and their children had limited opportunities of learning-by-watching either in person or vicariously, how the dying of older generations looks and is managed. This has a major impact on their learning about what decisions need to be made when.

Health care professionals' understanding of this phenomenon, can help them to have greater insight into why dying maybe a taboo for a generation who have missed observing older generations dying. Offering more information about what the dying process and decisions that will need to be made early in discussions about deteriorating illnesses is helpful for most relatives of the dying, however exploring previous experiences and being sensitive to the impact of migration histories on these displays cultural insight. Promoting discussion around decisions, and being a compassionate companion on this new road, can help to provide a space where individuals and families can think and talk about decisions before they need to be made. These are often complex family discussions [42, 48].

Study participants valued the way that WhatsApp Messenger family groups (mobile phone encrypted instant messaging service) facilitated family communication. Many migrant families, now split and living in different geographical places, use social media forums to navigate and communicate complex decisions around burial practices and end-of-life decision making for the seriously ill. This is an area that needs development in palliative care to harness a wealth of opportunities for all communities. Encouragement to use sharing platforms like WhatsApp to enable open discussions maybe helpful when families reside in different locations.

Most of the adult-children participants in our study had experienced the death of a sibling, had a sibling facing a serious illness such as cancer or had experienced a life threatening illness themselves. These are important learning experiences that may leave difficult legacies. Like previous studies, participants discussed how some family members, particularly elders, continued to hold cultural values and beliefs, some fuelled by high levels of religiosity, that resulted in stigma and fear of being associated with cancer [15, 42, 49, 50]. The adult-child participants felt caught in a hysteresis where felt they could only have more open illness related conversations between themselves, but not with older relatives for whom it was taboo [43]. Such cultural positioning is not easy to change or to navigate for families. This creates an element of collusion that can be stressful for all involved. Adult-children may appear 'difficult' when trying to manage the fears of their parents or their own fears of losing a parent to the sometimes naïve or ethnocentric health care professional who is foisting a culturally foreign approach to care. A sensitive approach is required to enable more open conversations in a way that retains respect for cultural values recognising the need to understand family histories and migration experiences [42]. Migration leads to hysteresis, pulling between different cultures, where some aspects of heritage cultures are celebrated and retained, but other aspects lead to tensions and mixed expectations, little of which is discussed openly within families or with health and social care professionals. The fracturing of observed and lived experiences of caring for dying people because of migration has an impact on the planning and preparation for dying of the first-generation immigrants and their children.

Much of the existing literature exploring the perspectives of minority ethnic heritage groups focuses on barriers and suggests that language issues and a lack of health literacy cause a reluctance to engage with a normative idea of palliative care and advance care planning developed in majority white non migratory populations. Our study uncovers a much wider complexity of different life experiences from which people develop a habitus or world-view from which they approach subjects such as end-of-life family conversations and decisions making. Exploring and understanding these can be fundamentally important when working with families going facing loss.

Implications for practice

There is a growing awareness of the impact of structural racism in palliative care [3, 10, 42]. This includes ongoing racial attitudes in the form of symbolic and social violence [51, 52] such as when the expectations developed by one community can be imposed on another reducing access and equality of experiences of healthcare when dying. Greater recognition is needed of the need to shift to a new order of palliative care and related ideas that recognises the need for intersectional structural change and a diversity of approaches that embrace a wider set of cultural ideas [6, 53, 54].

New relational and more individually nuanced models of palliative care are emerging with a focus on communities as sources of invaluable support [55, 56]. For health care professionals working with people with deteriorating health conditions, the need to recognise the role of adult-children in end-of-life decision making, particularly in many African and Caribbean heritage families, is imperative. The findings of this study provides further evidence to the calls to develop more family centred models of advance care planning [6, 12, 57]. Enabling opportunities for better family discussions around end-of-life preferences may help to break down the fears of both adult-children and their parents of burdening the other. All health care professionals working with people with life threatening conditions need to facilitate a better awareness by a range of family members of end-of-life illness processes and the decisions that may need to make in the future, as part of early care planning.

Finding ways of increasing community engagement with dying that perhaps has been lost as funerals become more private events may be useful to explore. Engaging with wider societal influencers such as authors and film makers to ensure dying is included in mainstream depictions of life and opportunities are made to consider and discuss these before the time arrives for families to be making these decisions in acute situations [58].

Clinicians need to offer culturally competent care. First steps in achieving this is having a cultural curiosity, and cultural humility. Knowledge and understanding of the world views of others makes it easier to communicate and reduces potential fear of things that feel different [59]. Exploration of previous serious illness and death experiences allows the clinician to build on these.

Advance care planning may need to include consideration of the complex needs of families living in different countries.

Implications for future research

Exploring different voices helps to create a wider understanding of how different communities interact and their perceptions about the value and nature of family conversations concerning end-of-life preferences. Despite active attempts, this study failed recruit many male participants, further research is required to understand how men in these communities' experience end of life care and decision making.

To enhance advance care planning at the end of life, it is crucial to conduct further research that builds upon these new insights and explores the best ways to facilitate open conversations for older adults and their families. This should include developing strategies that address the specific emotional, cultural, and communication barriers they face, ensuring that their preferences and values are respected and integrated into care plans.

Limitations of this study

This was the first study to explore the voices of people of African and Caribbean heritage living in the UK on this topic of end-of-life family conversations and the generosity of their disclosures and insights offers a rich picture into their experiences. This is a small snapshot of a much larger complex process of living and functioning in society where social capitals influence experiences. The insights gained in this study came from people who felt able to discuss issues such as end-of-life conversations. There was a lack of sociological variation, nearly all the participants were graduates and there only two men in the sample. Designing and conducting a study feels accessible for people from a broader spread of society would offer greater insights and possible new ways of working in this area of end-of-life family conversations and general death anxiety.

In conclusion, this grounded theory of living and dying between cultural traditions promotes an understanding of the impact of the migration identities of people of African and Caribbean heritage that are formed around having end-of-life conversations within families. This understanding is helpful in developing new approaches to the practice of palliative care and communication approaches which work better for a culturally diverse population.

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Author contributions

JDS (PhD student) & CW, YS, (PhD supervisors) KG (co-researcher) worked together on the design of this project. JDS & KG conducted the focus groups for the study. JDS analysed and interpreted the patient data in discussion with CW, YS, KG. JDS wrote the main manuscript. All authors edited and approved the final manuscripts.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethical approval and consent to participate

Approval to conduct the study was obtained by the research ethics committee at Lancaster University FHMREC18 (August 2019) and King's College London where the study was considered low risk and allowed to proceed. FHMREC18 amended to allow online focus groups (July 2020). All participants gave verbal and written informed consent to participate in the study. Details of measures taken to support participants for any distress caused by discussing difficult topics such as dying were outlined in the study ethics proposal.

Consent for publication

Consent for publication has been gained from all authors CW, YS, KG and JDS. No other materials used in this publication so consent to publish is 'Not Applicable'.

Ethical guidelines

This research has been performed in accordance with the Declaration of Helsinki. Participant information outlined how anonymity will be maintained in project outputs. The process of data storage and disposal were also outlined.

Competing interests

The authors declare no competing interests.

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Publisher's Note

7.1 Reflections on presenting the study as a presentation and in Paper 4

I was delighted and daunted to be selected to present the summary of my study, which is now published as Paper 4, as an oral presentation at the European Association of Palliative Care in Rotterdam in May 2023 (Appendix 5). This experience made me focus on my work and think about what its major findings were and how to convey them to an audience. It also made me think about the potential impact of these findings. The audience at the conference was mainly healthcare professionals and other parties interested in palliative care, with a focus this year on reducing inequalities. My work fitted well with the conference focus and with the motivations of many of the conference participants.

I presented my study as one of five in a group. Afterwards there was an interesting discussion about the experiences voiced by the participants in the study and the insights that the study offered for people from different cultural backgrounds. This positive reception to the work was encouraging. Since that presentation, I have presented the work at a forum of general medical practitioners in Lambeth in south London. Once the work had been published, I began presenting it as part of my teaching in palliative care to various groups of pre- and post-registration nursing students. I find that in the classroom the paper and the theory always promote reflective discussions for nurses about how it is in their own families. We then move on to talking about what they observe with their patients. Developing this awareness of the depth of what shapes people’s experiences is, I feel, what is so valuable about the use of theory in education. Creating opportunities to develop insight and attitudinal change is a fundamental aspect of my teaching with nurses who are so often on the front line of working with families when facing times of end-of-life decision making.

7.2 Quality appraisal: evaluation of the use of this construction of a grounded theory

Pursuit of quality in qualitative research has been progressively developed, and now quality appraisal tools exist around most qualitative approaches (Charmaz, 2014; Charmaz & Thornberg, 2021; Denzin et al., 2023). Charmaz (2017) would argue that grounded theory research is in itself a useful technique with which to conduct critical qualitative enquiry as the technique consists of asking probing questions of the data and its contexts, the researcher's interpretations and the research process itself. However, to seek clarity on the quality of an individual study, Charmaz (2014, 2021) suggests that the quality of a constructivist grounded theory can be measured using these quality criteria: credibility, originality, resonance and usefulness (Table 8).

Table 8: Quality indicators of constructivist ground theory research

Credibility	Can be assessed looking at prolonged engagement, persistent observation, peer debriefing, negative case analysis, progressive subjectivity and member checks
Originality	Offering new insights, fresh conceptualisation of a recognised problem
Resonance	Constructed concepts represent research participants' experiences and provides insight to others' abstract understanding
Usefulness	Clarifying participants' understanding of their everyday lives, foundation for policy and practice, contributing to new lines of research

This section is a critique of the development of the theory of living and dying across cultural traditions against these four criteria through a reflective account of the guiding principles that are promoted by the constructors of the constructivist grounded theory method to reach a valid or credible theory useful for developing practice.

Credibility

This study has captured a range of perspectives in the focus groups of people from African and Caribbean heritage living in the UK around this topic of end-of-life conversations. It is good to be able to add the new perspectives this voice brings to the existing narratives on this topic. To assess a study's credibility, the data needs to give the reader a full picture of the data so they could almost feel they are hearing it (Glaser & Strauss, 2017). Although the results of the study are contained in paper 4, the word count on the paper restricted the level of detail that could be given to illustrate the findings. More detail is given of these in chapter 6 in an attempt to enable that immersive experience for the reader of the data. This credibility was also evident within the focus groups. All the participants of the focus groups valued the opportunity to discuss this topic. Several commented on how useful it was to hear the perspectives of others and how this often resonated with their own experiences, although they had not articulated it before. Recruitment techniques resulted in a broad mix of participants in terms of age, occupation and life situations. This brought a richness to the discussions.

Credibility begins with having sufficient relevant data to ask incisive questions about the data, making systematic comparisons throughout the research process, and developing a thorough analysis (Charmaz & Thornberg, 2021). Constructivist grounded theory requires strong reflexivity throughout the research process. This means researchers must explicate their taken-for-granted assumptions, which requires acquisition of 'methodological self-consciousness' (Charmaz, 2017) on how hidden beliefs can enter the research process.

Near the start of this study, considerable time was spent in understanding my ontological and epistemological perspectives (Figure 4). Chapter 1, the storyboard in Figure 1, chapter 4 and the concept analysis in Paper 2 were attempts to be transparent and self-aware of the assumptions and understanding I had on the experiences being explored with participants. This transparency is also important when reading the theory, as both assumptions and world views influence the way in which the world of others is interpreted by the researcher.

When the work taking place in this study has been presented, it has been well received with good relevant questions. Each aspect has been illustrated with some quotes to help illuminate the constructs. When picking quotations to use to illustrate points, an attempt has been made to give enough of what was being said to give it some context. Quotations have been used in both Papers 3 and 4. Some in vivo voice was used in the final theoretical concepts.

Originality

Originality can take varied forms such as offering new insights, providing a fresh conceptualisation of a recognised problem and establishing the significance of the analysis (Charmaz & Thornberg, 2021). The concept analysis in Paper 2 was an attempt to explore some of the underlying assumptions and dynamics that exist in this field. This started the approach of looking at things differently. The topic of adult children as surrogates in African and Caribbean heritage communities has not been well explored. This study offers a number of new insights in this area. This theory offers a new level of detail in the experiences of people, understanding this detail and how people frame their experiences is an original contribution to this field.

Resonance

Several audience members have come to speak to me after sessions to reflect on aspects that resonate with their own experiences. Reading related concurrent studies, for example by Islam and colleagues (Islam et al., 2023), illustrates the importance and relevance of these findings.

Usefulness

The initial meta-ethnography has proven useful to many based on the number of reads and citations. Bringing forward the opportunity to deliberate and discuss both the question of having end-of-life family conversations and then the concepts illuminated by the theory created, has enabled study participants and audience members to consider the part they have sometimes played in either shutting down these types of conversations or in missing cues when they have arisen. Participants and audience members have also felt empowered to consider raising these issues with their families in a change from how they may have felt prior to exposure to the study materials and the theory.

My work exploring the dynamics of conversations within a focus group in Paper 3 has also had a lot of interest. The unexpected consequence of the changes required by the Covid pandemic led to an opportunity to explore this aspect of data collection. Adding clarity to how to gain this insight has been a useful addition to established data collection practice.

The wider usefulness of the theory is still to be developed following the completion of this PhD, as wider dissemination and its use provides a springboard for further work in this area. The next chapter explores in more detail the contribution of this theory to existing knowledge and potential future impact and developments.

Chapter 8: Reflexivity

8.1. A Reflexive account of this PhD journey

Prior to the final discussion chapter of this thesis, in this chapter, I outline my reflexive experiences as a developing researcher and academic writer in undertaking this PhD study. Having chosen to do an alternate format PhD thesis presentation, my final paper, chapter 7, offers a summary of my completed study including a discussion of my findings. So, when writing my integrated discussion chapter, chapter 9, it has become more reflective and contemplative than perhaps a traditional discussion chapter would be in a traditional format PhD. As part of most relativist research methodologies, it is important to offer a detailed reflexive discussion of what has influenced this study, and the decisions that were made in its conduct. I have decided to place this chapter here before going into the final integrated discussion chapter which looks at the work that has been done and where next, and what questions are still unanswered.

I started my reflexive account in chapter 1 exploring my original motivations for this study. There are further elements of reflexivity through the thesis. In this chapter I have tried to revisit the influences I feel may have shaped how I went about this study and have then influenced how I have made decisions through this PhD journey. I reflect on what my motivations were and acknowledge how this has influenced the aspects I have included in chapter 9, the final integrated discussion of this PhD study.

What is reflexivity?

The main purpose of reflexivity is for acknowledging subjectivity (Olmos-Vega et al., 2023). Reflexivity explains, elaborates and deliberates the way new knowledge is constructed (Davis, 2020). Reflexivity in qualitative research is a way of making explicit the assumptions, the interactions, the emotions and the subsequent the thinking that have shaped the research process. By critically capturing the processes of decision making around the methods of data collection, analysis and theorisation, reflexivity makes the research process as well as the research decisions transparent and rigorous (Palaganas et al., 2017). Bourdieu cautions against confusing reflexivity with simply reflection which he saw as narcissistic but saw reflexivity as making the study of the researcher and the research domain an equally important part of the research process as studying the study participants, a process he describes as participant objectivation (Grenfell, 2014). To reflexively explore this PhD project the guide proposed by Olmos-Vega et al. (2023) will be utilised. They suggest the following 5 areas of reflexive exploration: personal, interpersonal, methodological, and contextual reflexivity.

8.2. Personal exploration

8.2.1 Personal exploration of developing my understanding of ontology, epistemology and methodology

In chapter 4 of this thesis, I start to explore my ontology and epistemology therefore the ontology and epistemology within which this study was situated. Early on my PhD journey I undertook a module in the philosophy of research, and I read widely in this area. I learnt through this PhD process to name my positionality. I have a relativist ontological belief where what I understand of reality is that we exist socially in relation to others and that our social reality is created through our relationships with others and ideas from others about what the world is and how it operates (Wacquant & Bourdieu, 1992). My epistemology is that from my perspective, this knowledge about the world is something people co-create and one in which knowledge always has a social perspective and so knowledge is never finite and absolute. This extends to an understanding that when knowledge is created through research there are always social impacts on that process that stem from the way in which the world is perceived by the researchers. This influences their methodology even if they are using a quantitative, and what may colloquially be called, scientific research. Their previous knowledge and understanding of the world will influence all the choices made in their research even though work is done to try and minimise those biases.

One of the important aspects of social research, is the recognition of that influence we as the researchers, and all involved in the research exercise, have on the way the study is conducted and most importantly the way in which the data collected is analysed and managed (Gilbert & Stoneman, 2015). In social constructivist research methodologies, rather than seeing this as a bias, researchers are reminded about the importance of being explicit about the positionality of the researcher, teams and methods so that this is offered as part of the research process rather than making attempts to minimise its impact. It is important in this process to recognise the power dynamics that arise from different positionalities and how this may impact on the research process being undertaken (Bourdieu & Nice, 1977). In both the epistemology or methodologies of Bourdieu from his very early work in 1958 (Grenfell & Lebaron, 2014) and Charmaz in her first exploration of her constructivist grounded theory in 2006 (Charmaz, 2014), describe this process of exploring this positionality through a process of reflexivity (Davis, 2020).

8.2.2. A Personal exploration of positionality in this research area

I start with specifying my personal position and approach to this PhD process (Gentles et al., 2014). How has my personal or professional history influenced my choice of topic and how do my gender, culture and professional and personal background influence my positioning in the research process when choosing a methodology and collecting and analysing data (Davis, 2020; Patnaik, 2013)?

The other people involved in this PhD included my PhD supervisors Catherine Walshe, Katherine Froggatt, Yakubu Salifu and my colleague Karen Gillett, who helped me with data collection and conversational support around some aspects of my study, and the study participants. It is important to consider something of how my positionality impacted on my relationships and interactions with them through a process of interpersonal reflexivity and consideration of power dynamics.

My positioning in the field needs to be considered through several positions I hold. I feel like the most influential ones are my family background and up bringing, my role as a nurse and educator in palliative care and lastly being a member of a multicultural community in South London, so I will explore how I feel these positions shape my world view.

8.2.3. Ethnicity and race are complex things

I am the adult child of parents who are now elderly themselves and are of different ethnicities. I was born and brought up in Kenya. My father is a Kenyan Asian university lecturer, he met my mother, a nurse, who is white British, while he was studying in the UK. Although from different cultures, they and all my family are of the Christian faith. After they married, they moved back to Kenya, where my father's parents lived, where I was born and went to school at an ethnically and religiously mixed catholic school. I moved to live with my mother's parents in the UK at the age of 15 and enrolled in an almost entirely white local school, as my father was based in a German University on a year's sabbatical leave. I decided to stay with my grandparents, who were entering their 80's and needed a little care, when my parents returned to Kenya after the sabbatical. I lived with them for three years and then moved to London to study, their home was my main place of residence until they died just after I completed my nursing degree. I have lived in the UK since then, aside from short periods of living abroad.

I would say I lived my life between three cultures, English culture via my mother and her family, East African Asian culture via my father and as a Kenyan citizen. Society in Kenya as I grew up, was divided more by skin colour than named ethnicities, all white people were colloquially known as Europeans or 'mzungu's ', all brown people including myself were termed 'mhindi's 'and black people as wanawatu (or the people). I, as a person with a brown skin, did not at school, have the social permission to consider myself as either European or African. I had to be 'Indian'. Subsequently I feel that many of my life experiences involving other people have been shaped by the colour of my skin as it is such a visible identifier. In the main for myself, these have not been negative experiences, it is just life as I have always known it. As a result, although I am acutely aware of differences between individual nations and subcultures within them, I broadly see the world as operating in these three fields of white, brown and black, with religion subcultures being as strong a cultural definer as colour. Although I came from a practicing Christian home, the middle-class society I grew up in was culturally and religiously mixed, mainly Christian, Hindu and Muslim.

8.2.4. 1st type of bias - Personal family experience of dying

My paternal grandfather, whom I had grown up with, died in Kenya after I had moved to England and so I was not there for his final illness, death and funeral. My paternal grandmother then moved back to India and died there where I had intermittent involvement, via fleeting visits, to help my father organise home care for her. I was the main carer for my mother's parents in their later years. They both died in the year I turned 22 at ages 84 and 86. I watched my grandparents as they experienced the ailments of older age including cancer, its treatments and the resultant morbidities. My only aunt lived a few hours away in the west of England, and visited regularly, and my mother visited yearly from Kenya. Towards the ends of their lives, I attended hospital and outpatient visits with them and helped them mull over treatment choices. I was relatively well positioned for this having worked for a year in a local hospice after completing sixth form college and was then undertaking a degree in nursing. Near the end I was very aware of the dynamics between my aunt, my mother and my grandparents about what was best and what different people wanted. I saw my grandparents revert from being active life decision makers to taking on a sick role when with their daughters. My mother and aunt saw my grandparents as frail elderly people who had lost the capacity to make real decisions about themselves, and so felt they needed to become their decision-makers. I occasionally found myself having to advocate for my grandparents' autonomy in family conversations. It was a tricky time. However, we enabled my grandad to die at home with both my mum and aunt present. My grandmother died three months later after a short spell in hospital. The end of their lives fulfilled many of the components of a good death (Meier et al., 2016).

