Expressing end of life care wishes and preferences amongst Nigerian patients with advanced cancer and their family members: a grounded theory study

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A thesis submitted to Lancaster University in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for the assessment of taught modules within the blended learning PhD programme.

December 2020

Faculty of Health and Medicine

Lancaster University

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

degree elsewhere

Acknowledgements

All praises and adoration to the Almighty for His blessings throughout my research journey and giving me the ability to complete the research work successfully. The course of this PhD thesis has been a significant and demanding time for family and me, and I am grateful for all the people who have made it possible. Firstly, I would like to express my gratitude to all the patients and family members who participated in this study, sharing their most private and vulnerable moments with me. Their kindness through the smiles and insistence on continuing with the interviews despite their pain and sadness will forever live with me. I would like to thank my family for putting up with my busy schedules during this time. My husband, Habeeb and my children Hidaayah, Nuriyyah and AbdulRahman are my stars for always understanding why I needed time alone and bearing with me while I spent my energy and time pursuing goals that took me away from them. My deep gratitude goes to my supervisors, Prof Nancy Preston and Dr Sean Hughes for guiding me patiently through all these years and offering their valuable advice, support and boundless inspiration throughout the research process. The contribution of Dr Mary Turner, one of my initial co-supervisors also made an impactful statement in my work. Thank you all for your compassion and genuineness in seeing me through the PhD. To my parents, you are my world, thank you for always giving me the physical and emotional support that I needed to be able to see this work through, I couldn't have done it without you. Finally, a very special thank you goes to my friends and colleagues too numerous to mention who have always shown their support or helped by sharing their research experience and critiquing my work throughout the journey.

Abstract

Background: Expressing end of life care wishes and preferences is a vital component of Advance Care Planning (ACP) which facilitates the provision of end of life care that is consistent with the patient's expressed values, beliefs and goals of care outcomes. There is an acknowledgement of the impact of contextual values on the process of expressing wishes and preferences.

Aim: The aim of this study is to a gain a theoretical understanding of the process involved in expressing end of life care wishes and preferences based on the perspectives and experiences of advanced cancer patients and their family carers in Nigeria.

Methods: Using a constructivist grounded theory study approach, fourteen qualitative interviews from eight patients with advanced cancer and six family members of patients with advanced cancer were analysed to construct a theoretical model that explains the process of expressing end of life care wishes and preferences in Nigeria.

Results: "Rubbing minds together" explains a process by which patients with advanced cancer negotiate their way with their family members to facilitate expressing their end of life care wishes and preferences in the context of a cultural commitment to familial involvement in end of life decision making. The theory is composed of three interlinked components: controlling to seek relief, enduring and collaboration that acknowledges the ongoing overt and hidden compromises that occur in the end of life care communication in this context.

Conclusion: This constructed theory emphasises the relational nature of end of life care communication in the African cancer context. This may increase healthcare professionals' understanding and be crucial to achieving an end of life care context that acknowledges and encourages family members' involvement and not only that of the patients, thereby enhancing end of life communication with Africans nearing the end of life.

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Chapter 1: Introduction to the thesis

Talking about dying can bring up uncomfortable emotions for someone with a terminal illness and their family members (Bernard et al., 2020, Wright et al., 2008). Still, it can help the dying person to express their concerns and fears and allow them to make plans for what is important to them. We have no clarity about how Nigerian people express their end of life care wishes and preferences. The aim of this thesis is to construct a grounded theory on the process of expressing end of life care wishes and preferences among patients with advanced cancer and their family members in Nigeria. This study is based on the real-life experiences and perceptions of patients with terminal cancer and their family members. In this chapter, I provide an introduction with a brief discussion around the relevance of expressing end of life care wishes and preferences in relation to advance care planning (ACP) as well as the motivation for completing this study. This research contributes to a broader discussion around the provision of a culturally sensitive end of life care to people diagnosed with advanced cancer.

1.1 ACP and its significance in enabling expression of end of life care wishes and preferences

There has been increasing awareness of the importance of ACP in enabling patient's choices at the end of life (Brinkman-Stoppelenburg et al., 2014). ACP was originally conceptualised as a means of preserving individual patient autonomy and usually involves the completion of documents such as an advance directive (Robins-Browne et al., 2014). However, a recent consensus definition states that the goal of ACP is to help ensure the alignment of the medical care received by patients suffering from serious and chronic illness with their personal values, goals and preferences (Sudore et al., 2017). Importance should be given to identifying and

working towards outcomes which include but are not limited to respecting individual autonomy (Sudore and Fried, 2010). Improving the quality of care, strengthening relationships, preparing for the end of life, and reducing overtreatment are other identified outcomes of ACP (Fleuren et al., 2020). The diversity and variation in the envisaged outcome of ACP underscores the need for effective communication in ACP.

Expressing end of life care wishes is an important communication process that needs to be achieved before ACP can be achieved. Through patients' expression of wishes and preferences, a shared understanding of their values and care preferences in the context of their background and goals can be achieved by their family members and health-care-professionals. This discussion clearly needs to be conducted with skills and sensitivity. The outcome of such discussion ought to be regularly reviewed and communicated to all relevant people involved in the care of the patient. This is the process of ACP and this step cannot be achieved without the expression of end of life care wishes and preferences. ACP discussions involving expression of such wishes and preferences can occur at any time in a person's life but is especially more important for people diagnosed with a life-limiting illness whose medical condition will eventually result in the inability to participate in future decision making (Rietjens et al., 2017).

Systematic reviews have shown that preferences for shared or active decision making have increased over the last three decades (Chewning et al., 2012, Tariman et al., 2010) and patients are increasingly expected to participate in the decision-making process (Cribb and Entwistle, 2011). Healthcare professionals are expected to understand the patient's choices and preferences (Brom et al., 2014), through effective communication. However, end of life discussion and decision making is value-laden arising from the norms and values of the socio-

cultural setting (Kagawa- Singer and Blackhall, 2001, Bullock, 2011). Socio-cultural variation in attitude and practice is perhaps expected between continents, countries and even within the same country. While studies have consistently noted that African Americans participate less in ACP compared to white Americans (Sanders et al., 2016), research has also found that they are more likely to engage in informal conversation around end of life care than complete a formal advance directive document (Sanders et al., 2016). Furthermore, findings from South Africa show that ACP is deemed relevant and beneficial amongst the African population (Stanford et al., 2013).

As a word of caution, it would be imprudent to assume that the views and experiences of Africans living abroad are the same as those of people living in Africa. It is increasingly clear that context matters in the perceptions and actual experiences of people, especially in relation to ACP and palliative care (Russell, 2019). Also, there is a realisation that context is not solely dependent on the culture of people, but likewise other complex factors such as environmental and political considerations that the people are subjected to (Sanders et al., 2016, Bate, 2014). Therefore, improved understanding of previously unexplored contextual expression of wishes and preferences amongst people living in Africa is pertinent to the understanding of ACP in Africa. However, in the absence of research on this issue from patients and family members living in Africa, subtle inferences around the topic and the identification of possible essential elements might be derived from studies conducted abroad. For instance, research that demonstrated that family-centred ACP interventions improved ACP documentation amongst African Americans (Lyon et al., 2018, Lyon et al., 2013) suggests that reported poor engagement with ACP amongst African Americans (Rhodes et al., 2019)

might have some relevance to inadequacies in the understanding of the value of family members in the process of expressing wishes and preferences in the African setting.

Although the expression of wishes and preferences promote ACP by facilitating the knowledge of a patient's priorities about future care and where possible its implementation, much attention has been given to the content of the expressed wishes and preferences. Even outside the field of medicine, managers recognise the complex yet central role of process-centric understanding in comparison to content-centric learning when making high-stake decisions (Roberto, 2005). The process of making an important decision, particularly in a family-centric society such as that which exists in Africa is far more complex, nuanced and abstract than the content of the decisions (Lee, 2019). Furthermore, Lin et al. (2019) highlighted the limitations and problems associated with adapting Western-oriented ACP process logic for cancer patients to non-Western cultures. Therefore with the goal of exploring ACP in Nigeria, appreciating the 'why' and 'how' of expressing wishes and preferences will improve clinician understanding of patients decisions, making medical care more relevant and respectful (Berger, 2010). The focus of this thesis is to understand the process of expressing end of life care wishes and preferences in patients with advanced cancer in the Nigerian context.

1.2 Personal motivation for this thesis

I started this PhD as a medical doctor working in a newly established palliative care unit in Nigeria. Before this time, I had no exposure to palliative or end of life care, and the only thing I knew about it was from lectures on palliative or non-curative treatment of cancer as a medical student. In Nigeria, palliative care or end of life care is not yet part of medical school or healthcare professional curricula. Unsurprisingly, during my time at the palliative care unit,

I was struck by the suffering of patients going through the natural process of dying from terminal cancer and the distress of their family members. As a norm, discussion about the poor prognosis and end of life care for the cancer patients was at a late stage, even though the clear majority had cancer, which has one of the most predictable dying trajectories (Murray, 2008, Murray et al., 2005).

Timely formal conversations and documentation occurring between the patients, their family members and healthcare professionals were infrequent. ACP was in the form of family meetings with family members with or without the patients in attendance, as the conversation usually took place while the patient was too ill to participate or make a meaningful contribution to the meeting, as also observed by Agom et al. (2019) and engaging in such discussion might have been too late. However, when the delivery of meaningful and acceptable end of life care is congruent with patients' expressed wishes and preferences, high-quality cancer care is achievable (Walling et al., 2008). Therefore, to improve the dying experience of patients diagnosed with cancer and their family members in the Nigerian context, I ventured into this PhD.

The PhD work aims to construct a theory on the process of expressing end of life care wishes and preferences that will contribute to the evidence-based understanding of ACP in Nigeria and other societies with similar socio-cultural contexts. Although I have a positivist medical background, the social problem I witnessed calls for a constructivist stance. I understand that I bring my social status, privileges and perceptions to this research, and thus engaged in reflexivity and reflexive accounts throughout the research process.

1.3 Research focus

Study Aim and Objectives

This study aims to theorise the process of expressing end of life care wishes and preferences, based on the perspectives and experiences of cancer patients and family carers in Nigeria. The objectives are:

1. To explore cancer patients' and family members' interests in expressing end of life care wishes and preferences.

2. To examine factors that influence cancer patients' and their family caregivers' perspectives and experiences of expressing end of life care wishes.

3. To develop a theory that explains the views and experiences of cancer patients and their family caregivers in Nigeria regarding expressing end of life care wishes and preferences.

1.4 Definition of key terms

"**Advance care planning** is 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. For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions" (Sudore et al., 2017, p 823).

An advance directive is a statement (oral or written) made by a person with decision-making capacity stating his/her wishes regarding how to be treated or not treated at a stage when s/he loses such capacity (Salins et al., 2018).

End of life care is an approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life, and quality of dying rather than treatments aimed at cure or prolongation of life (Salins et al., 2018).

Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and appropriate assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2002). In this thesis, I might use end of life care and palliative care interchangeably because the focus of the research is on end of life care, which automatically falls into the domain of palliative care.

Terminal illness is a progressive condition that has no cure, and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant conditions and ageing (Salins et al., 2018).

1.5 The organisation of the thesis

The organisation of the thesis and the timing of the literature review reflects my methodological journey through the constructivist grounded theory on the process of expressing end of life wishes and preferences.

In **chapter 1: the introduction,** I begin with a brief understanding of the role of ACP and expression of end of life care wishes and preferences in recognition of the importance of patients' voices and effective communication in palliative care.

In **chapter two: the background, I** provide a background to the thesis with a discussion around the universality of ACP and the implication of relational autonomy. It then focuses on

describing end of life and palliative care in Nigeria. The chapter concludes with an overview of the existing contextual background in Africa with emphasis on Nigeria.

Chapter three: methodology examines my methodological and philosophical underpinnings as related to the research. It gives the justification for a constructivist grounded theory and my accounts of reflexivity.

In **Chapter 4: methods** the procedures for the research; recruitment and sampling, data collection and the analysis methods are explained.

Chapter five: findings represent the results from the constructivist grounded theory on the process of expressing end of life care wishes and preferences amongst Nigerian patients diagnosed with advanced cancer and their family members.

Chapter six: systematic literature review is focused on presenting the critical interpretative synthesis of the literature on end of life communication amongst African patients diagnosed with a terminal illness, their family members and healthcare professionals living in Africa. I make a comparison between the re-conceptualised model and the newly developed ground theory.

In the final chapter, **chapter seven: discussion and conclusion,** I present a broader discussion around the findings of the grounded theory of expressing end of life care wishes and preferences in the African context. I conclude the thesis with a discussion about the significance of the research, implications for practice and recommendations for future research.

Chapter 2: Background

2.1 Introduction

In this chapter, I expatiate on the discussion around ACP and end of life communication. I focus on the successes and failures of ACP with a discussion on why context matters. For more contextualised reasoning, I discuss relational autonomy. Finally, I conclude the chapter with the discussion on palliative care and end of life care and its contextual background in Africa with emphasis on Nigeria.

2.2 ACP and the expression of end of life care wishes and preferences

ACP is a prospective process that supports an individual to define and discuss his/her goals and preferences (Rietjens et al., 2017). It is also a communication process that involves reflection, deliberation and determinations of an individual's values, wishes and preferences for future care (Bernard et al., 2020). The process of ACP is to clarify a person's wishes and preferences in the context of an anticipated deterioration in their condition with the attendant loss of capacity to make a decision and/or ability to communicate wishes to others. Elements of ACP include patients expressing their wishes and preferences for types of care and other important goals and values (Rietjens et al., 2017). In the UK, an advance statement may be the outcome of ACP if the person wishes and must be taken into account by the healthcare professionals when deciding in a person's best interest. Best interests meetings may involve a substitute decision-maker nominated by the patients before deterioration (Silveira et al., 2010), and only take place when an individual has been assessed and found to be lacking in capacity to make their own specific decisions. Therefore, ACP helps the terminally ill person faced with a serious or life-limiting illness extend their involvement in

and control of the decision-making process beyond the point at which they lack the capacity to do so (Johnson et al., 2016).

The aim is to ensure people receive care that is consistent with their values, beliefs and goals for care outcomes (Sudore et al., 2017). Thus, ACP encourages and improves end of life discussions between patients and the healthcare provider (Song et al., 2016, Murray and Butow, 2016, Weathers et al., 2016). Effective end of life communication through ACP is recognised as an essential strategy for improving the quality of life of patients (Zhang et al., 2009, Detering et al., 2010, Brinkman-Stoppelenburg et al., 2014) and positively influencing caregiver's bereavement outcomes such as reducing anxiety and depression (Wright et al., 2008). Patients who engage in ACP are more likely to receive more goal-concordant care (Agarwal and Epstein, 2018) and less aggressive treatment (Brinkman-Stoppelenburg et al., 2014). Despite the promise of ACP, if patients and family members have not engaged in the process of expressing end of life care wishes and preferences before the time decisions are needed, these goals might be compromised. Therefore, it is essential to give good emphasis to supporting an enduring communication process among patients, families and clinicians (Wood and Winzelberg, 2020, Taneja et al., 2019).

However, given that ACP is a constellation of different strategies with their individual benefits, an assortment of factors can affect the effectiveness of ACP. For instance, despite the value of advance directive documentation, its role in clinical care is debatable. Research has found that this documentation does not necessarily change provider decision making (Carr and Luth, 2017, Fulmer et al., 2018). The documents are often underused, and their implementation sometimes inoperative due to multiple factors (Yadav et al., 2017). There are problems of inaccurate prediction of the cause and course of death and the associated complex end of life

decision making (Perkins, 2007). Furthermore, issues with the availability of trained staff with the time and expertise to engage patients and family members in ACP discussion make ACP discussion challenging for clinicians (Page, 2019). Surrogate decision making is also not infallible. Family members who act as the surrogate decision-maker, may feel confused, uncertain or lacking in confidence to get involved in medical decision making, even when their beloved ones trust them to make decisions for them (Bollig et al., 2015).

Critics of ACP such as Morrison (2020) question its real value in improving the end of life care outcomes for the patients, their family members and the healthcare system. The lack of a clear distinction between various ACP interventions such as communication and advance directive documentation in the literature (Jimenez et al., 2018) makes it challenging to determine what needs more focus in clinical practice. Indeed, the need for enhanced communication in end of life is well documented in the literature (Siouta et al., 2016, Waters, 2000), and the nature of this vital component could be a key to achieving ACP promises. Encouraging and facilitating engagement in high impact end of life discussions and communication could be a positive driving factor for ACP (Detering et al., 2010). For instance, this requirement for more communication and less routinised use of documentation was revealed in detail by the review of the implementation of the abolished Liverpool Care Pathway for dying patients in the UK (Seymour and Horne, 2013). More discursive and less structured ACP discussion is preferred to communication that is excessively bureaucratic and is based around documentation (De Vleminck et al., 2014). Even though documentation is often completed during the process of ACP, it alone is unlikely to improve outcomes. However, communication skills training for healthcare professionals consistently demonstrates significant improvements in healthcare professional reported outcomes

(Walczak et al., 2013). For example, it improved self-efficacy, comfort, readiness, for specific communication skills such as delivering bad news (Jimenez et al., 2018).

Besides, a recent overview of systematic reviews of ACP (Jimenez et al., 2018) found an overall positive attitude towards ACP and advance directive discussion amongst patients and healthcare professionals. Clinicians perceive their enhanced interpersonal relationship with their patients and families through ACP discussions as important and pertinent to easing burdens, resolving conflicts and improving understanding of patients' wishes and preferences (Rhee et al., 2013). Evidence from the literature (Pearse et al., 2019) suggests that the challenge relating to ACP implementation at the point it is needed might be minimised through early and multiple discussions around patients' values and goals of care, as part of an ACP process. In summary, ACP quality is enhanced through better communication and when it is supported by well-trained healthcare professionals (Kononovas and McGee, 2017). However, knowing the potential value of ACP, aside from improving end of life communication, attention should also be drawn to other aspects of ACP intervention and implementation, including the need to expand the realm of ACP.

ACP, as it is, is neither pervasive in its application nor universal in its coverage due to various factors. Firstly, it has been found to be more successful in specific clinical situations, especially in those with a predictable dying trajectory. For example, ACP is more acceptable amongst nursing home residents (Martin et al., 2016) and those with a diagnosis of cancer (Lovell and Yates, 2014) as opposed to those with chronic heart or lung diseases (Siouta et al., 2016). Secondly, the lack of universality as captured in the plethora of language use and the legislative support for ACP and advance directive documentation across and within countries (Lovell and Yates, 2014) makes negotiation of the literature and translation to practice

challenging (Russell, 2014). For instance, an advance directive is legally binding in England and Wales but not in Scotland. Lastly, research on ACP is concentrated in developed countries such as North America, Australia and Western Europe (Liu et al., 2020), and adopting healthcare programmes and interventions to a country other than where it was developed is found to be challenging (Billekens et al., 2015) .

The Respecting Choices programme, a well-known model of patient-centred ACP that is intended to assist individuals to reflect on, decide and communicate their preferences to healthcare professionals, has shown different outcomes across various settings (MacKenzie et al., 2018). For instance, Detering et al. (2010) in Australia and Schwartz et al. (2002) in the US reported positive outcomes, while Overbeek et al. (2018) in the Netherlands and Korfage et al. (2020) across Europe report limited benefits to it. While other factors could explain the documented disparities, Billekens et al. (2015) noted that the differences in the practice and policies relating to ACP across countries could be a plausible reason for the difference. Even within Europe, there is a no 'one size fits all' to the idea of best practice end of life care (Gysels et al., 2012). Evidence suggests that ACP in its current form might not be transferrable to all situations and contexts. Indeed, the diversity in the underlying goals and envisaged outcomes of ACP affects its acceptability and applicability across different contexts (Fleuren et al., 2020). Therefore, an alternative to the existing model of ACP is imperative; one that is responsive and acceptable to people in different contexts and with different needs. Country specific strategy documents such as "What's important to me – a review of choices in end of life care" (Department of Health, 2015), is an example of such a response. However, even in Europe, where modern palliative care originated, inadequate attention is being given to cross-cultural peculiarities in end of life care planning across healthcare intervention research (Gysels et al.,

2012). One such matter is the issue of autonomy and decision making, and this will be discussed in the next section.

2.3 Relational Autonomy in ACP

ACP relates to the Western individualistic approach to autonomy and decision making (Jimenez et al., 2019), originating from the liberal moral and political tradition of the enlightenment in Western Europe (Azétsop and Rennie, 2010). It assumes an individual to be independent, rational and self-focused. In order to be autonomous, an individual needs to make decisions freely based on a personal deliberative process and without any coercive influence (Sherwin and Winsby, 2011). That is, the assumption is that the individual is always in control and prioritises self-sufficiency in decision making (Walter and Ross, 2014). There should also be informed consent, truth-telling, and confidentiality (Beauchamp and Childress, 2019). While this individual concept of autonomy has some advantages, such as protection from paternalism and empowering patients to make their own decisions based on their values and beliefs (Walter and Ross, 2014, Grignoli et al., 2018), it can be problematic in ACP due to various reasons.

The critics of the above individualistic portrayal of autonomy recognise it as a misconception and misrepresentation of the individual self. The underlying assumption of individual autonomy fails to acknowledge the social context within which the individual is situated. Human beings are entrenched in a web of interpersonal relations with the people that surround them. This is particularly relevant in end of life care which has been described as a relational process (Robinson, 2012, Marx et al., 2014) due to recognition of the importance of interpersonal relationship and the need to depend on others (Lolich and Lynch, 2017, van Wijngaarden et al., 2018). Individual autonomy does not adequately capture the relational

and social component of the complex decision-making process of ACP (Johnson et al., 2016). However, relational autonomy highlights the social context within which the individuals exist, their emotional and embodied self, and acknowledges that individuals do not make decisions in a vacuum particularly at end of life (Ho, 2008). Relational autonomy acknowledges the need for human connection in its definition as an approach to autonomy that emphasises the socially entrenched nature of individuals (Sherwin and Winsby, 2011). Furthermore, Killackey et al. (2020) identify the relevance of relational autonomy in ACP. They highlight that the recognition of the importance of relationship, the acknowledgement of fluctuating autonomy in chronic illnesses, and the identification of vulnerability are all recognisable characteristic issues in the final phase of life, that makes relational autonomy well suited for ACP.