As an immigrant to the UK, I was in the unusual situation of being present for the last years of my maternal grandparents' lives. This early start in being involved in end-of-life decision making has been something that has influenced my habitus and given me some cultural capital in this arena. Although I am mixed race and have exposure to both Goan Kenyan family dynamics and white British ones, my approach to my working life is one where I value openness in a person-centred way and a sense of the value of family as an integral part of the caring team.

8.2.5. My position as a palliative care nurse and educator in a multicultural society

As a nurse I specialised first in oncology/haematology as a bone marrow transplant co-ordinator, and then in community palliative care where I worked as community Clinical Nurse Specialist in London and New Zealand. I have always had an interest in haematological palliative care. There are often complex relationships between palliative care teams and haematologists. There can be a belief in palliative care teams that haematologists are late referrers to palliative care. I knew from my working experiences, that haematologists often have very close relationships with their patients built over time, and they themselves often grapple with how to decide when interventions no longer offer symptomatic relief. My habitus is hugely influenced by working as a nurse who has cared for people dying both during intensive treatments, often surrounded by highly distressed relatives, and dying at home out of choice with family playing a major role and often peaceful. As a result of these experiences, I favour open conversations and reducing instrumental medicalised interventional care for people to only have interventions that can improve their symptom control and enable more peaceful dying. I feel that for myself I do not fear death as a consequence of a deteriorating illness but see it as a natural part of human development.

Working in different areas in London meant I often worked with patients and families of different ethnic heritage. I live in an area of south London where there are large communities of different African heritage and from the various Caribbean islands. As an active member of both a multicultural Christian church and several multicultural Christian school communities, I have friends and neighbours from a variety of ethnic backgrounds and religious faiths.

Lastly, I have been involved in a range of international education activities in Singapore, China and Somaliland, often in palliative care. All these countries have different approaches to how end-of-life care is managed, and through my work in teaching, I have learnt something about these approaches, but also the experiences of nurses working in areas where death is something feared, seen as failure, and little spoken about in professional settings. In Somaliland particularly, religiosity is a strong factor shared by all I met, and a belief that death is something only in Allah's control and he chooses up to the last moment when or if someone will die. Any kind of preparatory conversations around end-of-life are considered haram (blasphemous).

These different professional experiences leave me with a habitus that is much more familiar with dying than perhaps a non-health care professional person in my position would be. It has also left me with a bias to favour openness at the end of life, to see dying as a societal event not to be feared but to be mourned, as death is inevitable but sad as it involves the loss of close family relationships. I see health care professionals as people who can have skills that help people and their families to understand their deteriorating health and to start to prepare for the process of dying.

8.2.6. Third type of bias - Intellectual bias (Bourdieu)

My education as a nurse has been most influenced by the positivist nature of much evidenced based health care. Within that field I have worked as a nurse and run modules in research methods where positivist methods such as random controlled trials and ways of controlling any variability are held up with the most esteem. These fields have often been led by medical practitioners. I have always had an interest in the social and political sciences, where in healthcare, nurses often play a more leading role. My MSc research was a qualitative exploration of the social support needs of men caring for their wives who were dying. I also run a social science in nursing module partnered with two different sociologists during the life of the module. It was through these colleagues I had my introduction to Bourdieu and others such as Foucault and Giddens. The idea of viewing the world through a social relational lens has long been something I felt comfortable with. I only have a small understanding of the grand sociological theories, so trying to develop an understanding of the theoretical underpinning of a research study was a challenge for me. I feel professionally I live between these positivist and relativist worlds which are fraught with professional and gendered power relationships and social and symbolic capitals. Having always been conscious of the power dynamic and power play that exist in healthcare, I was interested to explore how these influence family dynamics in different cultural communities and its impact on decision making.

8.3. Interpersonal Reflexivity:

8.3.1. Power

To consider the power relationships that influenced this research, I need to consider how my position as a nurse, with this background, influenced the relationships I have had within this study. Firstly, with my supervisors, and subsequently with the participants of the study. What roles did I play within the study and what were the power dynamics at play?

Being a lecturer myself who had experience of supervising MSc students brought me some social power into my experience as a PhD student. I was familiar with some of the doxa and knew some of the mechanisms of a university and its operations at PhD level. I have several colleagues who have either undertaken a PhD before or were undertaking theirs at the same time as I was. This helped me I feel to have a reduced sense of imposter syndrome that is common amongst PhD students. I also feel my role as an academic helped my relationship with my supervisors as although I highly respected them as expert researchers in palliative care, I was also working as a research supervisor in post graduate health care so for me there was some balancing out of the power relationships. I found their positions as nurse researchers particularly inspiring and advantageous, both Catherine and Katherine had extensive palliative care research portfolios so their guidance through the research development was helpful. When Katherine Froggatt retired, Yakubu Salifu became my new supervisor, he also brought with him research experience but also the lived experience of being part of an African family with family members both here and in his home country of Ghana. It became helpful to have his perspective on things, and he often resonated with the themes and categories I was developing through the data.

My lecturing colleague Karen Gillett is also a palliative care lecturer, and we had a close working relationship. She had experience of running focus groups so was happy to help out by being a critical friend and to be the observer and co-facilitator of my focus groups. After each focus group we met to discuss both the dynamics she had noted as the focus group observer but also some of my provisional thoughts around the data I had started analysing, having transcribed the focus group conversations. I was able to annotate the printed scripts with some of those noted interactions. This was a useful contribution to the analysis process but also particularly useful when I was writing the third paper of the PhD in which I specifically explored the conversation dynamics within the focus groups.

As a lecturer and a nurse, I am experienced in discussing palliative care topics with many different groups of people. I run large and small group discussions as my job, and I have worked with adult and child patients who are dying and their families. I have done this with people from a wide variety of cultures and managed a wide variation of reactions to these activities. Going into the focus groups this gave me some confidence both on how to initiate these conversations and made me feel confident about being able to support the participants with the groups. I came into the study with a real familiarity with the topic.

I was recruiting people both who may not be familiar with talking about this topic and for whom PhD level study was not necessarily familiar but was in the main held in high esteem which I knew could raise new and different power dynamic issues. In the sessions I presented myself as nurse lecturer. I did not mention my own ethnicity, but I did put a picture on the participant information form, and I have an Indian/European sounding surname. I think this gave me some currency as an insider as most participants knew after talking to them that I was an adult child of elderly parents of mixed heritage. However, I doubt if I was seen by many as being of African or Caribbean heritage. I am not sure if this impacted on the flow on conversations within most of the groups as once rapport was developed, conversations seemed to flow quite smoothly, and often I was able to identify with aspects of the experiences they were describing. Some participants did say things like,” well in our culture …”. giving me the feeling they were sharing views they felt were tied into their culture that they were sharing with me as someone not of that culture. The two participants from Kenya said things like …you know how it is in Kenya …occasionally, acknowledging some of our shared history.

The dynamics in the final group where the participants were significantly younger than me did feel different and I felt much less an insider and rather than being part of a conversation of shared experiences, it felt much more they were describing experiences from a perspective quite different to my own. This resulted in a less easy conversation, however I feel, as discussed in chapter 7, this was more about the dynamic of being in a small group online, than the age differences.

8.3.2. Othering

One aspect of analysis of this research data and the process of abstraction I struggled with was how not to ‘other’ both older people and people of diverse ethnicities. There is often a tendency to write in the deficit and a failure to highlight strengths (Koffman et al., 2023; Sanders et al., 2018; Zubair & Norris, 2015). I became very conscious of this when revising my coding processes and developing my conceptual categories. I made a concerted effort to watch the language I used when writing. Several of the participants of the study were women of a similar age to me, and nearly all the participants were or had been, working professionals. This resulted in my being able to easily identify them as people not too dissimilar to myself, so I found that helpful in terms of writing about their experiences.

Having explored my positionality in the design and conduct of this study, the next section is a reflexive exploration of some of methodological decisions that I made as part of this study.

8.4 Methodological Reflexivity

8.4.1. Starting out

This desire to conduct this research was one the elements that influenced my move to taking a job in a research-intensive institution of higher education. I had done a research assistant post for a nurse researcher there previously in my career and I had been impressed with the research culture that existed, regular journal club, research methodology meetings etc. When I returned as a teacher it was not so easy to access those aspects of the institution. Any endeavours I took to start on this research PhD journey were hampered as I had not yet developed a research proposal, I was always told I needed to do that first before anyone could help me, I struggled to really know where to start so it got put on a back burner and I was not able to make progress with obtaining external funding.

Finally in 2015 a colleague who was doing the taught palliative care PhD at Lancaster assisted me to put some ideas on paper and following the conduct of a brief literature review in the area, I approached Katherine Froggatt, an ex-colleague now at Lancaster who I know had written on the topic of palliative care and ethnicity. Her positivity was very encouraging. She accepted me onto the research program. I was particularly interested in a paper written by one of her PhD students on asset-based co-design. At this stage as funding was not available to me via my own institution, I made the decision to self-fund this PhD and to conduct it mainly within my own time.

During this time, I attended a conference in oncology nursing where I presented my initial literature search on the topic. While I was there, I attended a session of other nurses undertaking PHD's. many from northern Europe where several were doing alternate format PHD's as they are known in the UK (de Souza & Gillett, 2025). It was interesting to see how these nurses had published their work as they progressed through their PhD. Working in a university , I had a number of nurse colleagues who had completed PhD's but had really struggled to complete their post PHD publications and this was a matter of some concern both for them as it had resulted in little dissemination of their work and it was also a skill that they still had to learn having already studies for an extended period of time. It also reduced the symbolic value of their PhD's within the institution. I was inspired to try and complete my publications as I moved through my PhD. Something I have learnt comes with many challenges.

During the course of this 7 year PhD, I met with my supervisors at approximately six weekly intervals, prior to the meeting I would try and send them a meeting agenda and reflect on both what had been previously discussed and my ongoing progress with the study and decisions that had to be made both about study structure but about data analysis and theory constructions as the study progressed. Alongside these I kept a reflective research diary. I also wrote memos on significant meetings with others and aspects of the research journey.

8.4.2. Exploring researcher influences on research design and decisions -Learning through PhD level study

In the first year of my PhD, I had to learn a whole new language around ontologies, epistemologies and then methodologies. I found this an incredible challenge, and it was here I first experienced as sense of imposter syndrome. As I read and developed my ideas, it provided for me a confirmation that this investment of my own time and money was worthwhile as this new knowledge helped me develop a much more enlightened approach to my own research methods teaching and supervision. As part of trying to make sense of what I was learning, I finally pulled together the poster I presented at a post grad conference at Lancaster (appendix 1). I have found through this PhD process that writing things down and presenting them really helps me to make sense of things.

Initially I was interested in the community participatory research and the work of Mathison (Matthiesen et al., 2014). Following some extensive literature reviewing, on discussion with my supervisors Katherine and Catherine, we concluded there were some gaps in knowledge around the views of people from different ethnicities here in the UK that needed to be explored before the community development work could take place so I changed tack and started to look at qualitative approaches that enable knowledge and theory to be derived.

I conducted my literature review favouring a meta-ethnography (more detail is given in Chapter 3 in my thesis), a form of qualitative synthesis I had been drawn to including the reading of examples such as this meta-ethnography around migrant women's experiences of illness (Schmied et al., 2017). Completing my meta-ethnography gave me some experience in synthesising the work of others in a start to the process of theorising and in the process of writing this piece of work up for publication.

8.4.3. Finding my focus: Role of adult children and theoretical perspective of Bourdieu

From the meta-ethnography I was particularly struck by the storyline about how adult children shut down conversations and by the extent to which these adult children become the decision makers for their parents in health care situations. My personal experience was that this occurred more in communities of ethnic diversity than in normative white families. The literature I reviewed also supported this.

I had already been introduced to the theory of Bourdieu through running a module with a colleague who was a sociologist and so we were using his theory in the module. I found myself very drawn to his ideas and they resonated with this idea of palliative care being constructed in a field that operated under set of rules or norms and values that came from a anglophone culture. To further develop my understanding of this I read widely about Bourdieu and explored where people had used his ideas in health care settings. During this time, I was able to attend several public talks around Bourdieu's ideas run at the London School of Economics, a neighbouring higher education institution. I was drawn to ideas about symbolic capital, social suffering and symbolic violence and this idea of hysteresis which was something I felt I had also experienced living between a variety of cultures and having made my home in three different countries over my lifetime to date, Kenya, the UK and New Zealand. I started to construct the concept analysis as I had found this technique of exploring complex concepts helpful in the past. I discuss this in chapter 4 of the thesis; this really helped me to explore these different facets of society with a focus on palliative care and discussions around future care preferences.

8.4.4. Choosing my population - Insider/outsider positionality

I was keen to capture a black perspective as I felt this was very underrepresented in the current literature (Chapter 2 page 24). Issues of ethnic identity and research populations are complex. I have explored this is chapter 2 of the thesis. Following discussions with my PhD supervisors, we decided it would not be right to research the views of black people as this was considered too generic, so I choose African and Caribbean heritage communities as this was the mix that existed in the communities of which I was most exposed and in which my research interest had arisen. For reasons identified in the first paragraph of this reflexive chapter I illustrated why I did not identify as black. I entered this research study considering myself as an outsider with lived experience of the field.

At the start of the study my two supervisors were also white women who had had experience of living, working and researching in mixed ethnic communities. As the study progressed one of my supervisors retired and my new supervisor was a Black Ghanaian man who had been brought up in Ghana. This brought into the research process some useful insights from a potential insider, I will discuss later how this influenced the research.

8.4.5. Choosing a methodology

My interest has always been at a community level exploring views that exist in society rather than exploring the views of patients and families who are already experiencing living with a terminal illness. I was also interested in a constructed social view rather than the in-depth exploration of individual's lived experiences. The importance of this was highlighted to me in a meeting I organised with Vera Hewatt who worked with an organisation called Compassion in Dying who had recently published a report on a community project she had run with Somali women about advance care planning (CID, 2016).

She spoke about when she first broached the subject, many of the women said how open their culture was to talk about dying because of their close relationship with the ancestors. On a deeper interactive discussion with them, the group almost surprised themselves with realising how although death was something spoken about the subject of dying was not spoken about, involved several taboos and was something they wished could be spoken about more openly.

This interactive discussion often offers a different picture to the one individual might talk about their own perceptions of how things are. This was something we discussed in detail in my research supervision sessions as often constructivist grounded theory involves individual interviews. Reading around community-based research and looking specifically for this sense of group construction revealed that it is something that is embraced as part of this type of methodology. I was able to have some discussions with Libby Sallnow and Heather Richardson (Sallnow et al., 2016) about their work on building compassionate neighbours and communities in areas of mixed ethnicity which were also informative. The process of developing the study and the decision making that was undertaking from here is explored in chapter 2, 3 and 5.

8.4.6. Success breeding motivation: Running the focus groups

Undertaking this first step of data collection felt like a significant step in this research journey. The first focus group was a group of adult children, all women within the 40-60 age group, and all who were employed in different roles in one institution of higher education. I knew all the women, but they did not all know each other. Karen, my focus group observer knew a couple of the participants. The focus group was convened via email to take place at lunch time with the provision of a light lunch beforehand as an opportunity for some interactions before the group started. Although a couple had said their participation would depend on what was happening that day at work, they all came.

Extract from my research diary and memo on the event

What happened

Snacks were laid out for participants when they arrived all were welcomed, and I had a bit of a chat with each as they arrived. There was a little chat between those who knew each other. P6 was last to arrive, and she knew the least number of people, namely only me. The group started with introductions. Some participants knew each other but none of them knew any of the others well. They all knew me. 3 knew Karen the observer.

Initially the conversation yoyoed between myself and the participants with me prompting each one to be involved at different times. There were some shared ideas e.g. the conversation around nine lives

As the group progressed there was more non-verbal supporting of what others were saying with nods, umms and a general sense of shared experience indicated through body postures. Injections by group members were of a reasonable length as they told their stories. Usually drawing on this that had happened in their families.

Halfway through the conversation started to turn towards reflections on what was being said and how one's person's experience related to another or caused them to think about it. As the group continued conversations grew shorter and more interactive between participants

How did I feel

Very excited with the discussion that had taken place. Helpful to know Karen was observing the interactions as keeping the conversation flowing took much of my attention. Tried not to *dominate the conversation, but tricky trying to balance letting people speak when they wanted to with wanting to step in to get folk to expand on elements they mentioned but then moved on from. Felt great when they took over this role of getting each other to expand through their own curiosity and identification with the experiences being discussed.*

At the end of the group, felt very edifying when they all commented how much they had enjoyed the conversations that had taken place and how they felt these were important things to talk about but felt they had perhaps not spoken enough about them with their families.

What an enjoyable exercise. Really feel the study has started now and is a worthwhile thing to be doing.

Successful events in my research journey such as this one were very motivating and provided both myself and my supervisors with a sense of encouragement, not only that the study had the chance of being successful, but also that there was some rich data gained from exploring these people's experiences. This is the positive part of being a researcher. It also left me with a feeling of responsibility that having received what is essentially a gift from people, I needed to ensure I worked with this data in an ethically appropriate way but also that I had a responsibility to ensure it was used for a beneficial purpose as outlined in the participant information leaflet I had given out. Finally publishing and presenting my study to others outlines in chapter 7 was a real sense of having started to meet this responsibility.

8.4.7. Hurdles

As I continued to recruit for future groups, I became more aware about who inhabits what spaces. Researchers around me were recruiting from Facebook, Instagram and twitter. These spaces were not successful in recruiting people from ethnic minority heritage populations. I realised I did not have access to alternative social media spaces that people from different culturally social groups may use. I never mastered tik-tok and wonder if I may have had some success there if I had tried. I handed out many participant packs to people I met at different occasions and asked if people were interested to come back to me, I had little success with these techniques. This was a difficult time, and I tried to refrain from thinking of these populations as challenging or hard to recruit from populations. I found repeatedly, direct recruitment of individuals through a conversation with follow up with a date and time was the most successful strategy.

Researcher influence on the analysis

To learn how to analyse the data using a constructivist grounded theory methodology was another learning curve on this PhD. I explored this by reading extensively around the topic and listening to recordings of conversations that Charmaz had had, I read several full PhD theses of researchers who had attempted to take this approach. (Bryant, 2017; Charmaz & Belgrave, 2018; Charmaz & Keller, 2016; Conlon et al., 2020; Cresswell, 2013; Matthews et al., 2021; Saldaña, 2013; Silverman, 2019; Wise, 2022).

Initially I learnt to use Nvivo and did the process of line-by-line coding on my own. Although I had coded data before, coding at this level in a particular style does results in a plethora of learning episodes.

Memo; Identifying study participants while coding- Coding after focus group 2

Today I have been coding my data, working on grouping codes into focused codes and started to work on writing analytical notes around the codes alongside quotations from the different focus groups I am finding it difficult to work with the data without attaching names to my participants. I have anonymised the transcripts to participant 1, participant 2 etc. but this did not feel conducive to thinking about this as a conversation between people. I can of course remember who said what, but I should not be writing down this in a form that makes it possible to identify individuals. I have been reading around what other people had done in this situation.

John Wise has written an interesting thesis on creating a multiethnic congregation in his PhD thesis. In his focus group analysis, he talks about 2 useful things:

1 How he used pseudonyms for his participants that reflected their ethnicity and gender (Wise, 2022). I like this idea but easier said than done. When I went to look up Nigerian names some were from different tribes, I do not know what tribes my participants were from … I decided to talk to friend who can help me select some appropriate names.
I need Nigerian, Ghanaian, mixed race Kenyan, maybe next time the participants could choose their own for me (Heaton, 2022) (Allen, 2016) .

In the end I just don't feel comfortable with pseudonyms, so I have decided to use initials while working with the data and to replace these with P1, P2 when working with the data with others or in any shared paperwork. I need to ensure all my study files are kept carefully stored in private files.

Facilitating difficult conversations

1. *Wise also moved from focus groups to interviews as he found people didn't want to discuss difficult things with each other.*

I have included this as an option in my ethics approval; however, I am not sure I am finding this in my groups. This maybe for several reasons, is there a gender element to this, do women find this easier than men? is this because people don't know each other well in the group whereas in Wise's study people were known to each other and were being asked to talk about things that were directly related to their relationships with each other
Is it something about me also. As a palliative care nurse and teacher, I have led many groups in conversations about this topic, does my facilitation skills help the group to feel safe to talk together?

As I started to develop focused codes, I had a session using a classroom white board with Karen to try and work out how to name these focused codes. This is something I worked a lot on when analysing the first three focus groups, I discussed some of these focused codes with my supervisors in supervision. For me it felt like having to learn how to create a new language. At first my focused codes felt flat, and it was on learning about gerunds from my studies of the work of Charmaz, I found my focused codes feeling more helpful and dynamic. In discussions with my supervisors, we explored areas to develop and working on some of these transitions form codes to focused codes and then tentative categories.

Working in a multicultural environment, teaching palliative care, being a keen reader of related research and having the opportunity to listen to other researchers in the field through work gave me lots of opportunities to reflect over some of the categories I was starting to construct along with being able to return to the original scripts.

8.4.8. Learning to create and demonstrate a theory

When constructing theory using Charmaz's constructive grounded theory approach, she councils about how you need to hold your existing knowledge lightly and be led by what you are learning from the data you have collected. I really tried to do this when constructing my theory. It was important to construct my theory from my data, also recognising I come to it with a world view and ongoing assumptions, and these will influence what I see as significant within the data and how I then interpret it.

As I developed the categories, I spent time working out how to describe the theory I felt I was developing, to try and offer a clear but multistranded explanation of what shaped the perspectives of people from African and Caribbean heritage communities. I write about this in chapter 6.7. It was more than just a hysteresis experience; it was the difference in the experience than that of others who come from societies not so influenced by traditional taboos as well as the hiatus of experiences of not observing the death of the generation before also felt an important influence. It was about the lived experiences of those who had lived this experience. Whilst people in all cultures miss observing the dying processes of say their grandparents, the migration experience around specific events like post war immigration drives, means this becomes a much more whole community event than what might happen in some families but not in others. I felt this was a significant thing here.

This was perhaps a time in my PhD studies I felt least able, creating theory felt like something outside of my experience and was not something that was easy for another to teach me. For me my solution to this is to read many articles from others who had tried to undertake the process before me. As a result, I read many grounded theory articles (Andrews et al., 2020; Horne et al., 2012; Matthews et al., 2021) which were helpful. With the construction of an explanatory model, I wanted to show the accumulative impact these different things had. Although there was some hysteresis, these layers remained important and highly influential to the family members in my study as part of their approach to this topic of having family conversations and preparing for the end of life. In the end, I concluded, you just must be confident that what you have constructed is explanatory to reasonable range of people to display what you mean it to. Presenting my work both as a conference presentation and then as a paper for submission helped to give me confidence in the value of what I had found out and created. I discuss this further in chapter 7 as a reflection on these presentations.

8.5. Contextual Reflexivity

8.5.1.A change in the narrative in palliative care

Following the pandemic where there was a heightened awareness of the inequality of experiences of ‘good dying’ and access to palliative care support services, a new narrative was emerging about racism in palliative care. This was something I thought a lot about, I read about it and spoke with my supervisors. I felt that the concept analysis I had written had allowed me to explore some of these issues. I decided to see if this came out in any of my focus groups. It wasn’t something that was raised and so I did not discuss it using those terms in my analysis or in my constructed theory. This was an issue I felt still need further exploring alongside the whole role of advance care planning. This is further explored in chapter 9 when exploring question 4: How can this start to rebalance social capitals?

Another issue that has arisen in palliative care research is the proliferation of research that has taken in place in advance care planning and whether it has had any measurable impact on achieving better dying for people. This has grown in interest in the past couple of years, which are since I published the final paper of my PhD. In the many conversations I have had with lay people around my PhD and its topic, the conversations that took place during the focus groups, and what others have reported, people often feel at the time there is a real value in having conversations with their families about preferences and practicalities. In chapter 9 I felt it was timely to explore some questions around this topic that are currently being debated that I had not included in my final publication of my study results. As well as continuing to read newly published literature, attend and present at conferences throughout my PhD journey, I feel this discussion of these continuing questions in chapter 9, are part of this contextual reflexivity of this piece of work.

I think I am someone who sees the world in a relativist way so rather than writing in a way I feel is judgemental, I feel much more comfortable to discuss, hear different points of view and then try to make sense in as an explanatory way as possible of the understanding I have constructed for myself. I wonder if this is heavy shaped by my gender and then professional socialisation as a nurse. I feel this is the conciliatory approach that is perhaps not so unusual in female nurses. Is it too passive? I am not sure. I find it has its place in trying to help people move forward in understanding and that was ultimately my goal in doing a constructivist grounded theory.

8.5.2. Collaborative writing of journal articles

Writing journal articles around elements of my study was a fundamental part of writing an alternative format PhD (de Souza & Gillett, 2025) and an essential part of ensuring research dissemination. This article writing became a collaborative effort between myself and my supervisors. I conducted the meta-ethnography and presented an early version to my PhD supervisors. They reviewed it and we discussed their thoughts at supervision. I would then rewrite it and re-present it to them until we felt it was almost ready for publication, Karen, as a critical friend, was a good sounding board for navigating the process of conducting a meta-ethnography and for discussing the concepts arising.

I engaged in two helpful exercises while going through this process of article writing. Karen and I ran an article writing group for colleagues at work, essentially designed to help them raise their scholarly outputs, I was able to write one of my articles as part of this process, and to help others trouble shoot issues in their work, through my previous experiences. The second process I undertook was to be a regular peer reviewer for 2 or 3 journals This helped me to develop my skills at critiquing studies at publication level. I reviewed papers for different impact levels of journal which also helps with increasing critique and discernment. This helped me understand the journal processes when I was awaiting and receiving peer review feedback from the pieces I submitted to journals.

This reflexive account has been an attempt to make explicit the subjective influences that have been present through the different times of decision making and interpretations that have taken place in the conduct of this study. It has also been a chance to evaluate how my own habitus has contributed to the experiences explored and ideas created in this study. Making this explicit will allow readers to evaluate for themselves some of the generalisability and transferability of this work to other contexts and times. Rather than seeing these impacts of self on the research as a bias, it should be seen as an integral part of the research process in generating and analysing data (Olmos-Vega et al., 2023)

The next chapter will be the final integrated discussion which brings together the results of the empirical study, the literature around the topics being explored and the implications of this study for policy, further research and practice.

Chapter 9: Integrated discussion

9.1 Introduction

This integrated chapter is an attempt to draw together the findings of the meta-ethnographic literature review, the theoretical underpinnings, the reflective memo's and the empirical findings of this study to consider how they contribute to existing knowledge. Drawing on the created constructivist grounded theory of living and dying between cultural traditions outlined in Chapter 6 and the paper summarising the study in chapter 7 (De Souza et al., 2024b), a discussion of the contribution of this theory will be considered. This will be done in conjunction with a critical reflection of some of the questions that remain and require further consideration. An evaluation of the strengths and limitations of this research process will be followed by suggestions of how this study contributes to palliative care practice, education and policy.

9.2 Summary of the thesis

The initial question that stimulated this research was why does there appear to be little take up of palliative care, advance care planning and end-of-life planning conversations from people of ethnically diverse heritage? Through doing a meta-ethnography of studies looking at experiences and perspectives, older people spoke of values around faith in both their families and in God to take care of decision making in the future (Boucher, 2017; Bullock, 2011; Cohen & Deliens, 2012). Elements of fear influenced behaviours of both older people and their adult children (Glass & Nahapetyan, 2008; Venkatasalu et al., 2013). For some fear about talking of death matters and for others fears of losing a parent were factors that inhibited involvement in anticipatory end-of-life planning (Ko & Berkman, 2010). One conclusion drawn from the meta-ethnography was that further exploration of the perspectives and experiences of adult children of people from ethnically diverse heritage about having end-of-life conversations would be a useful step in developing this work. My experiences of teaching in south London, an area with a high population of people of African and Caribbean heritage stimulated my interest. There was also a gap in the literature in this area focused on people of African and Caribbean heritage, so this seemed a useful voice to capture to seek further insights.

Chapter 4 of this thesis contains Paper 2**,** a concept analysis of experience of hysteresis in relation to palliative care and advance care planning conversations in minority ethnic heritage communities**.** In this paper I offer a structured exploration of what I find helpful from some of the underpinning theoretical understanding of the societal context in which this study is situated. I explore the impacts on the experiences of people from minority ethnic heritage communities, using a Rogerian (2000) concept analysis framework and Bourdieu's theory of a concept of practice (Bourdieu & Nice, 1977). This theoretical lens can be used to offer a critical exploration of the pervading social and symbolic capitals that exist in the field of palliative and end-of-life care provision in the UK.

Using this lens, the result of these forms of capital is the creation of the norms, values and expectations which become the rules and the resultant doxa or societal language that is expected people should conform to around dying and preparation for death (Tan & Foong, 2023). This prevailing doxa reflects the communities in which it was developed: in the main white western societies. Using Bourdieu's concept of practice as an epistemological lens, a social constructivist grounded theory approach using focus groups was used in this study to conduct relativist research and generate theory to enhance understanding of the social processes of family conversations, whilst preserving the complexity of social life (Charmaz, 2014).

The methods used for recruitment, purposeful sampling, iterative coding and an abstraction process of analysis and synthesis, as well as the challenges of recruiting participants is discussed in Chapters 5 and 6, and in Paper 4. and reflected on in the limitations section later in this chapter. The five constructs that were generated were compiled into a theory to provide an explanation about some of what is happening for people of African and Caribbean heritage when living and dying between cultural traditions (Figure 10).

9.3 Contribution intentions of this study

There is a desire through this study to contribute to three things. Firstly, to understand the stories of those who have been unheard and recognise the differences that may exist in their experiences, using a exploration route that can result in in-depth or deep methodological listening (Gunaratnam, 2012; Kimpel et al., 2023; McDermott & Selman, 2018). A decision to use focus groups was taken to allow participants to construct the community narrative themselves through the group debate that can be gained using a focus group approach. A critical discussion of how successful we were in this study of conducting this group debate is explored in paper 3 in chapter 6. Using these experiences, we sought to create an explanatory grounded theory to make this understanding more visible for others too. How this relates to or builds on the understanding gained from using the lens of Bourdieu's concept of practice is also discussed.

Secondly, it is hoped that this approach will tap into the enormous capacity that the community itself has to develop an understanding of what is useful and helpful in creating opportunities to improve the dying experience of people of African and Caribbean heritage communities.

Lastly, it is hoped that this study can help and start to change some of the prevailing doxa of palliative and end-of-life care service provision to reflect a more culturally inclusive perspective (Bullock et al., 2022). A goal is to raise awareness that doxa needs to take an asset-based approach rather than a deficit view of what multicultural palliative care could look like to ensure the values and attitudes it holds are in line with a wider proportion of society (Tan & Foong, 2023; Zaman et al., 2017). There is an aim to reduce the symbolic violence and resultant social suffering that can be, sometimes unintentionally, caused by providing a service that people feel excludes them (Bajwah et al., 2024; Gunaratnam, 2012).

Cognisant of the values and the doxa of those in the community of palliative care provision, **this theory of living and dying between cultural traditions** offers a deeper insight into some of the dynamics that exist. These experiences shape the habitus of people of African and Caribbean heritage and make this life experience uniquely different to other people who have lived in the UK for many generations (Gunaratnam, 2013). In the following discussion the initial outcomes of the study are discussed and then used to explore the areas that remain using a series of questions.

9.4 Aligning the findings to the epistemological lens of Bourdieu's theory of practice and his concept of Hysteresis

Central to Bourdieu's concept of practice are the components or thinking tools of habitus, field, doxa, capitals and hysteresis (Robbins, 2014). How these thinking tools can provide a way of exploring the influences of people's subjective agency and society's objective structures on the way in which people experience and perceive the social world is explored in chapter 3 and 4. In this section I will explore how the theory generated in this study resonates with Bourdieu's theory of practice and where it deviates or develops from ideas such as hysteresis.

9.4.1. Habitus, Intersectionality, and Cultural Construction

For Bourdieu the goal of sociological research is to explore how people experience society based on the structures that exists in social worlds and the mechanisms that develop that result in their reproduction or their evolving transformation (Reay, 2004). His concept of habitus is central to this experience of the person in society. Bourdieu argues that habitus is a constantly evolving experience that is layered with past experiences and cultural influences, but it is also transversed by the experiences of each individual and shaped by their interpretation and usage of those experiences, and becomes an embodiment of that social world (Grenfell, 2014; Reay, 2015).

The constructs of the theory of living and dying between cultural traditions offers some insight into how people of African and Caribbean heritage experience the phenomenon of talking about end-of-life preferences with their families. The constructs of this new piece of theory resonate with this sense of habitus that is constructed by each person honed by traditional values but shaped by experiences of living in the UK and their own developing values. This new piece of theory expands on how the melding of the constructs of living and dying between traditions and the intersectional influences on family decision making work together. It captures how families develop specific practices and values around this process of family conversations around serious illness and planning for dying.

In focus group 4 (chapter 6.8.2) participants discuss how they shape the conversations they have with their parents around illness between traditional values and their own more open views developing a shared habitus within the family about how these matters will be discussed and handled. What is complex is this is not always how things play out and previous studies have found the opposite where migrant older patients want to have more open conversations with treating physicians but their families prefer models of limited disclosure (Mitchison et al., 2012). Such differences emphasise how the construct of intersectional influences on family decision making creates this dynamic situation depending on who the conversations are with and in what situation they are taking place (Oetzel et al., 2015; Peterson et al., 2018; Peterson et al., 2019; Song et al., 2012). Understanding the complex nature of habitus is difficult as it is not as bound by the visible rules (societal expectations) as one may expect it to be. It is as much shaped by intra group dynamics as intergroup dynamics, which is what much of Bourdieu's work focuses on.

Bourdieu's hysteresis effect is seen as a disadvantaging force that prevents people who experience it within a field of being able to grasp the opportunities offered in that field. He suggests this arises as they are disadvantaged by the confusion and disruption of previous securing practices (Grenfell, 2014). In the construction of the theory of living and dying between cultural traditions, this sense of hysteresis feels both disadvantaging, as new life experiences can influence what seems right to do at the time, but also cementing a positive force of belonging. For many the pull of traditional values is strengthened around life's major transitions such as birth, adulthood transitions and death (Anderson & De Souza, 2021).

9.5 New insights beyond Bourdieu

9.5.1 Transnational Habitus and Cultural Hybridity

Several studies suggest that people with migratory histories develop a transnational habitus that they use to straddle the two identities they hold in the different life fields in which they consider themselves to live (Biondo et al., 2017; Radogna, 2019). This has constant impact on people's lives but particularly when nearing the end of life where this sense of cultural hybridity, can create social pain and suffering (Bray et al., 2018; Gunaratnam, 2014).

This cross-cultural experience also builds belonging into this new shaping of a transnational culture. One of the critiques of Bourdieu's work is the idea of latent determinism (Reay, 2004; Tichavakunda, 2019). As can be seen through the findings of this study and this theory of living and dying across cultural traditions is that as the experiences of both the older adults and the families navigate these multiple layers of emotional and cognitive experiences when thinking about preparing for the end of life, some families survive intact with a shared construction of a new cultural doxa with which to operate. This new doxa reflects the constructs of intersectional influences involved and is curated through family communication and negotiation represented by the category of 'who says what to whom' in chapter 6. For some families this complexity and change results in family friction and splits. For others it results in workable new ways of being and doing across international geographies.

Between the theory constructs of 'there is complexity in traditions' and 'it crosses oceans and living and dying between traditions', there are new ways of being and doing that are built on traditions but incorporate elements of new cultures that celebrate this hybridity. Existing in new spaces does not mean having to completely leave behind the old ways of being. For the families in this study, many families had members who migrated to different countries, so this cultural hybridity must be navigated, as the new places are different for different family members. Ideas must be brought together to care for and decision-make for the person who is dying. Social media has transformed the conversations that can take place. Social media platforms like 'WhatsApp' allow for the possibilities of transnational discussions in almost real time for groups of people, which helps to shape this transcultural habitus.

9.5.2. Role modelling or rehearsal: Lost learning as a result of migration

All cultural models incorporate a sense of slowly shifting sands and offer a picture of cultural change as being constantly evolving. Bourdieu describes people's habitus as dynamic and often influenced by some assimilation of new cultures shaping and changing existing schema built on traditional familiar learning. What is not often explored in Bourdieu's work is how migration can result in a whole layer of lost learning, a fracture of that process of slow evolving cultural change. One of the first conversations in focus group 1 was a story by a participant about how she had met her grandmother;

Quote 37

> *My first experience of somebody dying was when I went to Jamaica to see my grandma. My dad lived over here and his mom was writing him and saying I don't think I'm going to see you again and he goes yes you will. So we ended up going over to see her. It was my first experience of seeing her… I think it might have been two weeks later she died… (adult child, Caribbean)*
>
> ***Quote 38***
>
> *Yes Mum was often in Ghana, she went to look after him … But I didn't go… (adult child, African)*

For so many 1st and 2nd generation migrants there has been this break of experience of being with and slowly watching the whole dying process and the decision making, potential early conversations that may take place. It is important to recognise how much we learn and prepare ourselves for life transitions by watching those who go before us. I have memories as a primary school child of watching the secondary school children wander the playground just talking for the whole of the breaktime. To one who needed to use all spare time to play, it seemed so strange and unfathomable, but in no time at all I was there, filling that space I had watched from the margins, whilst learning the rules. As we watch, we question, we discuss the phenomenon with others, we think 'what I would do' in that situation, we rehearse.

In focus group 5 a grandchild and a daughter, reflect and discuss as they care for their elderly relative, 'what is important for me…..' is. When I am this age … I would like ……'. Not being in the same country as dying relatives completely changes the visibility of dying. Often only the funeral experiences, shared through stories and pictures is what is known by those who are distant. That opportunity for rehearsal and reflection is very different to that direct watching experience.

9.5.3. Using family trees and genograms to capture dying histories

Simple genograms are used in medical social history assessments as part of the core assessment tool kit. Their use as ways of exploring prior experiences of serious illness and dying is one that is currently less prevalent in general health care practice. These tools can offer a pictorial description of family history that is easily accessible to health care professionals (De Souza, 2014). They are widely used in social work practice and family therapy for exploring family dynamics. They can provide rich data in terms of prior family experiences in many areas of care including research (Alexander et al., 2022).

9.6. Using the generated theory of living and dying between cultural traditions

The purpose of theory can be described as providing insights or guidance to improve social life (Saldana, 2024). Whilst theory is commonly developed to seek explanations to help solve social problems (Kennedy & Thornberg, 2018), when we know something is happening through observation and quantitative fact finding, qualitatively derived theory can help to answer those why and how questions (Hamilton & Finley, 2019). The issue of different levels of referral take-up and engagement with different elements of palliative care such as early end-of-life planning conversations by different communities is nuanced and varied, so it is important to consider both structural and agency elements of why this is the case. The building of a theoretical framework helps to make transparent these different influences and provides a basis on which to build future research and practice (Kimpel et al., 2023).

Despite an increase in the take up of palliative care, advance care planning conversations remain unpopular amongst people from ethnically diverse heritage populations (Biondo et al., 2017; Hoe & Enguidanos, 2020; Ladd, 2014; Venkatasalu et al., 2013). At the end of life, adult children often become the decision makers for their parents and few report having had any conversations about their parents' wishes beforehand. Both bereaved family members and healthcare staff voice difficulties with dealing with the level of distress that can arise from having end-of-life care discussions with surrogate decision makers who are unprepared for this event and task, which results in these conversations not always taking place in a timely manner (Glass & Nahapetyan, 2008; Gutheil & Heyman, 2006a; Izumi et al., 2024; Periyakoil et al., 2015).

In the presentation of **the theory of living and dying between cultural traditions** in Paper 4 the role of adult children as frequent decision makers for older adults from African and Caribbean communities is highlighted. This decision-making role is often undertaken having not had previous conversations about the preferences of the older relative but carrying a high degree of trust by the older person that this surrogate decision maker will make the right decisions for them. The impact of oscillating values and preferences for both, these adult children and their elders, causes tensions. The oscillations are a result of a number of things which are explored in the theory. They include recent migration histories, the continued presence of some family members still living in different geographical locations, including the country of heritage, and an absence of having witnessed first-hand, in many cases, the death of the generations before them. All of this contributes to the lens through which these families view topics like family conversations around dying preferences and shapes their habitus (Green, Jerzmanowska, Thristiawati, et al., 2018; Gunaratnam, 2012; Ladd, 2014). Similarly, Jutlla (2015) in their study exploring the experiences of people with dementia and their families of Sikh heritage living in the UK, identified how integral migration stories and migration identities were to these Sikh families' sense of being.

In addition, this theory uncovers different complexity to the language barriers and health literacy barriers suggested by many previous studies (Zubair & Norris, 2015). Similar to the review of palliative care utilisation by Shabnam et al. (2022), we found through our work that economic and structural factors play a large role in the hysteresis experience of these families (Roenn-Smidt et al., 2020).

The contribution to understanding facilitated through this created theory will be further explored in this chapter by exploring a number of questions that remain in the field of palliative care.