Furthermore, the imposition of Western bias or ideology is discriminatory and neglects alternative ethno-cultural values, such as family harmony and filial piety that are important in collectivist societies (Tan, 2017, Ho, 2008). Formal documentation of treatment preferences is associated with an individualistic conceptualisation of autonomy (Killackey et al., 2020), as the document is there to ensure patients' wishes are considered when they are unable to speak for themselves. Individuals and family members, whose responsibility is to protect the dying from the burden of making a difficult end of life decision (Searight and Gafford, 2005), might associate such documentation with lack of trust in them (Braun et al., 2014). Unsurprisingly, international literature coming from countries with known diverse populations such as Europe, the US, and the UK have shown that people of minority ethnic and cultural groups have a low level of participation and engagement with ACP or the completion of an advance care document as compared to majority groups such as the white population (LoPresti et al., 2016, Wicher and Meeker, 2012, Rahemi and Williams, 2016).

While multifactorial influences such as lack of knowledge or awareness of advance care directives, poor health literacy or strong religious faith could account for this, strong cultural values relating to communalism and collectivism are an essential element. Cultural and racial values impact on end of life perceptions and perceived burden on family members (Lee et al., 2014, Ikuenobe, 2015).

For example, research from Asian (Lee et al., 2014) and African populations (Wicher and Meeker, 2012) show they value collective, familial decision making and do not ascribe autonomy to the individual as they perceive decision making to be a filial responsibility. Even though family involvement in decision making is not exclusive to these cultural groups, the familial involvement in some collectivist societies is not related to supporting the individual to make their own decisions but to significantly influencing the decision or taking on the decision burden themselves (Kagawa- Singer and Blackhall, 2001). While there is a paucity of research around end of life decision making, decision-making models and ACP from Africa, available research amongst Africans living abroad suggests that individual autonomy conflicts with the African cultural values and beliefs (Collins et al., 2018) African values often do not fit with the assumed values of patient autonomy and individual control over the dying process (Wicher and Meeker, 2012). Africans tend to depend on family members to communicate preferences at end of life to healthcare professionals. For those whose family is at the core of their reality, consideration of their advice, needs and mutual interests is part of their autonomous agency, as their idea of autonomy and self-determination is seen as aspects of communal existence (Ikuenobe, 2015).

Although many prefer to defer decision making to their family members or consider their interests extensively in the planning process (Collins et al., 2018), some African patients prefer

to be fully involved in the deliberative and decision-making process. Therefore, communication is essential to clarify issues and prevent barriers of misunderstanding in order to deliver a culturally sensitive ACP that explores differing values and beliefs of diverse cultures. As the world becomes more open and accepting of a previously unrecognised or unacknowledged phenomenon, respect for diversity needs to be elevated in our pluralistic world. Perchance, ACP will become more malleable, flexible and context-oriented in order to fit into varying contexts. Perhaps, there will be more acceptance of what different people regard as good end of life care, which might not necessarily be about individualism but collectivism. It is essential to understand what matters most to individuals, rather than fit them into reductionist preconceived tick boxes. The next section will focus on discussing contextual issues related to end of life care in Nigeria.

2.4 Cancer burden in Nigeria

A patient's country of residence still determines their chance of surviving an illness such as cancer (Arnold et al., 2019). As the cancer burden increases worldwide (Kanavos, 2006), developing countries carry the most burden (Parkin et al., 2008, World Health Organisation, 2018). This is especially the case in Sub- Saharan Africa, where cases of cancer are expected to increase by more than 50% in the next 20 years (Parkin et al., 2018). Of the 40 million people requiring palliative care yearly worldwide, 78% of them live in low and medium-income countries (World Health Organisation, 2020). Only 30% of low-income countries have cancer treatment services available to the general public in comparison to 90% in high-income countries (World Health Organisation, 2018). Delayed diagnosis due to poor preventive or early diagnostic strategies, poor treatment options (World Health Organisation, 2018), inadequate training of healthcare providers and the weak health systems all contribute to the

high mortality rate which has been suggested to be 1.5 to four times more than high-income countries (Parkin et al., 2018). According to the latest data, Nigeria records about 100,000 new cases of cancer a year, of which 60-70% present in the advanced incurable stage resulting in about 70,000 deaths annually (World Health Organisation, 2019).

Despite the reported high cancer death rate in Nigeria, cancer service provision has not been recognised as a priority, and there is no active government participation in cancer care. Cancer registration services in Nigeria are patchy, and data centralisation has only recently been attempted (Jedy-Agba et al., 2015). The Nigerian oncological services have limited functionality, with only seven partially working radiotherapy centres serving a population of about 200 million. A long-distance journey to the centres, travel and accommodation expenses all limits accessibility to these services. Most University teaching hospitals lack basic pathological laboratory, and only 70 clinical oncologists serve the whole of Nigeria. The vast majority of patients pay out of pocket. The national health insurance scheme is only available to about 5% of the population (Alawode and Adewole, 2021), and this does not cover the cost of chemotherapy and radiotherapy. Widespread poverty and poor affordability of cancer treatment, even amongst professionals such as medical professionals, make cancer care out of reach for most of the population. The cancer situation is dire and dying from incurable cancer is the most likely outcome for the Nigerian cancer patient. Despite this overwhelming burden of the disease, there is inadequate evidence to guide the provision of quality palliative care in the African region (African Palliative Care Association, 2020).

2.5 Palliative Care/End of life care in Africa and specifically in Nigeria

According to the (World Health Organisation, 2002), palliative care aims to improve the quality of life of patients and their family members facing problems associated with life-limiting illnesses, whether physical, psychosocial or spiritual. Palliative care begins when the illness is diagnosed and continues regardless of whether the patient receives treatment directed at curing the illness or not (World Health Organisation, 2002). When a patient is terminally ill with no hope for cure, as is the case for the majority of patients in Africa, palliative management becomes the only treatment option (Institute for Medicine, 2007) and ought to be available as a minimum (Economist Intelligence Unit, 2015). Unfortunately, for the overwhelming majority of Africans suffering from a life-limiting illness, there is no available culturally appropriate holistic palliative care for those who need it the most. Statistics on the provision of hospice and palliative care across Africa demonstrate that 45% of African countries have none, and only 9% were classified as having services approaching some measure of integration with the mainstream health system (African Palliative Care Association, 2020). Approximately, 10 million people per annum are estimated to require palliative care in Africa (African Palliative Care Association, 2020). Yet, most African countries have less than two palliative care services per million people (Rhee et al., 2017). Only five countries across Africa have palliative care integrated into their healthcare professional curriculum, and of these, only two are at examinable level (African Palliative Care Association, 2020).

In Nigeria, palliative care is still in the developmental stage. The African Palliative Care Association and the Hospice and Palliative Care Association of Nigeria contributed to the establishment of the existing 15 palliative care units in tertiary health institutions in Nigeria.

Many of these centres organise ad-hoc education and training sessions for their healthcare professionals (Oyebola, 2017). Nevertheless, only a few medical and nursing schools offer palliative care teaching to their students, and the subject is yet to be formally integrated into the general medical school or postgraduate curriculum (Oyebola, 2017). Palliative care is also not yet incorporated into the national health system. Research has demonstrated inadequate knowledge of palliative care amongst healthcare professionals, including those providing palliative care in the country (Fadare et al., 2014). Therefore, the low level of development of palliative care in the African continent underscores the need to have a model of palliative care provision in Africa that differs from what is delivered in advanced countries (Court and Jill, 2020). The challenges of transferring the principles of palliative care between developed and developing countries have been emphasised (Zaman et al., 2017), due to the marked variation of such provision across the world (Clark, 2010) and the risk of imposing Western norms in a different cultural context (Nobel, 2014).

Three decades after the inception of palliative care in Nigeria, a good death remains a challenge. The 2015 Quality of Death Index ranked Nigeria very low based on basic end of life care environment, availability of end of life care, affordability of life care, and quality of end of life care (Economist Intelligence Unit, 2015). Nigeria was recognised as the worst African country on the index and only better than Iraq, Bangladesh and Myanmar. This ranking is unsurprising due to the poor availability of strong opioids for pain relief, lack of national policies integrating palliative care into the health care system and inadequate clinician training (Agom et al., 2019). Social stigmatisation resulting from cultural and religious values discouraging conversations around death and dying is another major issue undermining provision of a good death (Ekore and Lanre-Abass, 2016) . Therefore, there is a need for a

nuanced and in-depth understanding of issues relating to providing good end of life care in this highly contextualised setting. Furthermore the evidence base guiding the delivery of appropriate and effective end of life care provision and policy is inadequate, despite the identified need to have methodologically robust research to help address the palliative care burden in Africa (Powell et al., 2014). There is a dearth of published palliative care evidence in the continent. Powell et al. (2014) identified the need to have African researchers with a sensibility to the specific challenges to palliative care in the African continent, undertake research endeavours in this region. They also note that descriptive study designs and qualitative methodologies are required for African palliative care research due to the need to have culturally meaningful and robust evidence on the background of inadequate palliative care research.

2.6 Cultural issues in end of life care and decision making in Africa with an emphasis on Nigeria

In a traditional African setting such as Nigeria, understanding the contextual background arising from the cultural worldviews, religious interpretations and socio-economic dynamics that can influence how meaning is given to illness, suffering and dying will give a better understanding of the expression of wishes and preferences at the end of life. In Africa, the way illness and death are perceived is unique compared to some other parts of the world (Umoh, 2012). Research has recognised the central role spirituality and religion have on ACP engagement among people of African origin (Wicher and Meeker, 2012, Hong et al., 2018) who rely on cultural and religious interpretations to make sense of death and dying (O'Kelly et al., 2011). The religious and spiritual implication and expectation of dying is more emphasised than the physical and social significance of death. Scientific evidence of illness and impending death is denigrated and often ignored.

For instance, many Nigerians attribute death, particularly from an incurable disease to witchcraft, rather than medical or physical causes (Okafor, 2017). They believe in the existence of spiritual beings and enemies who use their power to cause suffering and death (Nwozichi et al., 2020). Nigerian places of religious worship and traditional healers shelter young dying patients with the promise of curing their ailments and spiritually attacking person(s) that they deem to be responsible for inflicting the illness (Okafor, 2017). Irrespective of the specific religion, the Nigerian traditional belief system is intricately linked with African culture, and health-related concerns are strongly influenced by cultural values (Umoh, 2012, Nwozichi et al., 2020). Death from a terminal illness is only seen as 'normal' if it occurs in the elderly, it is slow and lingering, giving enough time to tidy up affairs and say farewell to relatives (Okafor, 2017, Onukwugha, 2008). The elderly or aged may give verbal instructions to their children concerning their care at the end of their lives. Such directives may include a preferred place of care and death and specifics about burial rites (Ekore and Lanre-Abass, 2016). Contrary to this, the young and agile are culturally discouraged from making end of life decisions, and it is considered a taboo to have discussions regarding this issue (Okafor, 2017).

As has been noted earlier, aside from religion/spirituality, the family's assumption of a position of dominance over individual interest dominates Nigerian culture. Decision making at the end of life is often left to the members of the family (Lanre-Abass, 2008). Individuals have a sense of obligation to their family members, and decisions are usually made after considering the opinion of other family members. Family solidarity is vital in maintaining patient dignity, especially at stressful times, such as when someone is suffering from terminal cancer (Mulaudzi and Makhele, 2012). The traditional African sense of pride relates to

communalism between individuals and their family members as opposed to Western individualism (Zaman et al., 2017). Consultation and collaboration are cherished and treasured, and independence and privacy is usually a source of embarrassment and conflict among family members (Mulaudzi and Makhele, 2012). A dignified African is not extremely individualistic, isolated, autonomous and capable of independent reasoning, but a rational person who values family and community contribution in times of health and sickness (Ikuenobe, 2015).

2.7 Advance Care Planning in Nigeria

There is neither an existing formal advance care planning in palliative care in Nigeria nor an advance directive document relating to health and end of life care. Collaborative work between patients, their relatives and the palliative care professionals occurs very late in the disease trajectory due to a late referral for palliative care. The palliative care team organises a family meeting where issues around the patient's end of life care are discussed. Most of these family meetings usually only involve the patients' relatives and palliative care clinicians. The patients are at the terminal end of their life and are too ill to participate (Agom et al., 2019). The meetings help establish patients' relatives' knowledge and understanding of the illness and give some moral support and information about what to expect to the patients' relatives as the patient's illness progresses (Hudson et al., 2021). Therefore, there are no formal protocol or guidelines for advance care planning in end of life care. The family meetings' findings might be recorded in medical records, but they are not legally binding. The standard norm is other family members making end of life care decisions for the patients.

However, patients and family members might have had established informal conversation around issues relating to practicalities after the patient's demise, such as instructions for the

place of death, funeral arrangement, and property sharing (Cadmus et al., 2019). These discussions are mainly related to religious or cultural beliefs surrounding death and dying. The traditional Nigerian culture believes repairing the relationship between the dying patients and their significant others is good preparation for death. Discussion about social relationships, communal values, and the common good and overarching traditional and religious values prevail over the discussion that might lead to individual gains (Jegede and Adegoke, 2016). These strong cultural norms in Africa, particularly in Nigeria, is likely to affect the conversations around expressing end of life care wishes and preferences. Therefore, an explanatory theory of the process of expressing end of life care wishes and preferences is pertinent to delivering culturally sensitive end of life care.

2.8 Summary

In summary, it is clear then that those reasons mentioned above imply a distinctive characteristic in the African context, which can inherently affect the process of expressing end of life care wishes and preferences. These acknowledged issues call for inductive research that is based on in-depth analysis of the data derived from the real-life experiences of the people primarily involved in expressing end of life care issues. In turn, this will result in an improved understanding of the process involved in the communication of end of life care wishes and preferences in general. Specifically, research in this context can confer significant benefits to end of life care in Nigeria and other similar situations, facilitating a culturally relevant end of life care policy and practice development. A bottom-up research approach is especially useful in this situation where a new outlook is required. The focus in the next chapter is the methodological considerations for the research process.

Chapter 3: Research Methodology

3.1 Introduction

An important consideration when choosing the methodology for this study was finding a good fit between the research question, the set of principles and ideas that inform the research and the underlying philosophical values guiding the study. The following research question is well suited to be answered by a constructivist grounded theory method:

- What are the views and experiences of cancer patients in Nigeria and their family caregivers regarding expressing end of life care wishes and preferences?

I begin this chapter by presenting a rationale for this qualitative research design using a constructivist grounded theory approach. Then, I discuss pertinent issues around the different epistemological and ontological perspectives of the three major approaches to grounded theory with attention to the constructivist methodology that guides this study. I reflect on my preconceptions, their influence on the research, and how I intend to manage them.

3.2 Rationale for a Qualitative Study - Constructivist Grounded Theory

The selection of the research methodology mainly depends on the context and purpose of the enquiry (Birks and Mills, 2011). This study is designed to explain the concept of expressing wishes and preferences in the face of cancer. Specifically, it is concerned with constructing a theory about the views and experiences of Nigerian cancer patients and their family caregivers considering communication of wishes and preferences about end of life care. This study seeks to understand the intricacies of the participants' realities rather than verify a previous hypothesis.

Many writers (Creswell, 2014, Denzin and Lincoln, 2011, Guba and Lincoln, 1994) highlight that a rich subjective understanding of a complex social process is best understood using an

approach that views social reality as a dynamic feature of individual creation. Issues concerned with the understanding of concepts that depend on the personal interactions and perceptions of social actors requires the use of a qualitative research design that favours the understanding of social and cultural contexts of the participants' lives (Gray, 2014).

Bryman (2007) contends that a study ought to be designed with the purpose of answering specific research questions to avoid data redundancy or methodology muddling. This research is committed to the understanding of the concept of expressing end of life care wishes and preferences in the Nigerian context based on the informer's viewpoint and individual lifeworld. Given the subtleties of the participants' context, regarding this matter under study, I found an inductive qualitative explanation of experiences and perception the most appropriate for this enquiry.

Furthermore, this study focused on the expression of end of life care wishes and preferences among cancer patients and family members attempting to fill a knowledge gap identified in the research proposal, that is, filling a vacuum created by the paucity of awareness around the concept of expressing end of life care wishes and the lack of existing theory on talking about future care in the Nigerian cancer context. In these two situations, Creswell (2014) and Polit and Beck (2012) suggest the use of an exploratory inductive qualitative approach to achieve a thick description of the social world by giving a detailed description of the phenomenon, thus providing a better understanding of relationships and human behaviour.

Various qualitative methodologies explore context and situations based on the informer's viewpoint. These include phenomenology, ethnography and narrative designs. However, not all of the methods are adept at capturing a rich narrative that keeps one interacting and

involved in the data and the emerging analysis (Charmaz, 2014). Phenomenology is intended to describe a lived experience and may miss information about the process of the experience (Bryman, 2012), what led to it or other factors associated with it. Ethnography also focuses on the cultural affinity of a group rather than the whole context. A narrative design can overlook overarching complexity (Silverman, 2013).

This research aims to go beyond mere thick description and exploration of the phenomenon or to give a simple narrative, it seeks to generate an abstract theory that explains the data and is grounded in it. The endpoint of the research process will be a theoretical framework that offers perspectives beyond existing theories (Bryman, 2012, Charmaz, 2006, Strauss and Corbin, 2008) centred around the Nigerian cancer patients' and families' experience and perception of expressing future care wishes. As such, grounded theory methodology, is a particularly useful approach to inductive reasoning as it enables the holistic exploration of the multifaceted social construction of human interaction is the best fit. Specifically, constructivist methodology is well suited, as this approach seeks to understand the differences and variation among the research participants and the co-construction of meaning between them and the researcher as will be explored further, below.

3.3 Grounded Theory Methodology

Grounded theory methodology, initially described by two sociologists, Barney Glaser and Anselm Strauss (Glaser and Strauss, 1967, Glaser, 1978) is a useful research approach for discovering a new conceptual theory, drawing generalisable inferences and constructing relationships from the data collected for this purpose. Grounded theorists advocate the development of new explanations for interrelated concepts that go beyond existing theories but remain close to reality (Glaser, 1978, Glaser and Strauss, 1967). However, the perception

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of the extent of the proximity of what can be known (epistemology) of reality (ontology) and the relationship between the researcher and the participants is a source of debate amongst earliest originators of grounded theory and advocates of the later versions (Mills et al., 2006b).

Glaser hold positivist and deterministic perspectives that believe in the existence of a single interpretation of reality (Glaser and Strauss, 1967, Glaser, 1978, Glaser, 1999). This reasoning contrasts with the constructivist thinking of Charmaz (2000, 2014) wherein there is a co-construction of reality between the researcher and the researched. Strauss, who later came to hold views different from those of Glaser, assumes a middle ground (Strauss and Corbin, 1990). Strauss and Corbin (1990) consider that even though the process of theorising is dependent on experience which can inadvertently affect the theory, researchers should aim for an accurate representation of the respondent's voice.

Many keen observers of this relationship (Devadas et al., 2011, Mills et al., 2006b) have noted that these variations in grounded theory methodology reflect the different ontological and epistemological values between grounded theorists. These debates and how they guide the choice of grounded theory methodology adopted for this research will be discussed next.

3.4 The Theoretical Perspective

Researchers utilising grounded theory have reported finding the selection of a specific methodology a herculean task due to significant diversity in grounded theory approaches discussed above (Jones and Alony, 2011, Evans, 2013, Nagel et al., 2015). Also, the failure of users of grounded theory to clearly identify and differentiate between different grounded theory methodologies in their writings has been implicated in this dilemma (Gynnild, 2011).

Birks and Mills (2011) observed that the originators of grounded theory are also not absolved of confusing grounded theory users by creating a methodological gap in seminal works. For instance, while many writers of grounded theory evolution have recognised Glaser's writing as being positivist, based on his use of words such as 'discovery' and 'emergence', Glaser (2001; 2005) persistently denies orientation towards any particular paradigm

Glaser (2001; 2005) is convinced that irrespective of the researcher's alignment, the original grounded theory approach described by himself and Strauss in 1967 is applicable as an alternative to all paradigms. Mills et al. (2006a) disagree on this, stating that the researcher's epistemology and ontology should be the deciding factor when choosing an approach. Charmaz (2014) shares this perspective and gives importance to identifying the investigator's positions in her argument as illustrated by the statement:

> "Diverse researchers can use basic grounded theory strategies such as coding, memo writing and sampling for theory development with comparative methods because these strategies, are in many ways, transportable across epistemological and ontological gulfs, although which assumptions researchers bring to these strategies and how they use them presuppose epistemological and ontological stances" (Charmaz, 2014, p.12).

Bryant (2003) affirms that Charmaz's argument on this issue is not a claim to superiority of any single philosophical paradigm. Nonetheless, Charmaz (2000; 2006; 2014) proposed an approach that she proclaims to be a modern modification of the original grounded theory, described in Glaser and Strauss's (1967's) pioneering book, *The Discovery of Grounded Theory*. Even though Charmaz (2006) newer version of grounded theory, *constructivist*

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grounded theory, adopts traditional grounded theory guidelines as initially described, it does not endorse its overt objectivist stance and its view on the emergent discovery of theory from data. However, Charmaz (2014) joins Glaser (2002) in refuting Strauss and Corbin's (1998) forced or prescribed method of coding and data analysis. Constructivist grounded theory explicitly advocates and portrays a methodological approach, that is, a set of principles and practices, not a prescription to be followed to the last letter (Charmaz 2006).