9.7. Question 1: Advance Care Planning – the right approach for all?

In this study, the older participants displayed some concerns about planning for their deaths; for some there is a religious underplay to this as has been found by others (Johnson et al., 2016; Ladd, 2014). To others, there are culturally bred notions of anxiety about speaking about serious illness as it may bring on death (Glass & Nahapetyan, 2008; Gott et al., 2017; Kirby et al., 2018; Ott, 2008). Finally there are also concerns about burdening children with having to think about such things, and also perhaps the burden of having to make what maybe complex decisions because of hysteresis experience of living and dying in two different countries (Biondo et al., 2017; Venkatasalu et al., 2013). Whilst as health literacy increases, fatalistic views about conversations bringing on death maybe decreasing, such perceptions can be endemic in the habitus of people as it is part of cultural doxa. The construct of **preparing for death but not for dying** in our constructed theory explores the juxtaposition elders hold in terms of advance planning. One of the questions that has arisen in the field of palliative care whilst conducting this study is that is having early conversations around end of life helpful or important, and how is this impacted by ethnicity? Does planning for future care needs make any difference to achieving a better dying?

The take up of advance care planning internationally is low. A misunderstanding and mistrust of advance care planning is prevalent across ethnicities where it can be seen as a mechanism to ration care and is seen by many as being synonymous with being thought to be in the last days or weeks of life (Canny et al., 2023). However, this level of concern was considered heightened in minority ethnic heritage communities and was discussed in several of the focus group discussions in our study (Bradshaw et al., 2021; de Graaff et al., 2010). The theoretical category of 'talking about cancer and dying is taboo in our culture' was abstracted into the construct of **complexity in traditions crosses oceans** in our theory. Adult children participants in our study spoke with sorrow about how taboo subjects remain even after people have lived in countries where high quality healthcare is available to most. They spoke of how their parents chose not to discuss serious illnesses until a late stage. Some spoke of the concerns their parents had of discussing a treatable cancer diagnosis, and of the journey they or their siblings were on due in all probability to their own fears about illnesses like cancer (Koffman et al., 2008). Others discussed how uncomfortable their parents were with the notion of palliative care and the implication that care may transition away from a curative intent (de Graaff et al., 2010; Kirby et al., 2018). The taboo of illnesses like cancer and missing out access to curative treatments are not surprising knowing that in many countries' cancer incidence is rising but treatments are still not available, so morbidity and mortality is high (Hamdi et al., 2021). If this is something people, like the elder participants in our study were talking about, still have first-hand experience of either for themselves or for other relatives still living in lower socioeconomic countries, these are realistic fears. This proximity to living in other places where healthcare is so different is one that is so important to remember when working with families of diverse ethnic heritage who maybe making or wanting to make different choices than may seem sensible from the perspective of a health care provider whose main life experiences have been in countries with developed and accessible health care systems. The process of acculturation to new systems with potentially higher levels of resources can cause poorer mental health outcomes possibly due to the impact of the hysteresis effect of living between systems (Roenn-Smidt et al., 2020; Schwartz et al., 2010).

All of these uncertainty and anxiety factors raises the question for people with a fear of the idea of life limiting illness: do they need to plan for future care needs to achieve a good death? Is this view shared and are these conversations helpful across communities? The work of Luth and Prigerson (2018) suggests it may not be equally protective across ethnicities where the families of non-Hispanic blacks indicated an increase in distress when an end-of-life discussion and appointment of a health proxy was made compared to when this had not taken place. For some family members, perhaps these early conversations and contemplation of their elder dying is more anxiety provoking than helpful (Bowling et al., 2010; Canny et al., 2023; Neimeyer et al., 2011; Piamjariyakul et al., 2014). Studies have found in some white communities, putting a plan in place reduces anxieties (Bowling et al., 2010; Ladd, 2014). Perhaps this is in situations where death anxiety is lower, and people have beliefs and values around personal autonomy. If coming from a standpoint that values personal autonomy, perhaps someone making their wishes known helps the surrogate decision maker have a sense of achievement that the autonomy of the dying person will be protected in the dying phase. Whereas, when people come from cultures which value dignity that is not so connected with personal autonomy and they value more collective or relational autonomy (Samanta & Samanta, 2013). It is important to be aware of the differing benefits and drawback of interventions like advance care planning when expecting everyone to conform to what has been conceived as a good idea by some (Zimmermann, 2012) .

Participants in our study found themselves caught between their heritage traditions of protecting either their elders or their adult children from harm by shielding them from painful conversations and wanting to take a more open approach to conversations as proposed by the normative culture in the UK promoted by palliative care. This is illustrated in the construct of **living and dying between traditions being transversed by the construct**

of hysteresis in our theory and the experience of adult children being pulled in two directions around having end-of-life conversations with their parents. This may also happen for older people as they assimilate into their host cultures (Biondo et al., 2017; Sharma et al., 2012; Venkatasalu et al., 2013)

There remains a lack of understanding of advance care planning in many communities (Canny et al., 2023). There is also concern that false hope is being offered to people (Pollock et al., 2024; Smith & Periyakoil, 2018). In the pursuit of a 'good death', increasing costs of providing complex care to a growing elderly population fuels an appetite for a philosophy that allows transference of responsibility for the provision of end-of-life care from the state to families and individuals by pushing a standard of good dying linked to dying at home. The argument of Pollock et al. (2024) is that for people with conditions other than cancer, prognostication is inaccurate. Periods of deterioration are long and complex so people need to be supported through this rather than promised unrealistic hopes of having choices during this period that can reduce the burdens of their deteriorating disease (Grindrod, 2020; Kellehear, 2024; Walter, 2017). They suggest that people are more comfortable talking about death than previous policy (Department of Health, 2008) might suggest, but realistically, end of life is hard to plan for as it is so unpredictable.

There is a need to balance this view with a growing visible societal conversation about death and dying, such as Katherine Mannix hitting one million views on her Ted talk 'What is it like to die' (Mannix, 2024) and other expressions of public health palliative care (Sallnow et al., 2016), where people often react positively, feeling freed and empowered to think about and speak more about dying.

In several of the focus groups in our study, there was a desire to have more end-of-life planning conversations. Similarly to the results of this study, other studies have found that people from ethnically diverse heritage communities were interested in having more end-of-life planning conversations but they found that healthcare professionals, who show little interest or understanding in their experiences and perspectives on things, became barriers to these types of conversations (Bray et al., 2015; Chiu et al., 2016; Islam et al., 2023; Izumi et al., 2024; Periyakoil et al., 2015; Worth et al., 2009). In Izumi et al (2024) and Islam (2023) 's recent studies, their participants had a heightened dependence on professionals leading conversations about things to consider, as they had more limited prior experiences of watching the dying process than those whose families were less geographically disparate.

In several studies explored in the concept analysis in Chapter 4, there were cultural expectations in the habitus of many, that any care decisions would be the domain of the healthcare team and decisions would be made with little input from patients and family; therefore, there did not appear to be a need for future planning (Chiu et al., 2016). How conversations are initiated and carried out has been found to be a major factor in their acceptability (Bullock et al., 2022; Chidiac et al., 2020). Many had encountered an authoritarian approach taken to healthcare decision making that had not sought their perspectives on previous health journeys, this then resulted in people having low expectations of the value and helpfulness of such conversations. The field of palliative care and the related decision making, like so many areas in life, can feel like areas of struggle (Collyer, 2018) rather than one of support. Person-centred culturally sensitive conversations around future care have been found to be helpful and welcomed in ethnically diverse communities (Bray et al., 2015; Bullock et al., 2022; Chiu et al., 2016; CID, 2016; Johnson & Stellwag, 2022; Zaman et al., 2017).

Our study, along with the others, calls for better relationship building between professionals and people of ethnically diverse heritage communities with a greater understanding of the impact a migration history may have on both the tensions between generations but also the different experiences of what dying may look like and what decisions may need to be made going forwards (de Pentheny O'Kelly et al., 2011; Gott et al., 2017; Islam et al., 2023; Izumi et al., 2024; Jones et al., 2021; Luth & Prigerson, 2018). However, also addressing the fear and anxiety for professionals of having these types of conversations will be paramount in improving this relationship building and trust and ultimately improving clinical practice around the provision of care for people who are dying (Chiu et al., 2016; Green, Jerzmanowska, Green, et al., 2018; Periyakoil et al., 2015).

9.8 Question 2: Advance care planning or serious conversations?

When used well, advance care planning has been found to reduce repeat admissions (Abel et al., 2013) but this is not commonplace. Some research demonstrates that although advance care planning has now been in existence for two decades and has had a considerable share of research funding in palliative care, there is little evidence that people coming into hospital with existing serious illnesses are making use of prior discussions to plan for more desired outcomes. A high number of people experience uncontrolled symptoms that result in repeat, potentially avoidable, emergency admissions into hospital in the last months of life, which are distressing and can result in extended periods of uncomfortable admissions (Pring et al., 2024). There is a debate about the value of pursuing advance care planning conversations in any communities outside the presence of serious illness (Morrison et al., 2021). There is a call to focus on managing symptoms well across communities and move to a focus on serious illness conversations when people are in situations where their health has deteriorated and death is nearer (Baxter et al., 2023; Ivo et al., 2012; Jacobsen et al., 2022; Rosa et al., 2023) rather than future forecasting conversations (Zivkovic, 2018).

The notion of decision making about future health events being a challenge for some minority ethnic heritage families was discussed earlier in this thesis both in the meta-ethnography (Boucher, 2017) and in the concept analysis (Zivkovic, 2018). Advance care planning brings with it a fear that future care may be rationed and choices available may be minimised (Canny et al., 2023) (Bradshaw et al., 2021). This results in complex dynamics between potential decision makers within the family. Through the construct of **intersectional influences on decision making** in our theory some of the factors that contribute to those dynamics are explained. Several of the discussions that took place in the study focus groups explored how decisions made about end-of-life care by the surrogate family members were in reality made by family members who were either geographically closer regardless of position within the family, or by those who were funding the healthcare that was required. Work by Carr et al. (2013) also illustrated that the state of interpersonal relationships also impacts who people nominate to make decisions for them which can be a very fluid entity at the end of life when priorities maybe changing due to the current circumstances of a person’s state of health or finances. This results in some imbalance between people geographically close and those who were geographically distant, sometimes changing the status quo of who might normally have been the main decision maker. Future planning by some may have little impact, dependent on the situation that occurs at the time the older person deteriorates, where they are being cared for and by whom. This is discussed using quotations in paper 4.

This phenomenon of proximal carers becoming more likely to become the decision makers in the moment is captured in other studies across ethnicities (Pollock & Seymour, 2018, Morrison et al. 2021 (Wallace, 2015)). Our participants spoke to the distress that is caused when those proximal caregivers choose different end-of-life care options than what an older relative had discussed with them on previous occasions. This phenomenon of the eventual care plan being shaped by the most proximal relatives rather than perhaps according to previously articulated ideas is one that can be seen in two ways. It can be seen as having created a potential for conflict by raising unrealistic expectations by early conversations, or it can have the benefit of raising the possibility that new circumstances may mean different plans, so when this does occur, it doesn't come as such a surprise. This mirrors in some way the situation with birthing plans, that again can often not go as ideally planned but continue to be seen as a positive intervention and helpful in creating realistic expectations (Bell et al., 2022).

It appears in some circumstances, when explored quantitatively, that evidence of advance care conversations may cause black participants to have more sadness and anxiety and more unmet psychological needs (Luth & Prigerson, 2018). Previous studies have indicated that people of ethnically diverse heritage do find discussions of death perhaps more anxiety provoking than of some white communities. However, when advanced care planning is part of a discussion in which treatments will be ongoing, an integrated conversation taking into account an individual's circumstances can make advance care planning more personalised and therefore meaningful (Izumi et al., 2024; Murray et al., 2024). For the participants who agreed to come on my study, apart from a couple of exceptions, most felt comfortable with discussing this idea of talking with family about dying preferences; however, several felt they were unsure how involved they would be in end-of-life decision making of their parents as they were living at a distance, often in another country, and pre-emptive conversations with siblings were rare. They spoke about the impact this had on their involvement with previous decision making, and how it mainly fell on the shoulders of those who were closest.

As a result of proximity being a major factor in who becomes the surrogate proxy, there is an argument that greater emphasis should be put on having serious conversations and learning to do these well rather than putting all the resources into advance care plans (Jacobsen et al., 2022). There is growing development in creating tools for serious illness conversations, and some propose this may be a useful avenue down which to direct more attention and funding than the funding that currently goes in to work around advance care planning (Baxter et al., 2023; Jacobsen et al., 2022; Koffman et al., 2023).

Questions remain about when serious conversations would take place, who should have them, and what if these opportunities are not taken (Tenzek & Depner, 2017; Tulsky et al., 2017)? These can be challenging for many healthcare professionals, and it is not always clear within teams who are considered suitable or allowed to have these conversations and as a result often happen very late in a person's illness which can be a source of much distress for families (Green, Jerzmanowska, Green, et al., 2018; Ombudsman, 2015). For serious conversations to be effective they need to be timely (Baxter et al., 2023). So often the people who do feel able to have these conversations are not available when needed. Admission to A & E, in what might well be a final admission, is perhaps too late to have any real impact on making choices that may have made that person's end of life significantly different. This raises many issues: firstly, how it may be helpful for as many people as possibly to have had some kind of earlier conversations with family members to help in preparing for the conversations that now need to be had and the decisions that need to be made, in the form of some death literacy (HQIP, 2023; Noonan et al., 2016; Tan & Manca, 2013). Participants in our study talked of preparing for death but not for dying; culturally adapted for the UK situation, death literacy was limited in those who had not experienced the death of a close family member in the UK. This area of promoting social death literacy is gaining media coverage in places such as the UK but can use unhelpful terminology and lacks some cultural diversity in its portrayals, so needs more input from knowledgeable health and social care professionals to change some of the doxa being used. (Mannix, 2024; Selman et al., 2021; Wilson et al., 2014).

Secondly, for healthcare professionals of different disciplines to feel more able to have person-centred conversations and also for teams to have more collegiate systems to enable trust between team members to be strong enough that all relevant team members can be part of these conversations. Theories like the theory of living and dying between cultural traditions may help professionals identify a little more with what may be some of the formative experiences that influence the fear and indecision they may see with their patients, families and colleagues when it comes to having conversations and making end-of-life care decisions (Igel & Lerner, 2016).

For many of the families in our study, family members are spread geographically around the world. For many families with migrant histories this will be the case. As places of healthcare get better connected with IT facilities by the bedside, geography becomes less of an issue in involving families in earlier discussions when news is being shared with patients on ward rounds. Issues such as healthcare professional expertise and comfort in using such technologies makes take up slow. Concerns about patient consent can be resolved by having conversations with the patient prior to the IT connection being made.

9.9 Question 3: Do prior experiences buffer current experiences?

My theory of living and dying between cultural traditions proposes that **watching the death of another prompt's conversation**. In Paper 4, we discuss how grandchildren now experiencing the illness and death of grandparents alongside their parents suggest this opens opportunities for conversations about their parents' preferences. Other participants use reflections on the deaths of family members who have died previously to shape some of their own preferences and discuss how they do or plan to speak of these with their children. Work in this area is ambiguous. Neimeyer's work suggests prior experience does not reduce death anxiety (Wass & Neimeyer, 2018); however, work in the USA and Australia suggests that prior experiences of caring for people who are dying increased death literacy, and this reduced death anxiety (Izumi et al., 2024; Noonan et al., 2016). This has been raised as an area that impacts people's ability to engage with future caring conversations; people with limited experience of dying find it harder to engage with advance care planning as they understand less about what planning is needed and perhaps what they might want to avoid happening (Izumi et al., 2024). Adult children play such a fundamental role in the care of dying elders and in particular the decision-making processes; this population should be the focus of more interventional research.

There is considerable literature around the coping experiences of healthcare professionals. Research has shown that experiences of looking after people who are dying, when properly supported, can help reduce death anxiety and emotional distress (Andersson et al., 2016). There is more limited exploration on how previous death experiences buffer death anxiety for patients and families. This is an area that could be further explored.

Complex prior death experiences

Recognising the complexity of previous deaths people may have witnessed when living as part of a community who have experienced recent migration, for some forced migration due to conflict and poverty, is also important. Neimeyer argues that not enough has been done to explore the impact on communities where people have either experienced or heard stories of difficult dying (Wass & Neimeyer, 2018). This, alongside the impact of many in the community having not directly experienced the deaths of their grandparents, leads to a complex type of death literacy that may, not surprisingly, result in raising death anxiety.

Communities play a strong buffering role (Rosenberg et al., 2015; Vijay et al., 2018) offering a variety of social capital. Supporting the development of compassionate communities is one way of developing both death literacy and cultural assets in the delivery of good end-of-life care (Sallnow et al., 2016). The role played by churches and religious affiliation is an interesting one (Johnson et al., 2016; Ladd & Gordon, 2017). Higher religiosity has been found to increase death anxiety and influence stronger choices for aggressive care at the end of life; however, the process of regular attendance at social religious gatherings like weekly church meetings can mitigate that concern and result in a higher rate of completions of advance care planning (Hoe & Enguidanos, 2020). Two of the constructs of the theory of living and dying between cultural traditions (Figure 10) refer to the linkage of heritage and current cultures and how they are integrally combined and create the habitus that many people with migration histories inhabit. Building on the strengths of community structures such as those that build social capital in ethnically diverse communities with a particular focus on the last years of life again is an area that needs development (Johnstone et al., 2016; Sanders et al., 2018; Uphoff et al., 2013).

9.10. Question 4: How can this start to rebalance social capitals?

How can this new knowledge help to change the field of practice of palliative care and start to rebalance social capitals in this field?

Listening to, valuing and giving credibility to voices that in the past have been sidelined through a lack of economic and social capital is imperative (Stajduhar, 2020). It is important to define and explore structural racism (Bullock et al., 2022). A clear example of this is the recent work by Chukwusa et al. currently in press, which highlights the ethnic disparities in opioid prescribing, highlighting how stereotypical stigma results in poor symptom management experiences. It is important to consider ways that this can be improved. Using the lens of Bourdieu (199) and being mindful of the way in which any field of practice is developed and how it can result in this unconscious symbolical violence and subsequent experiences of social suffering for those who are excluded by socially constructed doxa and capitals. This study was an attempt to explore the specific perspectives of people from African and Caribbean heritage living in the UK to add this perspective to the academic conversation currently on going about how to decolonise palliative care with a focus on family conversations. One first step is to ensure decisions are being made by a more diverse workforces who bring with them better understanding of how different communities function around inherent value systems (Tan & Foong, 2023).

Working with different ways of decision making and understanding and valuing the way in which collective decision-making works in most communities is an important aspect of healthcare professional development (Gómez-Vírseda et al., 2019; Igel & Lerner, 2016). More development of learning is required around how to take time to value family conversations when difficult decisions need to be made (HQIP, 2023; Hudson et al., 2021; Kishino et al., 2022). End of life and serious illness decision making is often very complex and nuanced and there is a danger in minimizing the complexity by seeking simple solutions like blunt advance decision forms like do not attempt CPR orders, these can cause great anxiety and distress (Bradshaw et al., 2021). Making family meetings a routine part of care delivery and developing the skills to encourage family conversations around future decisions that need to be made before that family is likely to next encounter healthcare professionals can be really helpful in enabling more effective participation in future decision making (Tenzek & Depner, 2017).

Healthcare professionals are so often focused on the immediate problem, and anticipatory planning is seen as the domain of specialists rather than all of the team. These types of conversations can also be dauting to professionals (Periyakoil et al., 2015). Developing the confidence to have these conversations has seen some success using observation of real examples and watching how experts manage to work with cues and prioritise in complex situations (Izumi et al., 2024; Parry, 2024). As well as having a workforce that is more diverse, it is also important to ensure that culturally cognisant palliative care is a core component of both pre- and post-registration training.

The importance of building trust between families and healthcare professionals and just spending the time to make meaningful, individual relationships was highlighted in recent studies of thinking ahead in ethnically diverse communities (Bradshaw et al., 2021; Carr et al., 2013; Islam et al., 2023; Izumi et al., 2024). In Islam et al.'s (2023) study, many of the terminally ill participants and family members were unable to identify a healthcare professional to nominate who they felt was closely involved in their care. We need to be identifying people on dying trajectories better and building support. The UK national End of Life Care Strategy (Department of Health, 2008) included a funded initiative called the 'identify your 1% campaign' for community doctors, encouraging them through incentives to identify and follow up on the probable 1% of their caseloads who required palliative and end-of-life care. This particular target has fallen away, perhaps in part due to a fear that was generated in the UK population about being identified as on a 'death register' (Neuberger, 2013). However, new and better ways of identifying and drawing alongside vulnerable people needs revisiting. A key task of healthcare professionals when supporting patients and families through serious and terminal illness is to elicit some kind of preferences for future treatments and to respond accordingly (HQIP, 2023). Continuing reference to working on increasing professional confidence at all levels in having conversations around such areas is something that needs to be maintained (Bullock et al., 2022).