Charmaz's approach is based on a theoretical perspective that assumes a relativist ontological position (Higginbottom and Lauridsen, 2014). The relativist denies the existence of static objective truth, believing in the existence of multiple socially constructed realities (Guba and Lincoln, 1994). Individuals tend to give varied subjective meaning to their experience in their search for understanding. These different contextual realities lead to uniquely diverse views, meaning people's perception of experiences differs even in similar situations. Thus, the constructivists believe that different contexts cannot be objectively and comprehensively measured using numeric standards that do not take individual peculiarities into account. In other words, relativism gives value to the context of the participants. A comprehensive explanation and understanding of complex concepts such as expression of end of life wishes that relate to human experiences and perspectives ought to value individuality and subjective standpoints.

Epistemologically, the constructivist values subjectivism, the mutual co-construction of meaning between the respondents and the researcher as opposed to objectivism, a single interpretation of reality assumed by the positivists (Wertz et al., 2011). The constructivist interviewer listens to the participants' stories with the hope of assimilating their meanings.

However, the observed reality is an interpretation arrived at through a connection and blending between the researcher and the researched through interaction with the data; in this case through one-on-one interviews.

Charmaz (2006, 2014) consistently describes the non-feasibility of a neutral interaction between the interviewer and the interviewee, rather acknowledging a shared experience, a relationship Glaser portrays as being prone to researcher bias. While Strauss and his latter ally, Corbin do not refute a subjective interpretation of data, they argue for a pragmatic approach, aiming for objectivity despite the possibility of bias by being able to separate the relevant from that which is not (Strauss and Corbin, 1990). Charmaz (2014) remains adamant, arguing that embracing the bias and subjectivity of the researcher helps capture the rich view of those being studied even from those perspectives previously unknown to them.

The consideration of the ontological and epistemological assumptions of the research, the research question and its anticipated endpoint justifies the selection of constructivist grounded theory as the most appropriate methodology for this research. Next, to understand the size and scope of preconceptions that could affect the theory that will be constructed and how to deal with it, I reflect on the timing of the literature review for this study and on my personal and professional assumptions that could impact on my role as a researcher.

3.5 Managing preconceptions - a reflection
3.5.1 Relationship Between Researcher and Data

Although Glaser (1998), Strauss and Corbin (2008) and Charmaz (2014) all agree on the basic tenet of grounded theory of being grounded in the data, they offer different views on how the researcher can stay true to the data. Based on the positivists/post-positivist tradition,

Glaser (1998) and Straus and Corbin (2008) have the notion that the researcher can be somewhat distant from the research through the appropriate use of the grounded theory method that improves objectivity. However, Charmaz (2014) recognises that the developing theory 'depends on the researcher's views, it does not and cannot stand out of it' (p.239).

Glaser, in his collaborative (Glaser and Strauss, 1967) and individual work (Glaser, 1992, Glaser, 1998), insists upon shunning the literature before the data collection to avoid preconception, to keep an open mind and prevent contamination of the developing theory. Bryant and Charmaz (2007) and McCallin (2003a), McCallin (2003b) oppose this position; they believe that individuals will consciously or unconsciously bring preconceived knowledge and ideas to their work.

Due to the impracticality of maintaining neutrality because of my previous experience with cancer patients and exposure to the literature related to expressing end of life care wishes in the cancer context, I need to acknowledge my subjectivity and its manifestation in the research study. Therefore, I explicitly accept that 'any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it' (Charmaz, 2006) and the investigator should account for this and not simply ignore it.

Nevertheless, the constructivists' version of grounded theory, like other grounded theory schools of thought, recognises the importance of sensitivity to the underlying meaning of the data including its theoretical implication: theoretical sensitivity, which can be developed through the reading of extant literature (Glaser 1978). However, due to differences of opinion regarding the role and influence of existing knowledge on the developing theory, the timing and extent of immersion in existing literature differ across the grounded theory groups.

3.5.2 The Use of Literature Review in Constructivist Grounded Theory

Constructivists position their research in past literature and suggest attempts at dissociating from it is an unattainable task considering that some review of the literature would have been instrumental in the choice of research focus and methodology in the first instance (Dunne, 2011, Charmaz, 2006). In contrast, Glaser (1992), (Glaser, 2005) claims that 'all is data', emphasising that reading around the topic area and literature from other disciplines improves the ability of the researcher to be theoretically sensitive to the emerging codes in the data. But he believes that the research literature review in the substantive area should be delayed, to minimise the risk of reducing the researcher's ability to remain open to the data.

Although Charmaz (2000, 2006, 2014) and Strauss and Corbin (1998) agree that engaging with extant literature in the substantive area of the research through a literature review could help improve sensitivity to the data, Strauss (1987) suggests that conducting a literature review can inadvertently suppress the creativity of the inexperienced researcher. For me as a constructivist researcher, my presence or subjectivity in the research process is recognised as neither being preventable nor could be detrimental to the study. Involvement in end of life discussions with terminally ill patients over five years and prior exposure to formal theories relating to end of life, through readings and attendance at conferences and meetings have been the antecedent to choosing this research area.

Furthermore, a requirement to produce a research proposal to identify gaps and justify the study in preparation for ethical review has helped situate the research in the existing literature and 'give earlier works their due' as Charmaz (2006) has suggested. This experience and interaction with the literature helped me focus the research. Therefore, despite not

having conducted an initial formal literature review in the substantive area of the research, I could not possibly approach the study without any preconception. I may also benefit from it by its enhancement of sensitivity to the data (Strauss, 1987, Strauss and Corbin, 1990, Strauss and Corbin, 2008). Although it is imperative for the constructivist grounded theorist to critically engage with the existing knowledge, to improve sensitivity to data, Thomberg (2012) suggests they ought to prioritise the data over previous readings and preconceptions by getting immersed in the data. In this study, a focused review of the literature was only conducted after analysis of the data, well into the construction of the grounded theory. This approach contributed to the avoidance of the imposition of a specific theoretical framework on my findings or prioritising prior knowledge that could impede fresh ways of thinking that could affect the grounding of the research. The results of the literature review substantiated the developing new knowledge related to expressing end of life care wishes and preferences in the Nigerian cancer context. While I was familiar with the literature at least to the extent of increasing my sensitivity to the data and the developing theory, the conclusion from the literature review enriched my discussion.

3.6 Summary

A case for the reliance upon a constructivist grounded theory approach that emphasises the reality of the cancer patients and their family members but the inclusion of the researcher in the field and final co-constructed fresh analytic theory has been made. The implications and benefits of delaying the literature review was discussed in relation to constructivist grounded theory. The next focus will be on the constructivist grounded theory methods that aid foregrounding of the data and enable the construction of the grounded theory on expressing end of life care wishes in the Nigerian cancer context.

Chapter 4: Methods

4.1 Introduction

In this chapter I outline the method that was utilised for this study, from the process of recruitment until data collection and analysis. First, I describe the sample, the sample site, and the process of recruiting. Then I focus on the sampling method that I utilised, data collection and data analysis methods. Although discussed successively, data collection and analysis were conducted simultaneously, with data analysis commencing immediately after the first few interviews and then concurrently until the end of the study. The constructivist grounded theory method was adopted to facilitate the construction of a theory that is intimately tied to the empirical data: the social process involved in the expression of end of life care wishes and preferences by Nigerian cancer patients and their family caregivers.

4.2 Sample site

Participants were recruited from a university hospital pain and palliative care unit in Northern Nigeria serving a population of about 2.5 million. This centre's proximity to some states in the Southern and Eastern part of the country makes it a major referral centre for specialists and generalists working in the surrounding towns and villages within and outside the Northcentral geopolitical zone. Although many patients get sent to the centre by their clinicians, patients sometimes self-present after interacting with other people who have had some contacts with the centre in the past such as family members of patients. Many of the patients referred to this unit are cancer patients in need of pain relief and other symptom management, but some patients with chronic disease such as chronic back pain and sickle cell disease also attend the clinics for pain relief. The weekly clinics involves a consultation with either a consultant anaesthetist or a family physician with palliative care nurses. The palliative care services

include family meetings involving the patient, their family members and clinicians wherein they engage in a discussion designed to clarify the patient's wishes. Therefore, the unit was an appropriate place for recruitment as its clients fit the inclusion criteria for this research.

4.3 Sample

Adult cancer patients with stage III or IV disease of any organ and their family members were the participants for this study. Although family member participants were family carers of patients receiving palliative care services, family members' participation is independent of the patient's participation or non-participation in the research and vice versa. However, as outlined in the inclusion and exclusion criteria below, family members need to have a patient who meets the patient-participant inclusion criteria even if the patient chose not to participate.

Table 1. Selection criteria: patient-participant group

Inclusion Criteria	Exclusion Criteria
Adult (18 and above) cancer patients	Patients with co-morbid dementia or any disease severely affecting memory, communication, and language.
Patients with any advanced cancer (stage III and IV)	Patients who are unconscious, semi-conscious or too weak to have meaningful conversation.
Patients who are aware of their diagnosis and prognosis prior to recruitment	Patients who have requested not to have further discussion about their diagnosis or prognosis.
Patient competent to make an informed decision.	
Patients able to communicate in English or Yoruba	

Table 2. Selection criteria: Family member participant group

Inclusion criteria	Exclusion criteria
Adult family caregiver of a patient with any cancer in stage s III or IV.	Family caregivers of patients who do not meet the set inclusion criteria.
Family caregivers who are aware of patients diagnosis prior to recruitment period.	Family caregivers who do not want to be involved in patient care or are not aware of patient's diagnosis or who have not had any relationship with the patient since diagnosis.
Family caregivers who are competent to make an informed decision.	
Family caregivers who can communicate in either English or Yoruba.	

4.4 The recruitment process

Recruitment commenced in August 2017 and ended September 2018. Colleagues working in the pain and palliative care centre with whom I have an established relationship with having worked in the unit were approached, and the purpose of the research explained. Furthermore, an email (Appendix A) detailing the research purpose and recruitment process was sent to the doctors and nurses in the unit, and a formal meeting was set up to make clarifications and answer any questions that the clinicians might have. In the first phase of recruitment, five patient and family member participant packs were distributed amongst the clinicians to restrict recruitment to a manageable number. A pack was given to interested patient-participant or family member participants who accompanied patients to their clinic appointments. Each package contained an information sheet (Appendix B&C), an expression of interest form (Appendix D&E) and a consent form (Appendix F). Of the initial ten potential participants approached, eight (five patients and three family members) returned the expression of interest form. Because recruitment levels exceeded expectations, at

subsequent recruitments only three to four participant information packs were given out at a time to limit enrolment to a convenient number particularly as recruitment became more focused and directed by theoretical sampling. The process of recruiting participants will be discussed before describing the sampling procedure.

4.5 Recruiting participants

The potential participants who showed a willingness to participate in the study by returning their expression of interest form were contacted by phone. A date, time and location of the interview chosen by the potential participant were chosen. Some patient and family members who had earlier shown interest declined, citing deteriorating health as the reason. No further attempt was made to recruit such individuals apart from one participant who showed a renewed interest. Initial participant recruitment was open without directing it to any specific adult demographics or disease type. After that, recruitment became more focused guided by theoretical sampling. Participation in the research was entirely voluntary, with each participant completing and signing the consent form before the interview. To contextualise participant response, demographic details were collected before the interviews. These include age, occupation, cancer type, time since diagnosis and for family members, relationship with the patient.

4.6 Sampling
4.6.1 Initial Purposive Sample

The grounded theory method requires sampling that is directed towards building the developing theory (Charmaz, 2008). At the initial stage, data is purposively collected using qualitative interviews based on a broad research focus and then analysed to identify categories that form the basis for subsequent theoretical direction. This initial purposive

sampling strategy was aimed at identifying issues that are deemed important to the patients and family members in the process of expressing end of life care wishes and preferences. All consenting patients who responded to the initial invitation and were well enough to participate in the discussion were interviewed. Those included were participants who met the inclusion criteria as outlined above in tables 1 and 2.

4.6.2 Theoretical sampling

Theoretical sampling, the process of identifying the subsequent set of participants that will best answer the research question in a way that is conceptually driven, was utilised after the initial purposive sampling phase. Theoretical sampling involves recognising a theoretical direction from previously collected and analysed interviews and then pursuing it by steering data collection in the way that refines the emerging grounded theory. It means that who to interview and what questions to ask the participants is determined by the product of the previous interviews and their analysis.

The purpose of this form of sampling is not to infer generalisability from diversity but to further develop and delineate conceptual categories derived from the grouping of codes also known as conceptual labels. This process of the development of conceptual categories by identification of their properties and dimensions ultimately leads to the construction of a theory that is grounded in data. Furthermore, these theoretical leads could not be predetermined in advance as this would be tantamount to forcing the emerging theory into a preconception. As a case in point, 'being strengthened' and 'persevering for a greater good' were identified as codes from the transcripts. These two explain some patient-participants expressed feeling of being encouraged by their family members to talk about their plans and a sense of being resilient despite the long length of time since diagnosis. As a result,

theoretical hints such as family dynamics and time since diagnosis of the participants led to sampling participants with strong family ties and some recent diagnoses (six months to a year) respectively.   Furthermore, new questions such as, 'What do you think is the effect of the length of time since diagnosis on how comfortable/uncomfortable you are in discussing your future?' and, 'What would you change about your family...' were added to the interview guide.

4.7 Data Collection through intensive interviewing

All the interviews were conducted face to face, over 15 minutes to an hour, with an average of 53 minutes. The 15 minutes interview was stopped at the participant's request but was included because its content was significant in answering the research question. The interviews were audio recorded using an encrypted hand-held device and downloaded on to a password-protected computer then transcribed by the researcher. Open-ended, intensive qualitative interviewing that was utilised in this research especially fits with constructivist grounded theory in that it allows for the iterative process of reframing and re-examining the emerging conceptual categories by following up on new leads during the interview. Besides, the possibility of revising the interview process provided an opportunity to develop and focus the interviewing strategy in subsequent interviews and modify the interview guide to suit the theoretical development. For example, at the initial patient-participant interviews, open questions such as, 'Can you please tell me a little about your illness?' elicited a lot of information that was irrelevant to the research focus. This early discovery led to a decision to change the opening question to, 'Can you tell me about your experience of talking to someone about your wishes and preferences for the future?', to emphasise the research focus right

from the outset. However, preambles were used to sensitively summarise a participant's stories prior to the initial question which served as an invitation to get the interviewee to explore and articulate the research topic in their own words starting from their experiences of having the discussions with people.

4.8 Data Analysis

I transcribed the interviews verbatim, translating the interview conducted in Yoruba simultaneously. Although I am a native speaker of the Yoruba language, only one out of the fourteen interviews were conducted in this language. As a bilingual researcher, I understand that the transcription and translation process is non neutral and reflects a mediation between the cultural worlds of the researcher and the researched (Wong and Poon, 2010). Transcription and translation in grounded theory research is a useful analytic resource and an advantage rather than a disadvantage (Tarozzi, 2013). Language plays a key role in the constructing of a grounded theory; transcribing and translating in the research is a form of linguistic and cultural negotiation to construct a theory. The important thing here was that the power and the efficacy of the original word is kept even when the translation is not word for word (Tarozzi, 2013). My familiarity and understanding of the topic as a palliative care clinician and a researcher was essential to effectively depicting a contextualised topic. This is an advantage over the work of a professional translator who is likely to become entangled with misunderstandings and misconceptions surrounding expression of wishes and preferences in end of life. The limitation of this translation method is that the words are literally not the words of the participants anymore (van Nes et al., 2010). I, however, replayed the audio while rereading the transcript to ensure consistency. The analysis of the qualitative interview data was conducted with the purpose of making sense of the volume of information

gathered during the interview using the grounded theory procedure outlined by Charmaz (2014). This involves a systematic back and forth movement between data collection and its analysis, with further data collection being guided by the analysis, leading to the construction of a theory that is grounded in the data. Qualitative data analysis (QDA) software, NVivo version 11 (QSR international, 2017) was used to facilitate the efficient and effective organisation of data and its analysis. Besides its usefulness in the centralising, enabling storage and retrieval of the ongoing analysis, it provided an audit trail which might be otherwise difficult to keep manually. The analysis starts with the coding of the transcripts that assists in breaking down the data, identifying processes and making data comparisons.

4.8.1 Coding

Coding serves a crucial role in transforming collected data into an emerging theory. As Charmaz (2014) explains, grounded theory coding is the process of identifying what the data depicts and serves to conceptualise the happenings in the data. It allows the researcher to break down the data and then move up the conceptual ladder to become the theory that explains the data (Glaser, 1978). Constructivist grounded theorists go through the coding process in two or three successive steps as described below.

Initial coding

This type of coding emphasises giving close attention to the scripts with the purpose of opening the data (Bazeley, 2013). In the first instance, the researcher labels the data in pieces, inductively, coding line-by-line or comparing incident with incident using gerunds or action words to sieve out what is going on in the data. While doing this, Glaser (1998) suggests asking some questions of the data such as, 'What is the data a study of?', 'What category does this

incident indicate' and, 'What is actually happening in the data?', forcing the researcher to transcend description of captivating experiences to reach a conceptually theoretical explanation for the stories.

Also, as those initial codes were provisional, as more insights emerged, they were reworded to fit the data (Charmaz, 2014) and used to explore relationships aimed at theory building (Urquhart, 2013). For instance, my initial coding of a piece of data from one of my interviews led to the descriptive code 'expressing self-happily' when one of the interviewees talked about how delighted he was that he was finally able to talk about the future with his family. Thinking about the questions suggested above, clearly, his statement points to the joy of being able to have the discussions after initially finding it difficult to convince his family to listen to and understand him. Then, I observed in some other interviews that the participants feel relieved when they could talk to their families about their wishes for the future, therefore, I came up with the more abstract code, 'deriving relief'. Subsequently, I discovered the code to be pertinent to some transcripts that I had earlier coded but missed, and these were revisited and re-coded.

Focused coding

Focused coding is the second primary phase of the coding process. As described by (Charmaz, 2014), it involves making use of the most frequent or significant codes to categorise, sort and synthesise data directly, clearly and completely. It identifies the codes that make the most analytic sense (Charmaz, 2014) which are then used to scrutinise the vast amount of data. Here the codes were linked to higher levels called categories where each category has different codes underneath it which are directly linked to the data. This form of coding is more conceptual than line-by-line coding and brings the researcher out of immersion in the data to

a more abstract level of thinking. Like the earlier stages of coding, the process of coding is neither linear nor final, so codes were re-checked with other codes in the same and different transcripts to determine fitness with the data. Without using a pre-set structure that might limit flexibility and stifle imagination, focused coding aids the true emergence of theory from data. I moved within and outside interviews unconstrained, comparing what was happening to identify categories with the most analytic power.

Theoretical coding

Theoretical codes serve a central role in the development of a cohesive and explanatory theory that identifies the relationship between the categories emerging from the initial and focused coding. This theoretical coding procedure involves transforming the constructed focused code into an integrated whole or a coherent analytic story. Theoretical coding helped to saturate the core categories identified in the focused coding and refine them to a more conceptual level without a need for the imposition of an external framework. Thus, theoretical codes underlie the focused codes, show the relationship between them and add precision and clarity to the data analysis process. Memo writing and constant comparison between the focused codes enhanced my ability to code the data theoretically. This theoretical coding process resulted in the construction of three categories that represent the overarching themes from the interview data. The relationship between these core categories will be discussed in subsequent chapters.
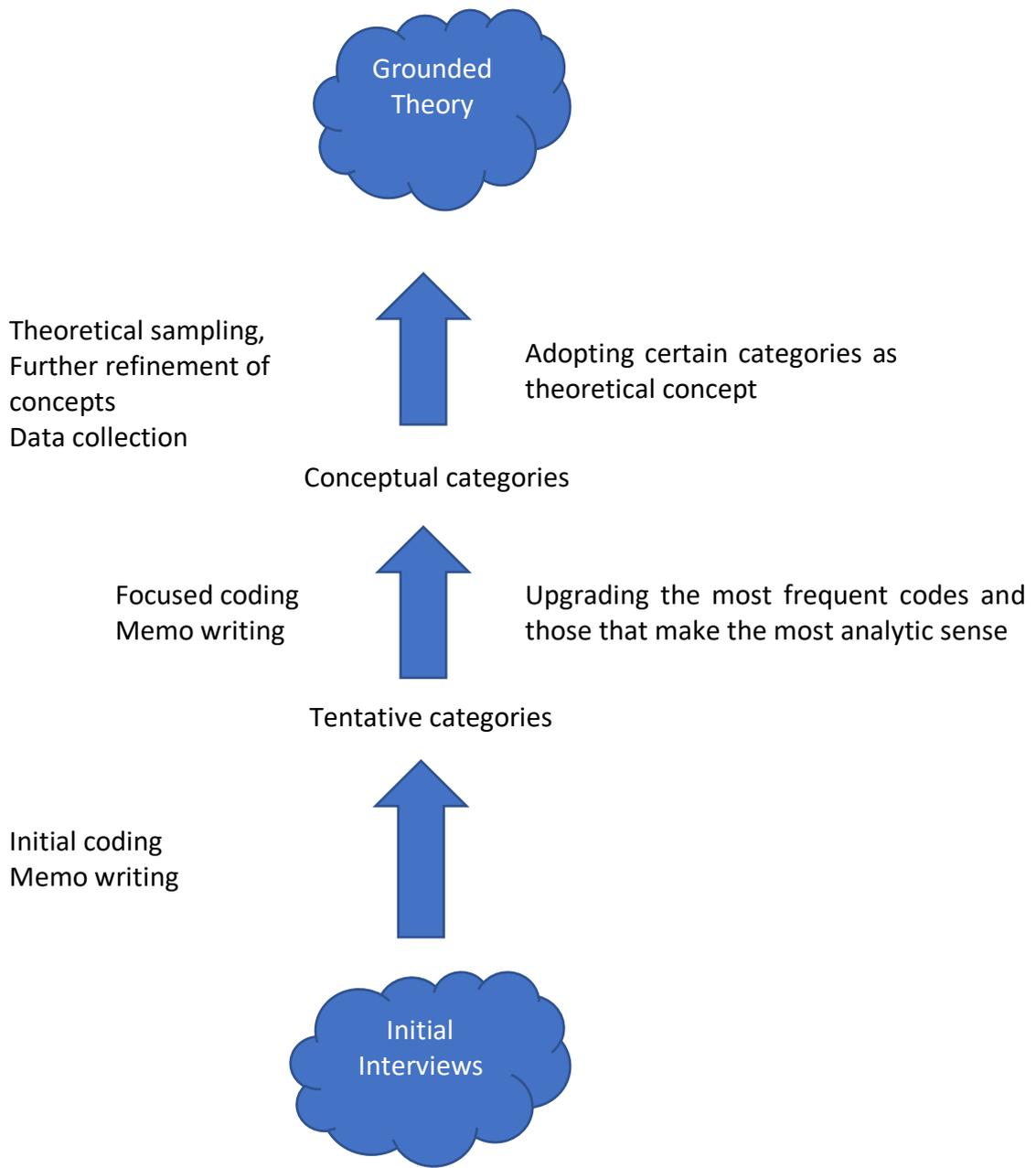
Figure 1. The Grounded Theory Process