9.11. Question 5: How are things changing?

How are things changing as society changes and the habitus of older adults and their children adapts into new ways of thinking about end-of-life care and decisions?

As the world becomes more digital, the participants on our study spoke to the value of being able to communicate through digital social media as families spread across different continents. Harnessing the positives of these channels is important (Bradshaw et al., 2024). Working on ways people's care preferences can be recorded in more diverse ways using digital tools, rather than as a written advance care plan, is one area of development that has been found to have acceptability and a number of promising advantages (Birtwistle et al., 2024; Bradshaw et al., 2024).

Understanding and taking note of the hysteresis that people dying transnationally experience

Further work is needed to explore methods to engage healthcare professionals, the palliative care community, and African and Caribbean heritage communities with the findings of this study. There is a need to be more empathetic to the sense of hysteresis that can occur both for older people and for their children when they are living between cultures in a society where their habitus is having to evolve more quickly than perhaps, they would choose. This greater sense of empathy and understanding, together with more modern co-creative research technologies can be used to develop new ways of working with families to increase opportunities for conversations to take place that are helpful and meaningful improving acceptability and understanding of services available (Nelson et al., 2021). Finding new ways of developing a better awareness of the decisions that need to be made in the future, and the things it is helpful for families to talk about before the end of life arises, with a sensitivity around what is and what is not helpful, needs to be a core message in these endeavours.

The eventual theory of living and dying between cultural traditions has resonated with healthcare professionals when shared with them. I have built this up into part of a teaching resource that I have been using and plan to present at the EAPC conference in 2025 (Appendix 6).

9.12. Critique of the study – strengths and limitations

The aim of this study was to develop theory to explain the dynamics that underpin the perceptions that older adults from African and Caribbean heritage and their children have about having conversations within the family about end-of-life preferences using a constructivist grounded theory methodology. The objectives of the study included developing ways of enabling healthcare practitioners to connect with this theory when working with families, and to consider strategies to engage communities to consider how this theory could be used to inform culturally sensitive approaches to having end-of-life family conversations.

9.12.1 Strengths

Methodological strengths

A range of perspectives in the focus groups of people of African and Caribbean heritage living in the UK around this topic of end-of-life conversations have been captured in this study. It is good to be able to add the new perspectives these voices bring to the existing narratives on this topic. All the participants of the focus groups valued the opportunity to discuss this topic. Several commented on how useful it was to hear the perspectives of others and how this often resonated with their own experiences, although they had not articulated it before. The recruitment techniques resulted in a broad mix of participants in terms of age, occupation and life situations. This brought a richness to the discussions. The role and lack of preparation of adult children as surrogate decision makers surfaced as an important feature of work to develop.

The timing of the focus groups worked well. The spaces between them allowed for preliminary analysis of the data obtained before undertaking the next group. When needed, this allowed both purposeful and theoretical sampling to take place which resulted in making the data collected richer. There was a period at the start of the pandemic when the study had to be put on hold; however, being able to start back by conducting online focus groups gave the opportunity to develop different ways of collecting this data, i.e. moving from face-to-face to online data collection. This had strengths and limitations as discussed in Paper 3. Using conversation analysis measures within this focus group study has highlighted how this can be done and the usefulness in understanding what types of conversations are taking place. This offers researchers the opportunity to plan for potential issues when conducting focus groups either online or in person and to monitor and adapt this as they progress through their research. Enabling interactive conversations led by participants is particularly important when looking to understand community rather than just individual perspectives on a phenomenon.

The research team involved in this study has been a strength. The study was hosted in the International Observatory of End-of-life Care, so early in the design phases of the study there was a rich resource of experienced theoretical researchers to draw on, including my three PhD supervisors. Between us, we also had a variety of ethnic heritage which was helpful and grounding. Both my critical friend. Karen, and I worked at King’s College London and had the benefit of working alongside colleagues in the Cicely Saunders Institute including Jonathan Koffman, Irene Higginson and Richard Harding who had worked in palliative care research in ethnically diverse communities for some years. The Institute ran a useful research seminar that helped in my own study design.

Strengths of thesis type

Choosing to submit this PhD as an alternate format multipart thesis resulted in aspects of this research study being published along the journey (Mason, 2018, Broome, 2018). I was fortunate to have the opportunity to present the work prior to publication at conferences. This experience allows the writer to condense and hone the messages that they wish to convey from that piece of work. I was able to use those presentation experiences to then write the papers. Publishing the papers, while receiving the support of my supervisors gave me considerable experience in this art. This can be a potential challenge for students taking this route to their PHD thesis (Frick, 2019) however apart from the time it takes for both of my supervisors, critical friends and myself, to bring these works to publication (appendix 4) the process was harmonious and developmental. Publishing concurrently also enabled me to share my findings in a timely manner which allowed them then to be used by others who were further developing these strands of work. Presenting to groups such as the Lambeth GP network and during teaching sessions to practicing health care professionals also meant the work was being disseminated as the study was ongoing.

9.12.2 Limitations

Assumptions and deficit reporting

So many research studies around issues of ethnicity focus on differences due to ethnicity as a social problem (Zubair & Norris, 2015). Although this was inherent in my initial assumptions, as explored in Chapters 1 and 2, time was spent trying to overcome this sense of deficit. The concept analysis in Chapter 4 was an attempt to explore the positioning of this in relation to palliative care access and other aspects of advance care planning. However, this piece of work was complex to construct and remains the one unpublished paper in this collection. These ideas are countercultural in a speciality that sees itself as one that is altruistic and centred on reducing distress. It is important for all researchers to develop a better understanding of the unconscious bias we hold and how to work cooperatively in research with others to created culturally nuanced protocols (Koffman et al., 2023; Sanders et al., 2018). Rather than having a strengths-based approach from the start in this research around diverse ethnicities, this is something that developed along the course of the research.

Although different strategies for recruitment were used, opportunities were lost to recruit a wider range of participants. This was in part due to the novice skills of myself as researcher. Potentially consenting men in the group who met at the Hindu temple were not effectively invited to join a prepared focus group at an early stage. I need to learn to work out a better balance between being seen as a complete outsider and recruiting as soon as you join a group of potential participants. My technique of taking time to build up rapport with the Temple group, such as eating together and getting to know people with the group as I did, needed to be better balanced so as not to miss the moment when recruitment may have happened.

Recruitment of ethnically diverse men to research projects has been found to be most effective through either approaching them via their families or informal gatekeeper or through creating activities they are keen to engage in (Bottorff et al., 2015; Fry et al., 2023; Law, 2019). More directed strategies needed to have been employed to recruit more men into the study to ensure their contribution to this study topic was explored.

Study Design

This was the first major research study I had designed and carried out and it took place over an extended period. As a PhD student it was the first time I was engaging with the philosophy of research and a real recognition of the importance of defining one's ontology, epistemology and then proceeding into selection of suitable methodologies for the study. For me, exploring Bourdieu's theory and seeing it as a tool for understanding my epistemology, was helpful. I felt however there was a gap in existing knowledge and so used a theory developing methodology to conduct my study.

There is some debate about where the exploration of philosophy, existing theory, findings and resultant discussions should be positioned when conducting theory developing methodologies such as grounded theory. This thesis is written up chronologically as to the stages that were undertaken. It has been difficult to be articulate reflexively all the decisions and thinking that resulted in the way the study progressed, as a result there is some ambiguity about how these processes meld together. This is something that serves as a lesson for me as a developing researcher and perhaps for others undertaking such studies.

9.13. Contribution of this thesis and its implications

Some implications for practice, research and education of different aspects of this study have been discussed in the published papers included in this study. The key implications are reiterated here including a discussion of the implications for policy and society.

9.13.1. Implications for Healthcare Practice

People of ethnically diverse heritage cultures have unique and often resilient family stories as discussed by the participants in our study. The need for practitioners to be more culturally aware and connected is a common theme in the literature. The pivotal role played by adult children and welcomed by the elders in these communities needs to be acknowledged. Conversations about differences needs to be welcomed and explored rather than seen as optional extras or items that can be discussed if there is time, so that changes in practices can be discussed and implementation plans can be valued and monitored. For individuals to practice with cultural competence, it is important for the structures in which palliative care is practised and developed to be redesigned. Bodies and teams involved in service development need to have wider representation of different cultural views in equal positions of decision-making power. Learning to be culturally safer organisations is a movement gaining momentum in some countries, including the UK (Curtis et al., 2019). However, they are vulnerable to the political appetites of people in power who allocate funding. Interventions such as carefully constructed online continuing development courses can be used alongside ensuring that some work around sensitive approaches to dying are made part of mandatory training for staff on an ongoing basis.

9.13.2. Implications for Healthcare Education

This is an area where more widespread impact can be made. Cultural competence is an area that is often explored but needs to be a core component of all pre-registration health care professional programs. Helping students understand the real issues voiced by participants of different cultures through research such as through this study is key to create a real understanding of the experiences of others. Learning cultural humility is important if the end goal is to create cultural safety for all patients and families. To date, pre-registration curricula is variable in its effectiveness in creating understanding. Work is needed to develop this aspect. A lesson plan developed to enhance better awareness in a classroom is outlined in Appendix 6. Developing this into a larger package of teaching and influence on heath professional education pre- and post-registration is needed.

9.13.3. Implications for Policy and Leadership

Current palliative care policy is sparce internationally (Meier et al., 2017). There is an urgent need to develop policy guidance for general palliative care provision, both in hospitals and in the community in a much more widespread way to prepare for the growth in people requiring palliative care worldwide as populations live longer with serious illnesses (Robinson et al., 2016; Sleeman et al., 2019; Sleeman et al., 2021). As policy is developed, care is needed to ensure there is systematic consideration of cultural equity in what is being proposed. This is best achieved by having good representation of a mix of cultures on policy making teams, working in an environment where that diversity is respected (Bajwah et al., 2024; Schweda et al., 2017). There is a need to evaluate the impact of policies to ensure that policies are set up not to provide equal services for everyone but equitable services. Care is needed to be thoughtful and considered about who decided what is what is measured in determining whether services are being developed in the right direction to meet the needs of a variety of communities (Bullock et al., 2022; Emmerich et al., 2015; Stajduhar, 2020). This may mean that some aspects of services require extra resources to ensure what is needed to enable all people requiring that service to be able to access it in a way that is helpful for them.

9.13.4. Implications for Future Research

When considering how the experiences in the field of dying and end of life can be improved for people from diverse cultural backgrounds, it is important to keep in mind that not all people who die in society have contact with health services (Kellehear, 2024). Dying is a societal event that for many who die of unexpected causes or unpredictable life events, and also those who choose the path Kellehear describes as anti-dying or make a choice not to acknowledge that death is imminent, they have little contact with healthcare professionals. This theory that seeks to explain the experiences of groups of people needs to be disseminated in society as well as within health services. This PhD study has focused on an exploration of this issue within the health service and so the implications will have this focus. By choosing a PhD process of publication as part of the process, the ideas generated by this PhD are already in the public domain and have been presented at conferences and through teaching opportunities to amplify the reach of this work. Further work is needed after this is completed to consider how this work might be used in a societal context to improve outcomes around reducing stress and distress around end-of-life decision making that may happen in the future.

Following the completion of this study and related discussion, these other areas remain underexplored: Exploration is needed around how continued taboos around illnesses like cancer impact families' discussions towards the end of life. What interventions may help adults who are adult children to work on their own fears of losing a parent and enable them to prepare for their role as future decision makers for their parents and older relatives? How does distance and distributed family's impact on end-of-life preparation and decision making? How can professionals develop a more confident approach when communicating with ethnically diverse families who may be geographically dispersed? Co-created research with people who live in African and Caribbean heritage communities, particularly adult children, may help to develop systems of communication about serious illness and end of life within healthcare that work better for different types and shapes of families where there are ethnic and geographical distances involved.

9.14. Conclusion

In conclusion, this study has been a journey of discovery and learning for myself as a junior researcher. Through this research process I have learnt not only how to generate and utilise knowledge in the form of different types of literature reviews, but then to use that knowledge to design and conduct a study which has generated new knowledge.

Reflecting upon my journey, I have gained a depth of knowledge into the design and conduct of a constructivist grounded theory study, whilst at the same time I have developed the skills to engage with the literature and wider research community. Beyond this, as I have developed as a researcher, I have also learnt how to combine these two approaches and appreciated how links between them can enhance research studies, their dissemination and their impact.

The participants in this study shared very valuable insights into their family experiences. It was a learning journey for me to understand how different and how similar but always how complex negotiating family conversations around topics as sensitive as the death of parents and precious older relatives can be. I hope that this new theory of living and dying between cultural traditions will be a catalyst not only for people within African and Caribbean heritage communities, but also for healthcare providers to gain greater insight into people's experiences and therefore what may be influencing different ways people approach the idea of having family conversations around end-of-life care preferences, which in turn will improve the provision of palliative and end of life care and hopefully provide opportunities to reduce the distress that comes from poor relationships and conversations at this difficult time.

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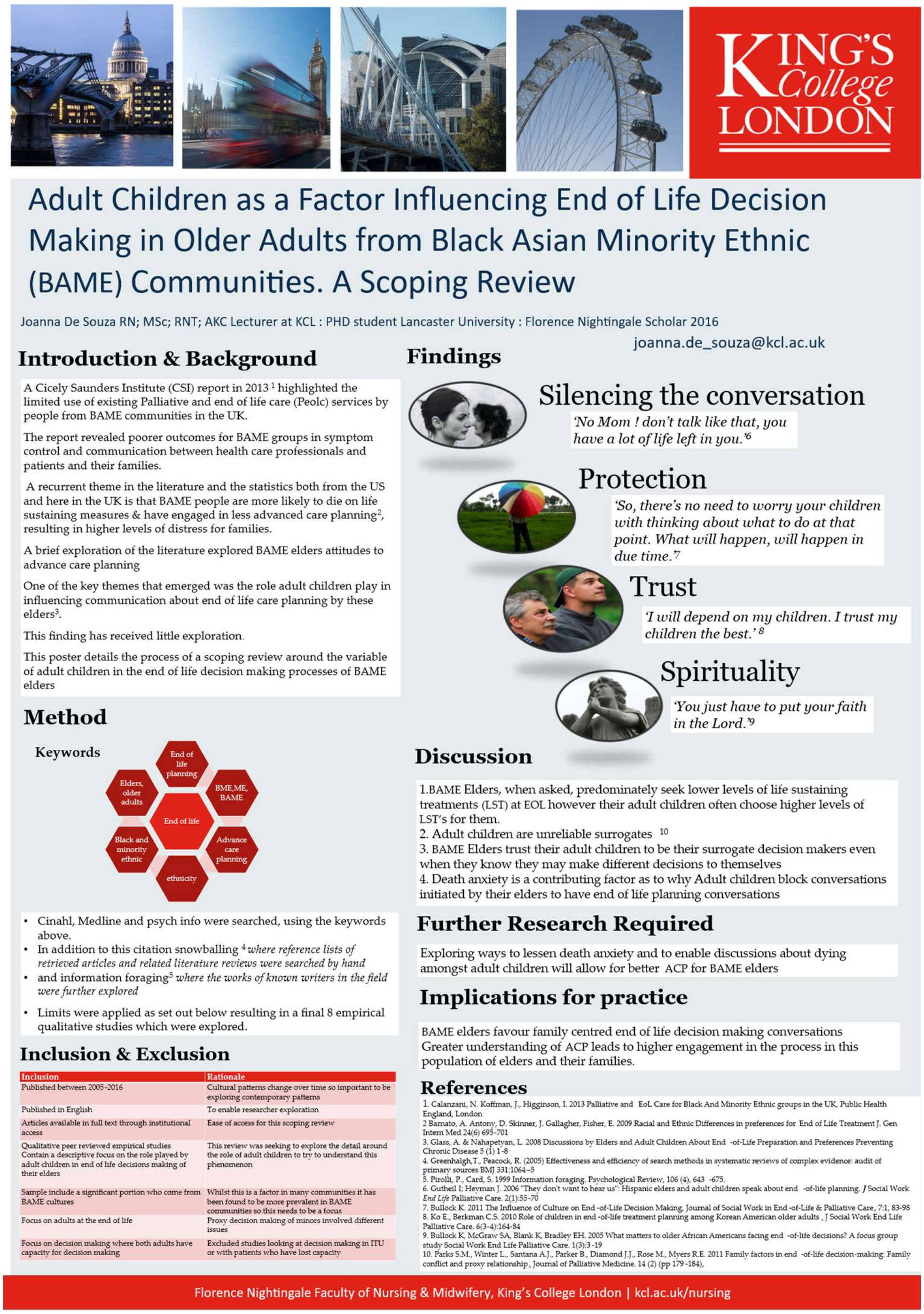
Appendix 1. Initial exploration of the literature



KING'S College LONDON

Adult Children as a Factor Influencing End of Life Decision Making in Older Adults from Black Asian Minority Ethnic (BAME) Communities. A Scoping Review

Joanna De Souza RN; MSc; RNT; AKC Lecturer at KCL : PHD student Lancaster University : Florence Nightingale Scholar 2016

joanna.de_souza@kcl.ac.uk

Introduction & Background

A Cicely Saunders Institute (CSI) report in 2013 [1] highlighted the limited use of existing Palliative and end of life care (Peolc) services by people from BAME communities in the UK.

The report revealed poorer outcomes for BAME groups in symptom control and communication between health care professionals and patients and their families.

A recurrent theme in the literature and the statistics both from the US and here in the UK is that BAME people are more likely to die on life sustaining measures & have engaged in less advanced care planning[2], resulting in higher levels of distress for families.

A brief exploration of the literature explored BAME elders attitudes to advance care planning

One of the key themes that emerged was the role adult children play in influencing communication about end of life care planning by these elders[3].

This finding has received little exploration.

This poster details the process of a scoping review around the variable of adult children in the end of life decision making processes of BAME elders

Method

Keywords

- Cinahl, Medline and psych info were searched, using the keywords above.
- In addition to this citation snowballing [4] *where reference lists of retrieved articles and related literature reviews were searched by hand*
- and information foraging[5] *where the works of known writers in the field were further explored*
- Limits were applied as set out below resulting in a final 8 empirical qualitative studies which were explored.

Inclusion & Exclusion

Inclusion	Rationale
Published between 2005-2016	Cultural patterns change over time so important to be exploring contemporary patterns
Published in English	To enable researcher exploration
Articles available in full text through institutional access	Ease of access for this scoping review
Qualitative peer reviewed empirical studies Contain a descriptive focus on the role played by adult children in end of life decisions making of their elders	This review was seeking to explore the detail around the role of adult children to try to understand this phenomenon
Sample include a significant portion who come from BAME cultures	Whilst this is a factor in many communities it has been found to be more prevalent in BAME communities so this needs to be a focus
Focus on adults at the end of life	Proxy decision making of minors involved different issues
Focus on decision making where both adults have capacity for decision making	Excluded studies looking at decision making in ITU or with patients who have lost capacity

Findings

Silencing the conversation

'No Mom ! don't talk like that, you have a lot of life left in you.' [6]

Protection

'So, there's no need to worry your children with thinking about what to do at that point. What will happen, will happen in due time.' [7]

Trust

'I will depend on my children. I trust my children the best.' [8]

Spirituality

'You just have to put your faith in the Lord.' [9]

Discussion

1.BAME Elders, when asked, predominately seek lower levels of life sustaining treatments (LST) at EOL however their adult children often choose higher levels of LST's for them.
2. Adult children are unreliable surrogates [10]
3. BAME Elders trust their adult children to be their surrogate decision makers even when they know they may make different decisions to themselves
4. Death anxiety is a contributing factor as to why Adult children block conversations initiated by their elders to have end of life planning conversations

Further Research Required

Exploring ways to lessen death anxiety and to enable discussions about dying amongst adult children will allow for better ACP for BAME elders

Implications for practice

BAME elders favour family centred end of life decision making conversations
Greater understanding of ACP leads to higher engagement in the process in this population of elders and their families.

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Florence Nightingale Faculty of Nursing & Midwifery, King's College London | kcl.ac.uk/nursing

Appendix 2. Ethics applications approval letter

FHMREC18

Lancaster University

Applicant: Joanna De Souza
Supervisor: Catherine Walshe, Katherine Froggatt
Department: Health Research
FHMREC Reference: FHMREC18

29 August 2019

Dear Joanna

Re: Perspectives of people of African or Caribbean heritage on having end of life conversations within the family. A constructivist grounded theory UK based study.

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC).** The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.

Appendix 3. Patient information pack

Patient Information Sheet

An exploration of the perspectives of people of African and Caribbean heritage on family conversations about health matters as people grow older

My name is Joanna De Souza, and I am conducting this research study as a student on the PhD in Health Research programme at Lancaster University, Lancaster.

What is the study about?