4.8.2 Memo writing

Before initial coding, my first attempt at analysis of the data was through a written memo of my experience and my observations of the first set of interviews and this continued throughout the research process. As described by Charmaz (2014), the memo serves as a reflective tool for contextualising issues around the interview such as participants' non-verbal clues, expressed emotions and happenings during the interview and represented analytic ideas which were built on as the analysis progressed. I developed these written ideas as I transcribed the interviews verbatim in the order in which they were conducted. This transcribing process gave me the opportunity to immerse myself in the data, to re-live the interview and refocus on the content of the recordings thereby giving a more intense reflection on the contextual meaning of the individual participant's voice.

For instance, typing while listening to the recordings reminded me of some subtle circumstances around the interview such as intense emotion expressed by an interviewee when talking about their frustration at not being able to communicate their wishes. This emphasized codes such as 'deriving relief' that I might have otherwise unconsciously disregarded. This reflects Schwandt (2015) observation that these memos, sometimes referred to as field notes, can serve as a tool that improves the understanding of the social situation being investigated. As I proceeded with the analysis, I continued to keep a memo bank of analytic memos (example in Appendix I). The analytic notes helped me to think about and explore the relationships; similarities and differences identified between the data, including methodological decisions that would be useful in my final write-up. They also served as a reflexive journal used to document my preconceptions and would lend a critical eye to my analysis. For me, engaging in memo writing enabled the capturing of a creative spark.

4.9 Ethical Consideration

Recruitment and data collection commenced after ethical approval was sought and obtained from the University of Lancaster Research Ethics Committee (FHMREC16120) (Appendix G) and the relevant Institutional Ethical Research Committee in Nigeria (UITH/CAT/189/ 19B/313) (Appendix H). Ethical considerations included ensuring informed consent and confidentiality. All participants were provided with participant information sheets and informed consent forms before the interviews. All interviews were conducted at the location of participants choosing to ensure their privacy and confidentiality. On the day of the meeting, before the interview began, the study was explained in plain English and reiterated in the participant's local language before a signed informed consent was obtained. Participants were informed of their right to withdraw without reason or repercussion up until two weeks after the interview.

Recognising potential power dynamics between myself, a medical doctor-researcher, and the participants to their detriment, various actions were needed to minimise the risk (Hunt et al., 2011). First, I did not withhold my status as a clinician from the participants to ensure transparency (Geddis-Regan et al., 2021). However, I made sure I had no professional relationship with the participants before and after the research. Secondly, the interview location was determined by the participants. I introduced myself by my first name and was dressed informally for the interviews. Also, to avoid sending mixed messages, I gave clear information about my role as a researcher, which was independent of my job role. Lastly, I theoretically sampled participants with varying ages and social status. Therefore, engaging in a reflexive process and making practical decisions on how to mitigate against power play was conducted throughout the study.

To ensure optimum consideration and sensitivity for patients and their family members, all recruited participants were aware of their diagnosis or family member's diagnosis respectively prior to the recruitment period. However, acknowledging that interviewing such participants could still be burdensome and distressing for them, unless participants mentioned this first, the word death or dying were not mentioned. One of the participants requested to stop the interview, and this was immediately stopped. Those who were perceived to be distressed were offered the option of having breaks or postponing the conversation to allow for some recovery. After the interviews, the participants were encouraged to utilise the hospital counselling services or have a discussion with their clinicians if they so wished to help with any distress the interviews might have caused.

All interview transcripts were anonymised by removing identifying information and replacing it with a code prior to analysis. This information was stored in a secured separate location from the transcript on the password-protected computer. All memos, data and writings related to the analysis were stored in a password protected hard drive to maintain the security of the data. Upon completion of the study, all the data will be stored on the Lancaster University server for up until ten years after the completion of the study.

4.10 Summary

In this chapter, I focused on clarifying and justifying the usage of the constructivist grounded theory research methodology and describing the method used for the research. Next, the findings of the study will be presented.

Chapter 5: Findings and theoretical model of *rubbing minds together*

5.1 Introduction

This chapter presents the grounded theory, *rubbing minds together* constructed from the relationships between the conceptual categories, which explains the underlying process of expressing wishes and preferences in the advanced cancer setting. First, a brief overview of the participant characteristics will be presented. Then a brief description of the context in which the interaction between the patients and the family members occurs is given. Finally, the grounded theory of *rubbing minds together* will be presented. Each conceptual category of the theory will be described separately in the subsections. Quotations are used to illustrate the raw data. Patient respondents are represented with PR (1-8), while family respondents are represented with FR (1-6).

5.2 Overview of participant characteristics

A total of fourteen participants were interviewed; eight patients diagnosed with advanced cancer and six family members of patients with advanced cancer who were not related to the patients recruited to the study. There was an equal distribution of patients in terms of sex, but there were four female and two male family members. All fourteen participants were Nigerians living in Nigeria. Their ages ranged from twenty-seven to eighty years. At the time of the interview, the minimum time from diagnosis of incurable advanced cancer was six months, and the maximum was thirty-six months. The types of cancer the participants or participants' relatives had were advanced terminal solid tumours, and they included gastrointestinal stromal cell tumour, renal cancer, colon cancer, breast cancer, ovarian cancer and prostate cancer. The table below gives information about the participants' age, gender, diagnosis and interview venue. It also includes those present in the interview: interviewer and

interviewee and in some cases other relatives, even when they did not talk during the

interviews.

Table 3. General overview of all respondent

Respondents	Age of respondent in years	Gender of the respondent.	Diagnosis of patient or the family member with cancer	Interview Venue	Those present during the interview
Family Respondent FR1:	44	Male (Brother)	Metastatic Prostate cancer	Palliative care unit	Interviewer and interviewee
FR2	56	Male (Husband)	Metastatic cancer of unknown origin	Palliative care unit	Interviewer, interviewee and his wife
FR3	28	Female (Daughter)	Metastatic breast Cancer	Hospital ward	Interviewer and interviewee
FR4	32	Female (Daughter)	Metastatic Prostate Cancer	Hospital ward	Interviewer and interviewee
FR5	27	Female (Daughter)	Metastatic breast Cancer	Palliative care unit	Interviewer and interviewee
FR6	45	Female (Sister)	Metastatic Colon Cancer	Palliative care unit	Interviewer and interviewee
Patient Respondent PR1	56	Female	Metastatic breast Cancer	Patient's own home	Interviewer and interviewee
PR2	52	Male	Gastrointestinal stromal tumour	Hospital ward	Interviewer, interviewee and his sister.
PR3	64	Male	Metastatic renal cancer	Hospital ward	Interviewer, interviewee and his son
PR4	53	Female	Metastatic breast Cancer	Patient's own home	Interviewer, interviewee and three of her children
PR5	63	Male	Metastatic Prostate cancer	Patient's own home	Interviewer, interviewee and two other relatives
PR6	64	Female	Metastatic breast Cancer	Patient's own home	Interviewer and interviewee
PR7	52	Female	Metastatic ovarian Cancer	Patients own home	Interviewer and interviewee
PR8	80	Male	Metastatic colon cancer	Patient's own home	Interviewer, interviewee and his wife and three other relatives.

5.3 The context of the interaction between the patients with advanced cancer and the family members

This is a brief overview of the family members'/patient interaction at home and during outpatient hospital appointments or in-patient hospital admission as observed around the time of the interviews and as perceived by the patients and their family members. It will provide a contextual background to the study and give a better understanding of the relationship between patients and family members after the diagnosis of advanced cancer in the context of the research.

Communal living of the immediate and the extended family members in the same house called the 'family house' is common in the African context. The right of residence is usually determined from their common ancestry. The family house is passed down from one generation to the next serving as a symbol of social identity and community recognition for the members of the family that live there (Jiboye and Ogunshakin, 2010). Some of the interviews conducted in the patient's own home showcased this way of living where families have limited privacy.

> *"I walked behind him towards the bedroom he shared with his wife along a long corridor lined with rooms on each side, other family members peeped out to say hello, and I could see the curiosity in their eyes. They seem to be wondering what I, a stranger was doing in the house. He introduces me to each of them- tells them I am a doctor who had come to have a chat with him about his wife."*
>
> Memo: family house

However, Patients seem unperturbed with this lack of personal space. Even though they were one-to-one interviews, in all but three patient-participant interviews, family members sat through the interview to support their relatives through the meetings at the patient's request.

"Some patients requested to have their family members with them during the interviews"

Memo: setting up

Family members' physical presence with their relative serves as emotional support both at home and when they accompany them to the hospital. However, in some cases, the support was also for practical reasons. Family members transporting their relative to the hospital and running errands within the hospital on behalf of them are some of the pragmatic reasons for accompanying them to hospital. The family members are usually responsible for transporting blood or tissue samples taken from the patients to the laboratories for testing and the collection of results from the laboratories and delivering them to the healthcare professionals. Therefore, family members have an essential role in the care of patients when they are admitted to the hospital.

For all but two of the participants, a diagnosis of cancer was made in the advanced stage where the patients had a life expectancy of a few months as documented in their palliative care registration forms. However, for most of the participants, referral by the primary clinicians (specialists) to the palliative care unit occurred without precise information about the possible prognosis of their illness. Therefore, for the patients and family members, the first information about their prognosis was from the palliative care specialists. On the other

hand, the palliative care specialist encourages open communication between the patients and their family members.