The purpose of this study is to explore what is important to people when thinking about their treatment and healthcare choices as they grow older in the UK. We want to find out the views of older people and their younger family members around discussing this within the family. We want to understand the views of people on this who are of African or Caribbean heritage.

Why have I been approached?

You have been approached because the study is recruiting people who are of African or Caribbean heritage, are currently reasonably well, living at home, are over the age of sixty or who have family members who are older than 60 living in the UK.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part, the process is entirely voluntary.

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

You would be asked to give your contact details to the research team; they will contact you to invite you to a focus group or an interview. A focus group is where you will meet with a group of people to have a discussion about talking about treatment and healthcare choices. Two researchers will be present at the focus group or the interview, one to facilitate the discussion and the other to make notes about what happens in the session. There will be some refreshments available. The focus group or interview is planned to last an hour. You will be given information about what is involved, and we will ask you to sign a consent form before the discussion. Following the session, you will be given information of people to contact if you are distressed or just want to talk further about the topics raised in the focus group. You will be offered up to £15.00 to cover your travel expenses.

Will my data be Identifiable?

The information you provide is confidential. The focus group/individual interviews will be typed out and both the transcripts and the recordings will be encrypted and stored securely in the Lancaster University computer systems and only the researchers conducting this study will have access to this data. All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to someone about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a written PhD thesis and submitted for publication in an academic journal. These findings will be shared with a variety of people who may be interested such as community groups like yours and also to healthcare professionals through conferences, teaching and via published information.

Are there any risks?

The only risks anticipated with participating in this study are any emotional reactions you may have to discussing these topics. The group facilitators are experienced palliative care nurses and will offer some immediate support and give you contact details of further places of support you can access after the focus group. You can withdraw from the study at any time. Once you have taken part in a focus group, it will not be possible to remove all your contributions to the focus group conversations as this will be mixed with what has been said by others, however we can remove specific statements you have said and can identify for us, or ensure they are not published as a quotation in the study outputs. You can still withdraw from the study and not receive any further correspondence from us. If you experience any distress during or following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Many people find taking part in these types of discussions interesting and informative. However, there are no specifically intended benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

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

If you have any questions about the study, please contact the main researcher:

Joanna De Souza via email on j.desouza1@lancaster.ac.uk *or by phone mobile phone 07769894121*

Supervisors: Professor Caroline Walshe & Professor Katherine Froggatt

Concerns

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact: Professor Nancy Preston Co-Director for IOEOLC Tel: (01524) 592802 Email: **n.j.preston@lancaster.ac.uk,** Health Division, Lancaster University, Lancaster LA1 4YG

If you wish to speak to someone outside of the Health Research Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746

Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine (Division of Biomedical and Life Sciences)

Lancaster University, Lancaster LA1 4YG

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

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance. .....

Age UK **Advice line on 0800 678 1602** open 8am to 7pm, every day of the year.

Age UK Lambeth on 0207 346 6800 email info@ageuklambeth.org.uk

Kate Admiral – Older people lead at HealthWatch Lambeth

Tel : 0207 0955746 email : Kate.damiral@heathwatchlambeth.org.uk

Invitation letter and reply slip

Participant focus group invite

Study Title: An exploration of the perspectives of people of African and Caribbean heritage on family conversations about health matters as people grow older

Dear (Insert title here)

I would like to invite you to take part in a focus group (small discussion group) or interview on (insert date, time and location) to discuss your views about discussing health matters with your family as you get older. The focus group/interview should last no longer than an hour. The focus group/interview will provide an opportunity for you to find out about the study outlined above. You will hopefully have received an information sheet about the study and if you would like to know before participating, please do contact me. Your views will be used to help us develop better understanding which we hope to use to inform healthcare professional education and working practices in this area.

If you would like to take part in the focus group/interview on (insert date) please let us know by contacting me, Joanna De Souza on 07769894121 or by emailing j.desouza1@lancaster.ac.uk. You could also use the reply slip attached and the prepaid envelop provided.

Travel expenses of up to £15.00 will be provided on the day.

Yours faithfully

Joanna De Souza

PhD student
Division of Health Research
Lancaster University
Lancaster LA1 4YT
j.desouza1@lancaster.ac.uk

Confirmation of Meeting:

Study Title : An exploration of the perspectives of people of African and Caribbean heritage on family conversations about health matters as people grow older

Thank you for the invite to the focus group/interview on ....

I ....((name)

(please delate the ones that do not apply)

1. Would like to attend on this date
2. Would like to attend but cannot make this date/time
   Please give some alternative dates/times in the next month that would be preferable
3. Would prefer not to attend
4. Other (please give details)

Any particular dietary requirements as there will be light refreshments provided.

....

Signature .... Date...............................

Contact number on the day in case of emergency cancellation

....

Advertising Poster

We need your help

Would you take part in a study exploring your views on when it is appropriate to have family conversations about your priorities when you reach the end of life

What is the study about?

To explore what is important to people when thinking about health in later life and their views about how they choose to discuss this with their families. We would like to hear the views of people from African or Caribbean ethnicity.

Who should take part?

We are looking to speak to people who are either over 60 themselves or who are younger but have a family member who is over sixty living in the UK.

My name is Joanna De Souza, I am a nurse and have lived and worked in South London for many years. I am conducting this research study as a student on the PhD in Health Research programme at Lancaster University, Lancaster, United Kingdom. For further details contact me on j.desouza1@Lancaster.ac.uk or 07769894121 (mobile phone)

Health & Medicine | Lancaster University

Consent form

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: **www.lancaster.ac.uk/research/data-protection**

Study Title: An exploration of the perspectives of people of African and Caribbean heritage on family conversations about health matters as people grow older

We are asking if you would like to take part in a research project which will be exploring what you think about the questions asked. Before you consent to participating in the study we ask that you 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 speak to the principal investigator, Joanna De Souza

Please initial each statement

1. I confirm that I have read the information sheet 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 focus group/interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected. ☐
5. I understand that the information from the focus group/interview I participate in will be pooled with ideas from other focus groups. ☐
6. I understand that it will not be possible to withdraw my entire contribution to the focus group once it has taken place however I am aware I can request for anything specific I have said to be removed or not to be used as a quotation in any study outputs. I know all the contributions will be anonymised before being incorporated into themes. ☐
7. I consent to information and quotations from the focus group/interview being used in reports, publications, conferences and training events. ☐
8. I understand that the researcher will discuss data with their supervisors as needed. ☐
9. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor. ☐
10. I consent to Lancaster University keeping written transcriptions and the audio data of the focus group for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐

Name of Participant__________________ **Signature**____________________ **Date** ___________

Name of Researcher __________________**Signature** ____________________**Date** __________

Focus group and interview schedules

Hello. My name is Joanna De Souza and this is xx (introduce co facilitator) . I'd like to start off by thanking each of you for taking time to participate today. We plan to be here for about an hour. The reason we're here today is to talk about your opinions, thoughts and experiences of thinking and talking within the family about what you would want and what you think may be important to you at the end stages of your life. I'm going to lead our discussion today. I will be asking you questions and then encouraging you to discuss these things with each other. XX will not take part in the discussion but will be listening and may make a few notes about some of the conversations that are taking place.

I also would like you to know this focus group will be tape recorded. The identities of all participants will remain confidential. The recording allows us, as a research team, to revisit the discussion for the purposes of exploring what was said and using this and what is said in other groups to get picture of what is important to people . I will use this to complete the study which will then be available as a report or for developing research papers and presentations. If after the focus group or during the discussion, you decide you do not want your contributions used in the study, we will explore this at the end privately. We can ensure that anything specific you have said could be removed or not be published as a quote in any study publications. However, we cannot delete all your contributions as partly it is not always a possibility to decide from the recordings who is speaking and secondly, your contribution may be linked to something another person is saying who chooses to stay in the study. This will be discussed before the focus group starts.

Ground rules

To allow our conversation to flow more freely, it is helpful just to have some shared ideas about the best way to conduct this group.

1. I would ask that only one person speaks at a time. This is doubly important as our goal is to make a written transcript of our conversation today. It is difficult to capture everyone's experience and perspective on our audio recording if there are multiple voices at once

2. Everyone doesn't have to answer every single question, but this is an opportunity to hear everyone's thoughts, opinions and experiences so I may at times just encourage people to share something, so we can also hear their thoughts on what is being discussed. We really want to hear from everyone in the group at some stage.
3. This is a confidential discussion in that I will not report your names or who said what to anyone outside the group. Names of participants will not even be included in the final report about this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.
4. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without fear your comments will be repeated later and possibly taken out of context.
5. There are no "wrong answers," just different opinions. Say what is true for you, even if you're the only one who feels that way. Don't let the group sway you. But if you do change your mind, let me know.
6. Let me know if you need a break. The toilets are **[location]**. Feel free to enjoy a drink and a snack that are laid out on the table here.
7. Are there any questions?

Introduction of participants (10 minutes)

Before we start, it would be great to know a little about each of you. Please tell me:

1. Your name
2. How long you have lived in the area, who you live with and perhaps something you enjoy about living in the area where you do.

Thanks for coming today and talking about these issues. I know it can be difficult. Your comments have given us lots of different ways to see this issue. I thank you for your time.

Participant Debrief Letter

Study Title : An exploration of the perspectives of people of African and Caribbean heritage on family conversations about health matters as people grow older

Thank you for taking part in this research study. It is important to talk to people about their experiences and ideas about the conversations within families about the future. We hope this study will be used to help healthcare professionals to have a better understanding of these matters.

The next stage of the study involves writing out the conversations that took place during the focus groups and interviews and together with information from other similar focus groups, we will explore some of the ideas and experiences people have. We will write these up as a report that will eventually be published. The reason for publishing our results is so that the results of our study can be used by both healthcare professionals and other people to develop their understanding of this area and hopefully use it to work better with when attending to the health needs of people when they are older.

The information you gave us will be held anonymously. This means that it will be impossible for people to know what ideas came specifically from you or that you participated in the study. If you think of any questions you would like to ask about the study now the focus groups have been completed please do contact me by phone or by email.

Joanna De Souza on j.desouza1@lancaster.ac.uk or by mobile phone number xxxxxx

However if you would like to find out or talk more about the subjects we touched on around future health needs and planning for them you can contact any of the following organisation and talk to someone.

Age UK **Advice line on 0800 678 1602** open 8am to 7pm, every day of the year.
Age UK Lambeth on 0207 346 6800 email info@ageuklambeth.org.uk

Kate Damiral – Older people lead at HealthWatch Lambeth
Tel : 0207 0955746 email : Kate.damiral@heathwatchlambeth.org.uk

End of life rights information line – Compassion in Dying
Tel: 0800 999 2434 email info@compassionindying.org.uk
Website : compassionindying.org.uk

Thank you (signature) Joanna De Souza

Confidentiality Agreement -Transcription of Qualitative Data

Name of Study:	Perspectives of people of African and Caribbean heritage on having end-of -life conversations within the family. A constructivist grounded theory UK based study
Study PI:	Joanna De Souza, PhD student, Division of Health Research Lancaster University Lancaster LA1 4YT j.desouza1@lancaster.ac.uk

In accordance with the Research Ethics Committee at Lancaster University (UREC), 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 by the agreed deadline and do so in password protected files
- to destroy any audio and electronic files held by you and relevant to the above study immediately after transcripts have been provided to the research team, or to return said audio files.
- to assist the University where a research participant has invoked one of their rights under data protection legislation
- to report any loss, unscheduled deletion, or unauthorised disclosure of the audio material to any third parties, to the University immediately
- only act on the written instructions of the University/researcher
- to, upon reasonable request, allow the researcher, or other University representative, to inspect the location and devices where the audio material is stored to ensure compliance with this agreement
- to inform the University's Data Protection Officer if you believe you believe you have been asked to do something with the audio material which contravenes applicable data protection legislation
- to not employ any other person to carry out the work on your behalf.

Your name (block capitals) ______________________________

Address at which transcription will take place

Your signature & Date ______________________________

Appendix 4. Published papers journey to publication

Paper 1:

Submitted: 20.11.2018

Editorial acceptance and sent for peer review: 07.12.2019

Application for APC waiver supported with confirmation of student status: Yes

Reviewers' comments received: 30.06.2019

Response to reviewers: 20.08.2019

Paper accepted: September 2019

Response to reviewers

Reviewer comment	Response and Change made	Page
1. Introduction- I would recommend rephrasing the second paragraph as it reads awkwardly at present.	The beginning of the article has been reworked and labelling has been added to help add clarity. The 1st two paragraphs were reorganised to focus more clearly on topic in question.	
Methods 2. I did get initially confused over whether papers reporting the views of adult children were being included as well as those of elders, due to seeming inconsistency between objective 4 'how do children of BME elders describe their experiences…' and your earlier stated objective at the start of the methods section and inclusion criteria which suggest that only studies of views of elders would be included. This could do with clarifying.	The view of both adults and children were explored , however there were very few studies that included the views of the children independently , this has been raised as area needing further exploration.	
3. I also thought your paragraph under 'Phase 1 Determining the area of investigation…' needs to be re-structured. I would suggest that it would be more realistic to state that the purpose of the review is to increase understanding of the ways some families operate…, and from this identify implications for improving end-of-life care discussions, rather than the purpose of the review being to improve end-of-life care, which seems a little over ambitious.	Wording changed to *The purpose of this review is to increase the understanding of the ways some black and minority ethnic families operate around end-of-life decision making It is hoped this process of exploration may help to firstly engage people in black and minority ethnic communities to think about strategies to enable better awareness of each other's preferences and perhaps open up conversations around end of life in these communities; and secondly to promote a better understanding amongst healthcare professionals working with black and ethnic minority families. The following aim and objectives of the review were formulated;*	
4. Your objectives also currently read as questions (but without question marks at the end). Either re-phrase as objectives e.g. To explore what older people within BME communities…, or call them research questions and end each one with a ?	On reviewing the meta-ethnography guidelines, questions or objectives are acceptable. I have chosen to use review questions ***2.1.2 Review Questions*** *1. How do older people within black and minority ethnic communities describe their experiences of having end-of-life conversations with their adult children?* *2. How do children of black and minority elders describe their experiences of having end of life conversations with their parents?*	

	3. *What influences do these experiences have on the way these elders feel and think about initiating discussions about their end-of-life preferences?*	
5. Your heading 'Phase two: To define the area….' is inconsistent with other headings and would read better if reworded as 'Phase two: Defining the area…'	Yes this has been changed to be consistent with how the rest of the phases have been titled. *2.2 Deciding what is relevant* 1. *2.2.1 Search strategy*	
6. Study selection paragraph. I think a full stop is needed at the end of 'creative and purposeful searching is required.' It is currently a long and awkward sentence and needs breaking up in some way.	Full stop added and capital C on citation snowballing applied. Sentence better worded. *Qualitative studies are not always identified by traditional search methods such as MeSH identifiers are often variable so creative and purposeful searching is required. Citation snowballing (Greenhalgh & Wong, 2013) and information foraging(Pirolli, 2007) including google scholar searching was also employed to identify a further eight studies that fitted the inclusion criteria (Prisma Flow Diagram; Figure 1).*	
7. Search strategy: why you didn't just use two sets of terms (e.g. BME terms AND End of life discussion terms), rather than restricting with the 'children' set which may have meant relevant papers were missed, especially given that this set contains relatively few key words (Table 3) and does not include "children" (only "adult children"), "families" or "next of kin".	Searching was complex. In reality I did a range of database searches none of which yielded many more that about 7 hits that met my inclusion and exclusion criteria (it is interesting to note that the review by Hong (2017) found the same and found no further qualitative papers. As illustrated half of the papers where found through information foraging techniques which included google scholar searching of key terms. it was not possible to do a search that retrieved all the articles even after extensive MeSH heading analysis Search re written in Table 3 .	
8. You should also indicate which words are truncated. In your first set you state Ethnic* but this is the only word which appears to be truncated, when I would expect that many of these should have been truncated too e.g. Son*, Daughter*, Family prox*, advance care plan*.	Truncated words indicated in Table 3 . In the family search the family related terms were not used as it was found that this facet caused a number of irrelevant hits and reduced the number of valid useable hits achieved.	
9. Did you consider using the names of particular ethnic groups as key words? e.g. Bangladeshi, African Caribbean, African American, or did you check to see that studies reporting the experiences of particular ethnic groups are indexed in the databases as Minority Ethic etc, and therefore would be expected to be picked up by your MeSH terms. If so might be worth explaining this in the manuscript.	Rather than including all nationalities possible, during my original search I did search for African and afro Caribbean but this did not result in any more studies. So in my current search I used the term race which gave me the MeSH headings of Black, White and Asian. I also included Hispanics as so many studies are done in the US with this group. I originally used the term minority but had to remove it as it picked up a high number of studies which talked about 'a minority of people did …' Minority groups was one of the MeSH headings searched.	
10. In your prisma flow diagram the 'studies included' box currently states quantitative synthesis, when it should say qualitative synthesis.	Correction made	
11. Results I think you need to use Results as a heading above 'The Storylines' so that it is clear that we are moving from methods to results sections.	Title added, it will be called findings rather than results as described in the eMERGE guidance Storylines come from Noblit (2016) explained in text on page	
12. I think you should also use quotation marks or italics when introducing your storylines in the first paragraph.	Quotation marks and italics added. Also added to metaphors across the piece	
13. My only suggestion would be to try and relate more to any relevant literature on the experiences of people from white majority cultures, so we have more of a sense of what	To address why I have chosen to focus on people of black and ethnic minorities, is due to the evidence from previous reviews that end-of-life conversations are particularly difficult to have and consider taboo in those societies than in majority white	

the similarities and differences are and why these might occur. You do allude to this in places, but if more explicit comparisons or explanations can be made this would add weight to the first line of your conclusion	populations. Wallace (2015) was a particularly useful review. I have added this on page 3&4 *In part, difficult conversations at the end-of-life arise when family conversations about the end-of-life wishes of the dying person have not taken place and cannot be elucidated due to their deteriorating conditions.(Clarke & Seymour, 2010) Many older people feel they do not need to discuss their end-of-life preferences with their families because their children will know what they would want. (Wallace, 2015) (Ke et al., 2017) In general, older people do not want to live a long lingering existence and white majority populations find doing some kind of advance care planning is a comfort. However in black and ethnic minority populations, discussing dying is thought to be taboo more often than in the white majority population which results in much lower levels of evidence of end-of-life family conversations. (Sanders et al., 2016) (Ke et al., 2017; Ladd, 2014) Studies show similar differences between northern and southern European countries.(Evans et al., 2013; Sinclair et al., 2014)*	
14. This would also help mitigate the potentially homogenising effect of looking at ME groups as one category of people (as you yourself acknowledge), as the basis for categorising in this way must be less about the particular cultures of ME groups which will obviously vary significantly, but their status as 'minorities' in relation to majority culture and systems. You begin to do this in your reference to Bourdieu and cultural capital, but if you are able to develop any further explanations of similarities and differences with host cultures I think that would strengthen this section and the conclusions that you draw.	Within the review the perspectives towards having end-of-life conversations within the family have some common traits across many non-white western populations. These have consistently been identified in previous reviews and individual studies in different cultural groups. The meta-ethnography seeks to explore these in more death and to draw out the lines of argument or storylines that explain and illustrate these held perspectives. I have removed the references to Bourdieu as I feel these need greater exploration that the word count on the review allows.	

Reviewer 2

Reviewer Comment	Change made	page
1. The review needs to be brought up to date (I suggest the date of first submission to the Journal for consideration: I assume this was early 2019).	Search re run with an end date of 2019. No new studies were found to include in the meta-ethnography; however, two new integrative reviews were found looking at black and minority ethnic groups and ideas about end-of-life care planning. They mainly supported what had been previous reported in other reviews.	
2. You say that you are using the term 'black and minority ethnic' but your wording slips into use of other terms in various places (e.g. in the abstract you use the term 'minority elders' and on page 5 'minority families'). I suggest that you use the widely accepted acronym 'BAME' and check that you have used this every time you refer to your population of interest. On page 14 you use the term 'Canadian Indian Elder': surely this should be Canadian First Nations Elder?	These have all been changed to say black and minority ethnic consistently When referring to Canadian Indian Elder – I have tried to make this more specific by referring to people as Canadian Asian Indian Elders, this refers to people who originate from India. Another study looked at people of Canadian South East Asian origin so people from South East Asia..	
3. When the paper started, I assumed you were going to focus on futility (which is a well-developed concept in the literature), however, you veer away from this and instead refer to end-of-life decision making and end-of-life conversations. Your language about your focus is rather imprecise here and later in the paper. It seems to me that you are referring to a group of phenomena which might be called 'conversations about care and treatment decisions at the end of life' or some similar umbrella term. Some authors might call this advance care	This point was also made by reviewer 1 point 1. I have moved the first paragraph from my discussion to be the introduction to my paper. This paragraph focuses more clearly on the role of family discussions prior to dying can result in higher levels of futile treatments being delivered. I have made the focus of my review to be more consistently about end-of-life conversations.	

planning (although I can see why you might not want to use this term). Whatever term you use, it would be good to explain the context and rationale for its use and then apply the term consistently throughout the paper.		
4. I am not sure why, but I was irritated by your first few words: 'Many older people express a preference for a peaceful death'. This seems a very obvious statement that everyone can agree with.	I have changed the start of the piece and removed the offending statement. Whilst I agree the statement : 'Many older people express a preference for a peaceful death' seems obvious, as the research in this area shows, when older people themselves are not able to make end-of-life decisions due to deteriorating illness, their children often assume they would want to persevere with life extending interventions and that forms part of their reason for requesting life sustaining treatments, 'I am sure dad would have wanted us to do everything we could.'. However that has been explored by the reviews I have referenced in this section, so I have removed it from here.	
5. You use a statistic (33%) at the start of the paper that does not seem particularly robust to me: it is based on a review and most of the evidence is from the USA. Suggest that you change the wording accordingly to make this a more tentative observation (or get rid of it). Your paper does not go onto address this issue as its main focus (see point 6 below).	Statistic removed and wording changed to be more general as part of introduction and background.	
6. Your first paragraph needs to be carefully crafted/ edited to more closely reflect the issue you address in the paper (i.e. the ways in which families / adult children and older parents converse about end-of-life care and decisions). It's too broad at the moment.	I have changed the first paragraph to include the aim of the synthesis which I hope makes it more focused.	
7. I was not sure why you felt the need to define end of life as the last six months of life (line 44 page 3): I guess that your included studies used various time frames?	In the UK there remains some assumptions about palliative care and end-of-life care meaning different things. I have added in a section 1.2.1 on definitions to ass clarity for readers about the assumptions of meanings being used in this piece. *Over the last decade there has been an increasing debate over the best way to define care given to improve the way people die, with particular disparities around the terms palliative and end of life. (Hui et al., 2013; Hui, Nooruddin, et al., 2014) For the purpose of this review, end-of-life was defined as the time when people are considered to be in the last six months of life, acknowledging this timing can be difficult to predict.*	
8. Your text both in the introduction and the discussion has little to say about end-of-life care conversations between non BAME older parents and adult children (in which there are likely to be many parallels to your observations). I understand the word count issues but think the paper would be much improved by some comparative references to the literature on older people more generally in this area.	This matter was also raised by reviewer 1 in point 13. I have made an attempt to address this as outlined in my response to that point. In particular I have made reference to some good reviews in this area.	
9. You refer to the objective of the review on page 4 (line 46-49) and then on the next page articulate a slightly different aim/objectives. Be consistent here. Likewise with the text about aim in the abstract: this is different to the title of the paper.	I have clarified the review aim have changed this through the document to try and ensure better consistency. ***2.1.1 Review Aim*** *To develop a deeper understanding of the perspectives of black and minority ethnic elders and their children, about end-of-life conversations that take place within the family, using a meta-ethnographic approach.*	
10. Your use of the terms 'in vivo' and 'descriptor' metaphors I found confusing, especially as you also at times refer to themes/ interpretations/ storylines. Why do you need storylines and	I have revised the terms I am using to more clearly reflect the eMERGE reporting guidelines.	

metaphors? You say that in vivo metaphors are quotes from study participants: perhaps you could make this clearer in the text as well as in the table. Does the text relating to the metaphors (in bold) need to be linked to a particular paper if they are direct quotes? Please look at the wording and language here and see if you can make it clearer for the reader. I can see that Table 7 is helpful here: is there any way it can be brought into the main paper?	First order metaphors for direct study participant quotes (replacing NVivo) and 2nd order for quotes taken from study authors (replacing descriptor) These are outlines on page 8 in section 2.4	
11. Also regarding methods reporting: you need a reference for CASP	I have now added this in on page 8	
12. Your discussion needs some polish: suggest that you start with the helpful summary of key findings you provide on page 17 and then relate each of these points to wider research to identify their resonance/ difference. You make a point about educational initiatives that I did not see to a great extent in your findings (for example, you make passing reference to educational initiatives on page 14): it might be better to make a broader point about cultural adaptation of advance care planning interventions.	The description of the storylines in the findings section has been abbreviated to *The storylines illustrated firstly the role elders envisioned their children will play in end-of-life decision making "My family will carry out everything for me; it is trust". The second aspect was the perception that adult children inhibit end-of-life planning conversations: "No Mum, don't talk like that". The third was the sense of fatalism often associated with religious beliefs: "I leave it in God's hands." The fourth is the recognition of change and realisation that things may need to be done differently:" Who's going to look after us? " These* storylines are explored below. The original paragraph has been adapted to be an introduction to the discussion by also returning to the aim and outlining the storylines, This is then used to frame the discussion more clearly. There is also a short addition of discussion around the 4th storyline that provides what Noblit and Hare might refer to as a refutable metaphor.	
13. The 'What this paper adds' text: it would be better to avoid the first two points under what is known. They are not of core relevance to your review. Focus on what is already known about family discussions of end-of-life care planning of relevance to older people and in BAME communities. Similarly, I would avoid the first point made under 'what this paper adds': that would be more appropriate for a population based study. Carefully consider whether the other points reflect the conceptual understandings that you wish to communicate.	This has now been changed. The first two points have been removed from what is known about the topic to provide a clearer focus on the topic of family conversations. In 'the what is new' these three points have been retained as they relate most directly to this synthesis. *Black and minority ethnic elders avoid end-of-life planning conversations with their children to protect them from distressing conversations* *Adult children from black and minority ethnic communities block attempts by their parents to have end-of-life conversations with them.* *Black and minority ethnic elders express a preference for end-of-life decisions to be made by family proxies acknowledging that these decisions may not reflect their own preferences*	
14. Some wording and punctuation issues: • See my earlier comments about being careful to be precise in use of terms. • You refer to a collaboration on page 5: what was this?	To make what is meant by the collaborative process clearer, the wording has been changed to this: *A collaborative process of discussion of these metaphors was undertaken by the review team to seek links and translations between the studies being explored.*	
The sentence on lines 52-58 page 7 starting 'An example of this…..' is too long and unclear.	Wording of lines 52-58 changed to shorten the sentence and add clarity *Examples of this was the difference in attitude towards healthcare professional instigated advance care planning. There was more distrust of the system in the US than in other countries, and attitudes towards advance planning were more positive in south*	

	East Asian communities in the US and Canada where educational levels were higher.	
Please explain what you mean by reciprocal translations and refutable translations' page 8.	Definitions of reciprocal and refutable translations are in table 2 which will be situated in the text so more available for readers to see.	
Page 12, line 55: you should not start a sentence with 'Or'.	Page 12 This has been changed to make this more clear *Some people expressed a more fatalistic view that that life and death matters were beyond people's own control so necessitated little formal decision making regarding the future*	
Suggest you delete the reference to Bourdieu on page 15 if included, it would need further explanation.	This has been removed.	
Below, you refer to digital communication: this does not seem to relate that well to what you have presented in the paper	This has also been removed	
Page 16 line 12 'different' not difference	Thanks, this has been changed	
Same page and line: your work is not just about 'death conversations'	Death conversations changed to end-of-life conversations to be more in fitting with the study aim	
	Thank you to both of these reviewers for taking the time to do this detailed analysis for these helpful comments, hopefully it is now a stronger piece.	

Paper 2. Prepared for submission

This supplementary table of papers used in the concept analysis will be submitted as an online supplementary table.

Supplementary Table 1: Table of papers for Paper 2 – Concept Analysis

Date	Reference	Type of material
2023	Tan, & Foong (2023). Important to distinguish between end-of-life values and preferences for improved advance care planning.	Letter to editor
2022	Kishino, M., Ellis-Smith, C., Afolabi, O., & Koffman, J. (2022). Family involvement in advance care planning for people living with advanced cancer: a systematic mixed-methods review.	Systematic mixed-methods review
2022	Bullock, Gray, Tucker, & Quest, (2022). Race Roundtable Series: Structural Racism in Palliative Care.	Roundtable Delphi discussion
2022	Ma, & Joshi, (2022). Unpacking the Complexity of Migrated Older Adults' Lives in the United Kingdom Through an Intersectional Lens: A Qualitative Systematic Review. UK, Australia and China	Qualitative systematic review
2021	Hussain, J. A., Koffman, J., & Bajwah, S. (2021). Invited Editorials.	Editorial
2021	Bajwah, S., Koffman, J., Hussain, J., Bradshaw, A., Hocaoglu, M. B., Fraser, L. K., Oluyase, A., Allwin, C., Dunleavy, L., & Preston, N. (2021). Specialist palliative care services response to ethnic minority groups with COVID-19: equal but inequitable—an observational study (pre print, published in 2024)	Cross-sectional online survey
2021	Zaman, Espinal-Arango, Mohapatra, & Jadad, (2021). What would it take to die well? A systematic review of systematic reviews on the conditions for a good death.	A systematic review of literature reviews
2021	Shabnam, J., Timm, H. U., Nielsen, D. S., & Raunkiaer, M. (2022). Palliative Care Utilization Among Non-Western Migrants in Europe: A Systematic Review.	Systematic review
2021	Chidiac, C., Feuer, D., Flatley, M., Rodgerson, A., Grayson, K., & Preston, N. (2020). The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation.	Service Evaluation
2020	Stajduhar, K. I. (2020). Provocations on privilege in palliative care: are we meeting our core mandate?	Discussion paper
2020	Borgstrom, E. (2020). What is a good death? A critical discourse policy analysis. *BMJ Supportive & Palliative Care*.doi: 10.1136/bmjspcare-2019-002173	Critical Discourse Analysis
2020	Dirk, (2020). Symbolic violence, academic capital and reflexivity. *African Sociological Review/Revue Africaine de Sociologie*	Discussion paper

2020	Roenn-Smidt, Shim, Larsen, Hindhede (2020) Hysteresis – or the mismatch of expectations and possibilities among relatives in a transforming health care system, *Health Sociology Review*, *29*(1), 31–44. https://doi.org/10.1080/14461242.2019.1704425 *Denmark*	Ethnographic study using observation, interviews and documentary analysis
2019	Sanders, Johnson, Cannady, Paladino, Ford, Block, & Sterba, (2019). From Barriers to Assets: Rethinking factors impacting advance care planning for African Americans. *Palliat Support Care 17(3), 306-313* *USA*	Qualitative interview study
2018	McDermott, E., & Selman, L. E. (2018). Cultural factors influencing advance care planning in progressive, incurable disease: a systematic review with narrative synthesis. *Journal of pain and symptom management*, *56*(4), 613-636.	Systematic Review
2018	Kirby, E., Lwin, Z., Kenny, K., Broom, A., Birman, H., & Good, P. (2018). "It doesn't exist…": negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliative Care*, *17*(1), 90.	Qualitative interview study
2018	Gardner, D. S., Doherty, M., Bates, G., Koplow, A., & Johnson, S. (2018). Racial and ethnic disparities in palliative care: a systematic scoping review. *Families in Society*, *99*(4), 301-316.	Scoping Review
2018	Hong, M., Yi, E. H., Johnson, K. J., & Adamek, M. E. (2018). Facilitators and Barriers for Advance Care Planning Among Ethnic and Racial Minorities in the U.S.: A Systematic Review of the Current Literature. *J Immigr Minor Health*, *20*(5), 1277-1287.	Systematic mixed-methods review
2018	Green, A., Jerzmanowska, N., Green, M., & Lobb, E. A. (2018). 'Death is difficult in any language': A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. *Palliat Med*, *32*(8), 1419-1427.	Qualitative grounded theory study
2018	Zivkovic, (2018). Forecasting and foreclosing futures: The temporal dissonance of advance care directives. *Soc Sci Med* *Australia*	Ethnographic research with Asian families living in South Australia. Explores how people view individual and future oriented approaches to medical decision making
2017	Biondo, Kalia, Khan, Asghar, Banerjee, Boulton, Marlett, Shklarov, & Simon, (2017). Understanding advance care planning within the South Asian community. *Health Expect*,	Qualitative study
2017	Zaman, Inbadas, Whitelaw, & Clark, (2017). Common or multiple futures for end of life care around the world? Ideas from the 'waiting room of history'. *Social Science & Medicine*	critical conceptual paper

2017	Portanova, Ailshire, Perez, Rahman, & Enguidanos, (2017). Ethnic Differences in Advance Directive Completion and Care Preferences: What Has Changed in a Decade? *J Am Geriatr Soc*	Discourse analysis discussion
2017	Schweda, M., Schicktanz, S., Raz, A., & Silvers, A. (2017). Beyond cultural stereotyping: views on end-of-life decision making among religious and secular persons in the USA, Germany, and Israel. *BMC Med Ethics*, *18*(1), 13.	Qualitative study
2017	Tenzek, K. E., & Depner, R. (2017). Still searching: a meta-synthesis of a good death from the bereaved family member perspective. *Behavioral Sciences*, *7*(2), 25.	Metasynthesis
2017	Collyer, F. M., Willis, K. F., & Lewis, S. (2017). Gatekeepers in the healthcare sector: Knowledge and Bourdieu's concept of field. *Soc Sci Med*, *186*, 96-103	Qualitative Interview study
2016	Willmott, L., White, B., Gallois, C., Parker, M., Graves, N., Winch, S., Callaway, L. K., Shepherd, N., & Close, E. (2016). Reasons doctors provide futile treatment at the end of life: a qualitative study. *Journal of Medical Ethics*, *42*(8), 496-503.	Qualitative interview study
2016	Igel, L. H., & Lerner, B. H. (2016). Moving past individual and “pure” autonomy: the rise of family-centered patient care. *AMA journal of ethics*, *18*(1), 56-62.	Discussion paper
2016	Andriani, L., & Christoforou, A. (2016). Social capital: A roadmap of theoretical and empirical contributions and limitations. *Journal of Economic Issues*, *50*(1), 4-22.	Discussion paper
2016	Sanders, J. J., Robinson, M. T., & Block, S. D. (2016). Factors Impacting Advance Care Planning among African Americans: Results of a Systematic Integrated Review. *J Palliat Med*, *19*(2), 202-227.	Literature review
2015	Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2015). Informal caring networks for people at end of life: building social capital in Australian communities. *Health Sociology Review*, *24*(1), 29-37	Literature review
2015	Jutlla, K. (2015). The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing & Society*, *35*(5), 1032-1054.	Narrative interviews and constructivist grounded theory
2015	Periyakoil, V. S., Neri, E., & Kraemer, H. (2015). No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PloS one*, *10*(4), e0122321.	Mixed method study
2014	Wilson, Ingleton,Gott, & Gardiner, (2014). Autonomy and choice in palliative care: time for a new model? *Journal of Advanced Nursing*	Critical discussion paper

2014	Sinclair, Smith, Toussaint, & Auret, (2014). Discussing dying in the diaspora: attitudes towards advance care planning among first generation Dutch and Italian migrants in rural Australia. *Soc Sci Med*	Qualitative study
2013	Calanzani, Koffman, Higginson, . (2013). *Palliative and EoL Care for Black And Minority Ethnic groups in the UK*. London: Public Health England	Report
2012	Venkatasalu, M. R., Arthur, A., & Seymour, J. (2013). Talking about end-of-life care: the perspectives of older South Asians living in East London. *Journal of Research in Nursing*, *18*(5), 394-406.	Qualitative study
2012	Williams, R., Hewison, A., Wagstaff, C., & Randall, D. (2012). 'Walk with your head high': African and African-Caribbean fatherhood, children's mental well-being and social capital. *Ethnicity & health*, *17*(1-2), 89-103.	Qualitative study
2012	Gunaratnam, (2012). Learning to Be Affected: Social Suffering and Total Pain at Life's Borders. *The Sociological Review*	Discussion article
2011	de Pentheny O'Kelly, Urch, & Brown, (2011). The impact of culture and religion on truth telling at the end of life. *Nephrol Dial Transplant*, *UK*	A conceptual discussion
2008	Ahmed, & Rees Jones, (2008). Habitus and bureaucratic routines', cultural and structural factors in the experience of informal care:	A qualitative study
2001	Kirschner, & Lachicotte, (2001). Managing managed care: Habitus, hysteresis and the end (s) of psychotherapy. . *Culture, medicine and psychiatry*	Ethnographic qualitative study

	Related Articles on Bourdieu's concept of hysteresis	
2020	Graham, H. (2020). Hysteresis and the sociological perspective in a time of crisis. *Acta sociologica*, *63*(4), 450-452	
2015	Emmerich, N., Swinglehurst, D., Maybin, J., Park, S., & Quilligan, S. (2015). Caring for quality of care: symbolic violence and the bureaucracies of audit. *BMC Med Ethics*, *16*, 23.	
2013	Dumenden, I. E., & English, R. (2013). Fish out of water: Refugee and international students in mainstream Australian schools. *International Journal of Inclusive Education*, *17*(10), 1078-1088.	
2013	Uphoff, E. P., Pickett, K. E., Cabieses, B., Small, N., & Wright, J. (2013). A systematic review of the relationships between social capital and socioeconomic inequalities in health: a contribution to understanding the psychosocial pathway of health inequalities. *International journal for equity in health*, *12*(1), 1-12	
2010	Schwartz, S. J., Unger, J. B., Zamboanga, B. L., & Szapocznik, J. (2010). Rethinking the concept of acculturation: implications for theory and research. *Am Psychol*, *65*(4), 237-251.	
2005	Wacquant, L. *Pierre Bourdieu and democratic politics: the mystery of ministry* (Vol. 20005). Polity.	

	Wacquant, L., & Akçaoğlu, A. (2017). Practice and symbolic power in Bourdieu: The view from Berkeley. *Journal of Classical Sociology*, *17*(1), 55-69. https://doi.org/10.1177/1468795x16682145 Wacquant, L. J., & Bourdieu, P. (1992). *An invitation to reflexive sociology*. Polity Cambridge.	

prior to submission

Paper 3:

Submitted: 02.05.2023

Application for APC waiver supported with confirmation of student status: 22.01.24

1st Reviewers' comments received: 22.11.2023

1st Response to reviewers' stage 1: 23.12.2023

2nd Reviewers' comments received: 13.02.2024

2nd Response to reviewers stage 2: 22.02.2024

Article accepted: 27.02.2024 Published online 21.03.24

Nov /dec 23	Reviewers Comment stage 1	Response to reviewer	
	This article arises from the authors' decision (necessitated by social distancing during the pandemic) to change the mode of an investigation relying on focus groups from 'traditional' face-to-face to online groups.	Thanks this is a clear reflection of the report.	
1	The front end of the article sets out the 'state of the art' regarding purposes, strengths and weaknesses of focus groups as a research method. Some information is provided about the research project that led to this article, but I think it would benefit from considerably more contextualisation (although I understand this can be hard to provide at this stage, given the wish to anonymise project). Some of the basic information about the research design and data is only provided towards the end of the article (e.g. participants per focus group) - it would be better to present this information much earlier so as to guide the reader.	Thank you. The description of study has been moved to the introduction to allow the reader to orientate to the study early in the paper. 'Five focus groups of between 4-6 participants were conducted with older adults, adult children and adult grandchildren. The results of this study are discussed and published elsewhere (De Souza et al., in press) ' has been added to offer a little more information about the study.	
2	Also, some details are a bit confusing e.g. why did one of the groups consist of academics/researchers?	This is made clearer on p 22 line 8 Focus group 4 ran quite differently. One successful recruitment strategy for the focus groups during the pandemic was via internal communication bulletins in two academic institutions. This resulted in focus group four involving four academic participants and one lay person. The academic participants demonstrated both a real understanding of the research and a keen interest in it, they also had confidence speaking in this type of online space.	
3	Figure 2 (sociograms of the focus groups) is a useful illustration for the reader but please note that at least in the review PFD copy, some of the text in the headings above each figure overlaps and group five illustration appears incomplete. Instead of numbering participants sequentially, I think it would be clearer if they were referred to in the text as (for example), P2 in FG3 etc.(when reading this version, especially because the detail I refer to above was only presented towards the end, I thought at first that participants with high numbers (P11, P17) had been participants in very large online groups...mea culpa but clearer signposting earlier will prevent such misunderstandings.	Thank you , I have saved each image differently now to prevent the overlapping.	
	Because 'group discussion' is a fairly established synonym for focus groups, the authors could pay more attention to making	Thank you, I have tried to make this clearer as I have gone through.	

	clear that by group discussion they are referring primarily to the online mode, and more generally the cases where focus groups 'degenerate' to a set of multiple discussions between facilitator and individual participants. However, this is something that could happen in the f2f mode as well e.g. if facilitation or group dynamics are less than ideal) so to some extent there is a tendency here to conflate the disadvantages of the online mode with poor practices / lack of inexperience on the part of facilitator which might hamper in-person focus groups also.		
	The point about the facilitator 'controlling the narrative' (top of page 26) could perhaps be made more subtly - again, this is something that could happen in f2f groups as well (e.g. if rushing to 'cover' a complex topic) and also seems to be something that the facilitator in an online focus group setting could seek to ameliorate by various techniques (e.g. when asked something, put that question back to another participant instead of answering it themselves).	I have added to page 30 to recognise this	
	The conclusion (one short paragraph, no heading) is the least satisfactory part of the article both because it is too vague and because the term co-creation starts to feature here prominently, which comes as something of a surprise for the reader (please note that co-creation carries a very specific meaning and there is an extensive literature associated with the term - for clarity, the use of this term is probably best avoided in this article).	Thank you for this. I have removed the term co-creation and agree this refers to a specific type of research which is not part of our study's methodology. The conclusion has now been titled and amended to the following. Conclusion 'Qualitative researchers are increasingly using online data collection as it reduces complexity of gathering participants, can be less costly in time and traveling costs, and can provide a space in which some participants feel more comfortable to disclose information. Focus groups are used as a data collection method where ideas offered by participants generate thoughts and opinions for other study participants in the group, and the discussion that ensues offers insight into the positionality of different group members on the phenomenon under study. Analysis of the interaction in the focus group is also important in situating the data gathered using the process. Through this discussion, questions have been raised about whether the interaction in focus groups changes when data is collected online and how this can be analysed, considered and perhaps mitigated. It is important to be clear about the rationale for using focus groups as a method of data collection and to ensure these aims are achieved when using this method online.. '	
	The article is generally reasonably well written but there is evidence that it was not carefully proofread (several typos, missing apostrophes, on page 22 the heading at the top of the page should read online rather than face-to-face etc.).	Thanks, we have proof read it more carefully and corrected a number of errors.	
	The article would benefit from better structure, more carefully formulated sentences in places, and in particular greater clarity in the conclusions. The conversation 'fragments' were not particularly well anchored in the rest of the text so more work could go into explaining their role in the line of argument.	This comment has been considered and the articles has been reworked. As many of these changes involved moving paragraphs, the track changes were not kept as it made it difficult to read the piece. However, we hope it reads more clearly.	
	The 'hints and tips' section towards the end is quite nice but feels a bit detached - perhaps positioning it in a separate Box would be better stylistically and also enhance readability?	The recommendations have been moved into a box as suggested	
	I am not familiar with the most recent literature on focus groups but assuming there is no comparison of f2f and online modes, this article seems to make a useful contribution that many readers would find helpful, subject to improvements suggested here and by other reviewers.	Thank you.	

Feb 24	Reviewers Comments stage 2	Response to reviewer	Page no.
	Overall, the authors have done a good job of replying to the previous reviews. I think there are just a few minor adjustments that need to be made.	Thank you	
1	On the abstract, I do not believe that this journal uses structured abstracts, and the limit is 300 words.	Thanks well noted. The abstract has been reformatted and now flows as a discussion with a word count of 286	1
2	With regard to the first three fragments, it would be interesting to know if similar "building "occurred in any of the online groups.	We have addressed this by adding in another fragment of conversation fragment 4 . 'In the online focus groups, initially conversation started serially with conversations between the facilitator and individual participants (fragment 4). Fragment 4 *Adult child (P11FG3): What I find from my mother's generation is that they've made provisions for their funeral arrangements who's going to play the organ, what hymns are going to be sung …* *Moderator: ummmm… silence … and what sort of age were they when they did that?* *Adult child (P11FG3): oh when I was still in school….. (fairly long descriptive conversation of several things)* *Moderator: maybe if we first of all, just talk about funeral planning and that kind of thing, what's it like in other people's families? Is it similar or different?... silence* *Moderator' participant 12? (by name)* *Adult child (P12FG3): I was going to say it's quite interesting to hear P11's (by name) explanation. I can relate to a lot of that when I think back for my mom and dad…..(again a fairly lengthy conversation)* *Whilst this took place two other participants used the raised hand feature, so the moderator called them into speak in turn after participant 12 had finished.* This was followed by quite an active conversation, all participants had interactions with other participants however the arrows to the moderator are noticeably bigger than in the face-to-face groups and the moderator choose who to invite to speak next from those who had raised their electronic hands. This resulted in quite a serial conversation. P11 (FG3) said the least but did have some interactions directly with other participants. '	17
3	In the new Table 4, I did note a couple of typos. Item #1"Make a clear about whether" should probably be "Make it clear about whether"	Thanks, this has been corrected.	Table 4
4	Item #3 "the raised hand function is not moderated" should probably be" "the raised hand function is not monitored"	Yes, this is clearer so has been changed	Table 4
5	Table 4 also mentions use of the Chat function in the online groups, but this received very little attention in the rest of the articles. I would like to hear more about how it was used, if at all.	This has been reworded to say: Starting an online group with a discussion about how interactions are different online to in a face-to-face situation may be helpful. Explaining that participants do not need permission to speak and make it clear the raised hand function will not be monitored by the moderator, but instead participants can use it to indicate to fellow participants that they have a point to make or that they wish to respond, and then they should do so when they feel it is an appropriate time to come into the conversation.	Table 4

6	I did not find Figure 3 on "positionality" (and I would question this choice of wording, since the classic use of the term positionality in qualitative research refers to the researcher's personal and structural position with regards to the research topic).	Apologies this was not loaded. The wording has been changed to P19 line 1 Position perception P23 line 10 engagement P23 line 14 physical position On p30 line 35 I have left in positionality as it fits what is meant here.	19 23

Paper 4:

Submitted: 16.11.2023

Editorial revisions received: 22.11.2023

Editorial revisions submitted: 01.12.2023

Application for APC waiver supported with confirmation of student status: 20.01.24

Reviewers' comments received: 22.05.2024

Response to reviewers: 29.05.2024

Thank you for taking the time to review this submission and for the suggestions you have made, work is always stronger when it is considered by people with different perspectives. Please see below where we have attempted to address any concerns and to add to the work to incorporate your suggestions.

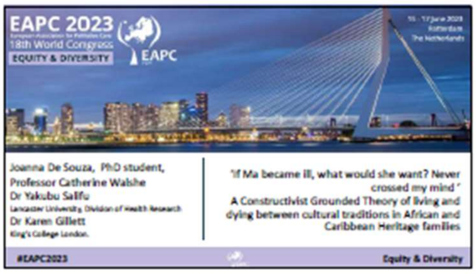
Feedback from reviewer 1	Thank you for your work and for the contributions made in a very important topic.	Thank you, this is encouraging.	Page
1.	The sample size is very small and gender-one- sided but still it raises important topics for more in-depth and focused work. I may have missed it; but is this part of a larger/wider research project? If so, perhaps there will be value in contextualizing this in the abstract or elsewhere.	This was an unfunded qualitative study independent from any other studies. As it was an exploratory study the sample size was determined at the outset. Aa a wide range of themes was developed from the data collected in the focus groups; the sample size was considered sufficient for this type of study.	1
2.	*In addition, when surveying the relatives of family members of people who have died, having a documented advance care plan resulted in a higher level of unmet mental health needs for people who identify as black (Luth & Prigerson, 2018).* Perhaps consider naming a few reasons why this is so	This has been adjusted to read : In addition, when surveying the relatives of family members of people who have died, having a documented advance care plan resulted in a higher level of unmet mental health needs for people who identify as black (Luth & Prigerson, 2018). Causes for this are unknown, but the study authors call for caution and additional research as advance care planning may not work the same way for black and white individuals. The benefits of such plans may be based on an assumption that control of future care is a good thing and that choice will be available to people equally(Zivkovic, 2018). Zivkovic's discussion of temporal dissonance and the risk of advance care planning not only forecasting futures but also potentially foreclosing possible futures indicates the complexity of this practice when used by people of different cultures (Grindrod, 2020; Zivkovic, 2018). References for this: 20. Luth EA, Prigerson HG: **Unintended Harm? Race Differences in the Relationship Between Advance Care Planning and Psychological Distress at the End of Life**. *J Pain Symptom Manage* 2018, **56**(5):752-759. 21.Zivkovic T: **Forecasting and foreclosing futures: The temporal dissonance of advance care directives**. *Soc Sci Med* 2018, **215**:16-22. 22.Grindrod A: **Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life**. *Progress in Palliative Care* 2020, **28**(2):94-100.	5
3.	Please consider unpacking the concepts of 'death' and 'dying' within this population and how	This is a complex subject and one that is the subject of our next paper. However we have added the following , does this offer some guidance in this area.	7

	it differs (if at all) from (e.g.) the western world.	The view of what constitutes a good death remains a 'contested space' in many aspects. One aspect is that much of the expectation of good dying in the literature is informed by evidence gathered from mainly white communities, rather than a more plural global perspective (Borgstrom, 2020; de Pentheny O'Kelly et al., 2011; Zaman et al., 2017). When facing a terminal diagnosis and seeking healthcare support, independence, individualism, autonomy, fear of relentless efforts extending poor quality life, choice and veracity are the values that shape the provision of palliative care (de Pentheny O'Kelly et al., 2011). These take the shape of open discussions about prognosis and options, autonomous decision making in the form of formal advance care planning and acceptance of input from healthcare professionals that are focused on symptom management and comfort rather than cure. Rates of completion of formal advance care planning remain lower in all minority ethnic groups (Portanova et al., 2017). As with all cultural processes this is a field that changes constantly due to prevailing influences. However, whilst completion of care plans amongst black minority populations in the United States is rising, they remain low and indicate a higher preference for continuing 'aggressive' care than white populations. Amongst most minority ethnic populations, choosing collective family decision making models remains an expressed preference. This is a complex matter and is explored more fully in a subsequent paper by this research team that is still in construction.	
4.	Please consider a footnote very briefly unpacking the pandemic (or attach a link) and explain the concept of 'social distancing'.	Thanks, yes, important to consider this was different in different countries. The impact of the pandemic and related social distancing is unpacked and explored in an earlier paper we have published so I have added a citation for that as it is a methodological issue to be aware of. Data were collected using focus groups. The first two focus groups were face-to-face and the last three were online due to the need for social distancing during the COVID- 19 global pandemic (de Souza et al., 2024a). 33. de Souza, J., Gillett, K., Salifu, Y., & Walshe, C. (2024). Changes in Participant Interactions. Using Focus Group Analysis Methodology to Explore the Impact on Participant Interactions of Face-to-Face Versus Online Video Data Collection Methods. *International Journal of Qualitative Methods*, *23*, 16094069241241151.	10
5.	*Oscillating values and preferences create tensions. Norms and values of the cultures in which people are currently living sometimes jar with those of the heritage cultures.* For whom? Provide references please	Thanks. The citations were not well placed here so they have been moved and added to. Oscillating values and preferences create tensions (Ma & Joshi, 2022; Roenn-Smidt et al., 2020; Zivkovic, 2018). Norms and values of the cultures in which people are currently living sometimes jar with those of the heritage cultures. Families must seek ways of living between these tensions. There is a sense of hysteresis or 'being pulled between' as families navigate illness and dying when family members live in different places in the world(Shabnam et al., 2022; Tan & Foong, 2023). Refs 8. Tan SM, Foong PS: **Important to distinguish between end-of-life values and preferences for improved advance care planning**. *BMJ Supportive & Palliative Care* 2023, **0:1–2**. 9. Shabnam J, Timm HU, Nielsen DS, Raunkiaer M: **Palliative Care Utilization Among Non-Western Migrants in Europe: A Systematic Review**. *J Immigr Minor Health* 2022, **24**(1):237-255. 21. Zivkovic T: **Forecasting and foreclosing futures: The temporal dissonance of advance care directives**. *Soc Sci Med* 2018, **215**:16-22 42. Roenn-Smidt H, Shim JK, Larsen K, Hindhede AL: **Hysteresis - or the mismatch of expectations and possibilities among relatives in a transforming healthcare system**. *Health Sociol Rev* 2020, **29**(1):31-44. 43. Ma M, Joshi G: **Unpacking the Complexity of Migrated Older Adults' Lives in the United Kingdom Through an Intersectional Lens: A Qualitative Systematic Review**. *The Gerontologist* 2022, **62**(7):e402-e417	23

6.	*family communication using WhatsApp family groups.* Please consider a footnote explaining this app	Hope this makes this clearer Our study participants valued the facilitation of family communication using WhatsApp Messenger family groups (mobile phone encrypted instant messaging service).	25
7.	*New relational and more individually nuanced models of palliative care are emerging with a focus on communities as sources of invaluable support.* Is this your observation or are you referencing literature? If it's the latter then please cite that as such	Thanks for noting this, yes referring really to the public health palliative care movement so have added two references. New relational and more individually nuanced models of palliative care are emerging with a focus on communities as sources of invaluable support (Lessard et al., 2023; Sallnow & Paul, 2018). 54. Lessard É, Marcoux I, Daneault S, Panaite A-C, Jean L, Talbot M, Weil D, Rouly G, Sallnow L, Kellehear A *et al*: **How does community engagement evolve in different compassionate community contexts? A longitudinal comparative ethnographic research protocol**. *Palliative Care and Social Practice* 2023, **17**:26323524231168426. 55.Sallnow L, Paul S: **New public health approaches to end-of-life care**. In: *Textbook of palliative care.* edn.: Springer; 2018.	27
Feedback from Reviewer 1	This is a competent paper with no methodological issues. Some very minor language changes are recommended.	Thank for this encouraging feedback. We have re reviewed the paper and made some minor language changes.	
Feedback from Editor	My only recommendations are quite minor. In general, the paper has too much jargon and could benefit from inclusion of more plain language. For example, replace "usage" with "use." And use more active voice rather than passive voice. For example, p7 line 9 is a passive sentence. P6 line 17 is a sentence fragment. It should begin with "Our aim was to construct...." There are several other instances of overly complex language in the paper. But these should not impede the paper's ability to get published	Thanks for your acceptance of our paper. We have made several minor changes in line with your feedback to the text to attempt to simply it and make it less passive.	

Appendix 5. Oral presentation of Theory

This was presented at the European Association of Palliative Care 2023 – Also used for other teaching groups

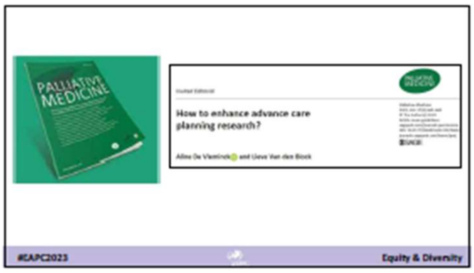


EAPC 2023
18th World Congress
EQUITY & DIVERSITY
EAPC
15 - 17 June 2023
Rotterdam
The Netherlands

Joanna De Souza, PhD student,
Professor Catherine Walshe
Dr Yakubu Salifu
Lancaster University, Division of Health Research
Dr Karen Gillett
King's College London.

'If Ma became ill, what would she want? Never crossed my mind'
A Constructivist Grounded Theory of living and dying between cultural traditions in African and Caribbean Heritage families

#EAPC2023 Equity & Diversity



How to enhance advance care planning research?

Aline De Vleminck and Lieve Van den Block

#EAPC2023 Equity & Diversity

The Question

Why don't people from black and minority ethnic communities access palliative care and advance care planning?

#EAPC2023 Equity & Diversity

Perspectives of elders and their adult children of black and minority ethnic heritage on end-of-life conversations: A meta-ethnography

What is known ?

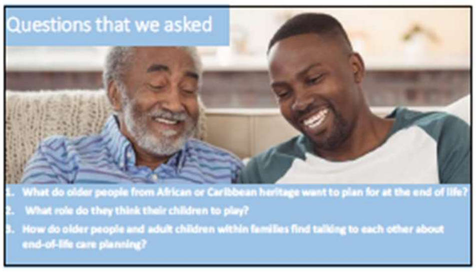
My family would do right by me

No mum don't talk like that

I leave it in God's hands

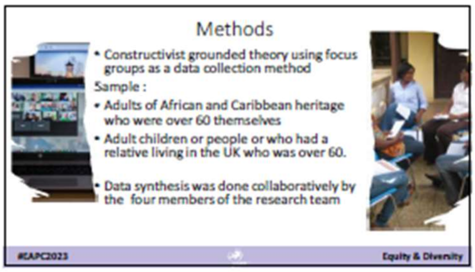
Who will take care of us

#EAPC2023 Equity & Diversity



Questions that we asked

1. What do older people from African or Caribbean heritage want to plan for at the end of life?
2. What role do they think their children to play?
3. How do older people and adult children within families find talking to each other about end-of-life care planning?



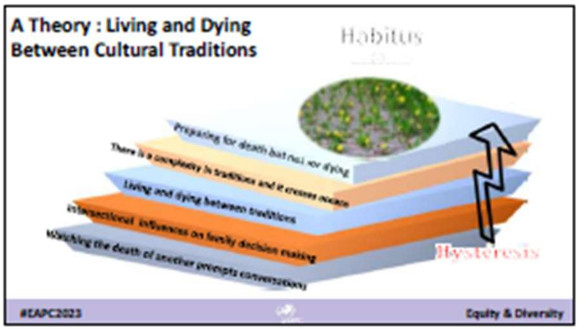
Methods

- Constructivist grounded theory using focus groups as a data collection method

Sample :

- Adults of African and Caribbean heritage who were over 60 themselves
- Adult children or people or who had a relative living in the UK who was over 60.
- Data synthesis was done collaboratively by the four members of the research team

#EAPC2023 Equity & Diversity



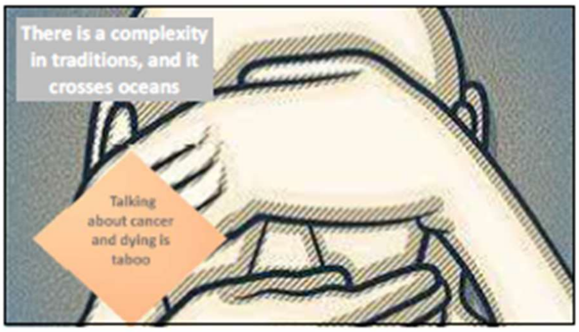
A Theory : Living and Dying Between Cultural Traditions

#EAPC2023 Equity & Diversity

Preparing for death but not for dying

We are planners of funerals but not of care

#EAPC2023 Equity & Diversity



There is a complexity in traditions, and it crosses oceans

Talking about cancer and dying is taboo

Living and dying between traditions

I am a London girl, things are different in Ghana

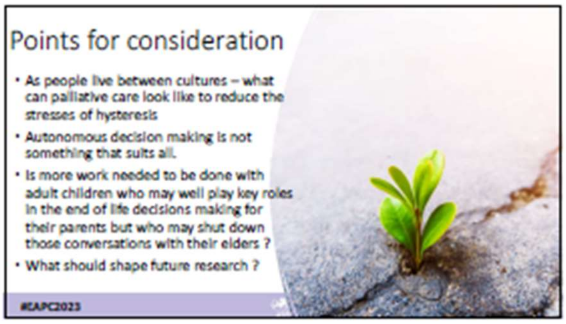
There is Culture, Gender and there is Personality

Who discussed what with whom and when

I talk with mum because her mum needs care now

Watching the death of another prompts conversations

Hysteresis



Points for consideration

- As people live between cultures – what can palliative care look like to reduce the stresses of hysteresis
- Autonomous decision making is not something that suits all.
- Is more work needed to be done with adult children who may well play key roles in the end of life decisions making for their parents but who may shut down those conversations with their elders ?
- What should shape future research ?

#EAPC2023

Thoughts and Questions ?

Appendix 6: Lesson plan for classroom session

Ethnic diversity and Palliative and end of life care

Date: 2024

Group: Nurses

AIM : To allow students to explore the palliative and end of life care experiences of people from different ethnicities

Learning Outcomes:.

- Raising awareness of different experiences of palliative care
- Consideration of the different research approaches that can be used to explore this area
- Articulation of how this new understanding can change personal and institutional practice

Time	Activity	Content	Aids
	Pre-sessional reading	Divide students into 6 groups. Provide each group with an article to read (articles should be selected as suitable to the study group and ensure they are current studies)	List of research articles and student groups
10 mins		Introduction self and topic Break into groups	
30 mins	Discussion Of designated study	In groups students discuss the research study they were allocated with review sheet to complete.	Review sheets
30 mins	Cooperatively led feedback session	Presentation of seminar session using powerpoint allowing each group to feedback on their study when appropriate	PP presentation
10 mins		Break	
10 mins	discussion	Feedback session continued	

30 mins	Planning	Preparation of action plan for practice	Action planning sheets

Session review:

This session has been completed with both undergraduate pre-registration nurses and post graduate post-registration practicing nurses.

Feedback: Very interesting session

Something I had not really thought about

Helpful to see what the research found

I really resonate with this, we see this a lot where I work

That was helpful, it has made me feel less nervous about opening up conversations.

Session development: Using the action planning sheets helps people to really think about their own setting and where areas of practice exist that could be improved.

Session Created by : Joanna De Souza

Reviewed : December 2024