> "*We did not understand that this thing will kill him; the doctors said the chemotherapy will not cure it but will help to shrink it. Because I must confess to you. They have never told us that the treatment is no good, they should have told us a long time ago. Nobody has ever counselled us to this extent about the implication of the rate at which the disease is progressing. The sister and doctor told us [palliative care nurse and consultant], they said the treatment would not keep him alive. He [palliative care consultant] said I should talk to her about what she wants.*"
>
> FR2

In most cases, the family members serve as an intermediary between the patients and the healthcare professionals if there is a need to pass on information about wishes and preferences. The palliative care team keeps in touch with the patient and the family in case they need symptom control. Even though the palliative care team offer home visits, these visits are not regular and are unlikely due to funding and staffing issues. Therefore, there is little or no role for professional carers when patients are in their own homes, and family members take up the role of carers.

5.4 *Rubbing minds together* - the process of expressing end of life wishes and preferences among patients diagnosed with advanced cancer and family members

The data analysis using the initial and then focused coding led to the identification of three conceptual categories: *controlling to seek relief, enduring* and *collaborating*. However, as the analysis and constant comparison proceeded, it became evident that an in vivo code, *rubbing minds together,* linked and underpinned all three constructed conceptual categories and was thus raised to be the theoretical concept. The term is a peculiar Nigerian English expression meaning "to consult and work together" or ''to confer ''or ''to negotiate'' or "exchange of ideas with someone". Therefore, it was adopted as the theoretical concept. The choices and actions of the patients through the process of expressing their wishes and preferences demonstrated their focus on consulting and working together with their family members. The *rubbing mind together theory* seeks to explain the dynamics of communication between the patients and the family members, leading to the expression of wishes and preferences after the diagnosis of advanced incurable cancer. The choices and actions taken by the patients in the course of expressing their wishes and preferences demonstrated a commitment to rubbing minds with the family members although this was not always easy or straightforward.

In the following three subsections, an overview of each construct is provided. The first subsection explains the overwhelming need for control expressed by the patients in their efforts to rub minds together with the family members. The *controlling to seek relief* concept recognises the power of influence although imbalanced held by the patient or the family members on the process of expressing wishes and preferences. The subsection gives an insight into the techniques utilised to gain control by the patients who want to express their wishes and the preferences and the family members who have reservations about open discussion. The second subsection, *enduring* reveals the internal changes, personal and

collective developmental journey that that the patients and the family members go through in the process of *rubbing minds together*. Finally, the third subsection, *collaborating* demonstrates the collectivist orientation of those involved, that is a reliance of patients on family members to express their wishes and preferences. Figure 2 illustrates the constructed grounded theory. It shows the interrelationship between these three conceptual categories that explains the process of expressing end of life care wishes and preferences in the Nigerian cancer context.
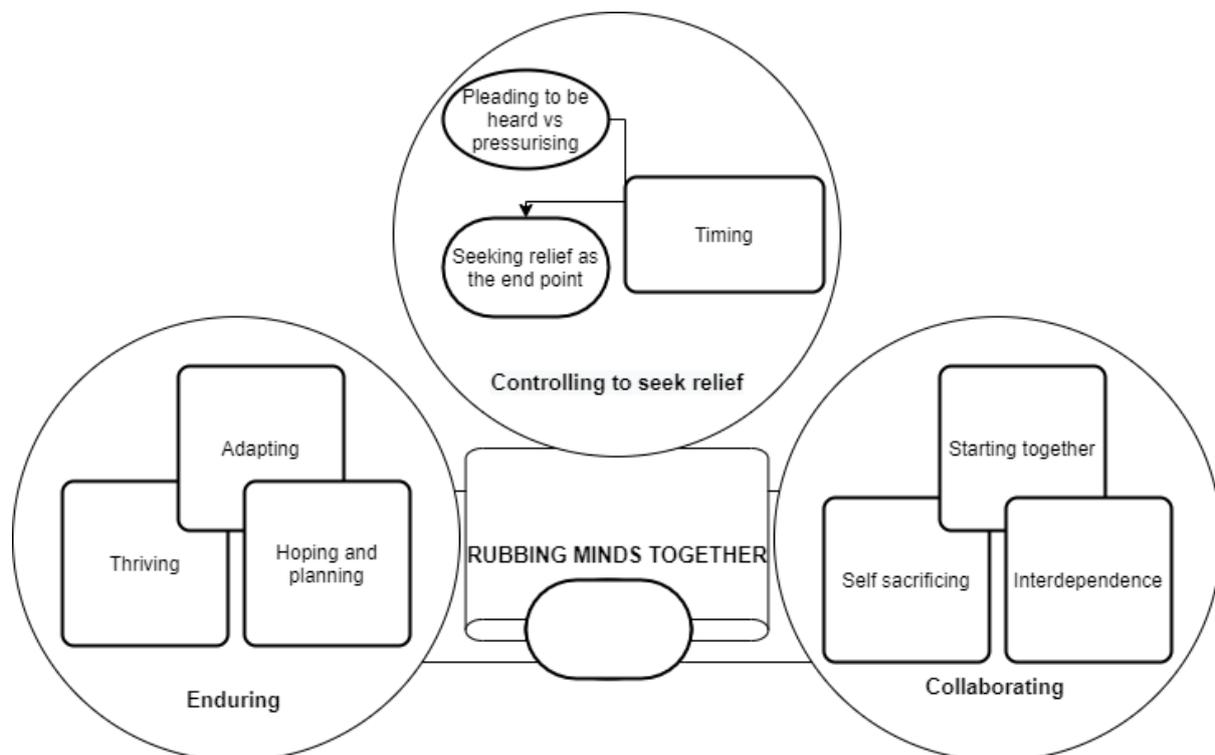
Figure 3. Theoretical model of rubbing minds together

Rubbing minds together emanates from the inner and outer conflicts experienced in the process of expressing wishes and preferences. For example, patients might experience a conflict between the need to talk and their experiences and perceived barriers arising from the collectivistic values held by them and their family members.

> *"Sometimes, I want to talk, but it is difficult. They [the relatives] will not allow me. I try as much as possible, but it is not easy."*
>
> PR2

Inner uncertainties related to the terminal illness or an outer conflict resulting from the predisposition of other people, such as the patients for the family members and vice versa creates difficulties. To overcome this conflicting perspective arising from the process of participating in end of life discussion, the participants engage in *controlling to seek relief, enduring* and *collaborating.*

5.4.1 Controlling to seek relief

Starting up the process of expressing wishes and preferences was found to be difficult as patients and their family members tend to have an unbalanced level of influence on the process involved in expressing wishes and preferences, and the person with the most convincing power determines the course of events. Patients may find themselves manipulating the situation to be able to express their wishes and preferences, in other words *controlling to seek relief*. Although this was not always explicitly identified or acknowledged from the outset, seeking relief was identified as an end target in the control process for most patients. Although family members can support the process of expressing wishes and preferences, for most of the time, their position is that of undermining it due to various reasons. However, to ensure that their voice is heard, when patients are committed to

seeking relief, they utilise tactical strategies to gain control despite the antagonism. Figure 3

illustrates the conceptualisation of the interrelating components that makes up *controlling to*

seek relief and this is followed by a discussion on the mechanisms involved in the process.
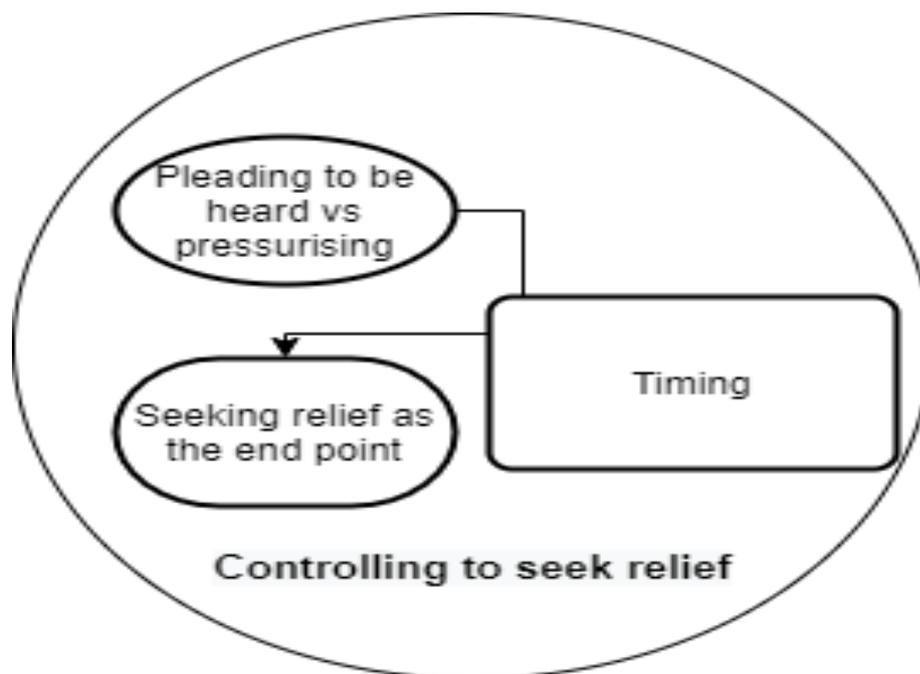
Figure 4.Controlling to seek relief

Pleading to be heard means that the patients are in a position where they need to be persuasive, and it is necessary to justify or defend their stance to themselves and their family members. For the patients, there was an overwhelming need to influence the family members to facilitate expression of wishes and preferences. Patients find themselves in a situation where they need to plead to be allowed to express themselves. A man in his sixties talked about his frustration from finding it hard to persuade his older children about his need to have a conversation about dying.

> *"I need to be firm with them, they sometimes think I am not serious, but they are the one that is not serious, we know this cancer has no cure, why do I need to beg them to listen? It is something simple and straightforward, yet it takes all my energy to convince them that I am dying."*

> PR 8

Some patients try to connect with their inner self with the hope of convincing themselves to have the discussion about dying. For example, a patient respondent sees the constant contemplation of possible death as a negative thing that he needs to overcome to be able to express himself.

> *"but I beg myself to remove all negative thoughts from my mind, I can do this... I need to control my emotions to be able to say what I need to say, I have learnt to do it without crying."*

> PR3

Some of the patients' justification for the plea mostly relates to the terminal nature of the illness; they use the possibility of dying as the logical explanation for wanting to express their wishes and preferences.

"I have discussed with my doctors about the chemotherapy… and they have told me the cancer has no cure … what do I have to lose by talking?"

PR4

Some other patients cite the cultural expectation of having a primed successor after their death as the reasoning behind their need to express their wishes and preferences to whomever will succeed them. As a case in point, a retired blacksmith talked about his disappointment at his inability to hand over his work to his children and facilitate the continuity of his ancestral traditions after his death. He thinks he would have been able to do this if his children very receptive to open discussion.

"My father taught me a lot of things about the practice of ifa just before his death, just like his fore fathers taught him before his death, but I cannot teach this to my children, they are not ready to listen…I have to make them listen … please talk to them, is it not just to listen?"

PR2

Interestingly, it is the same cultural reason that the family members mention when opposing discussion about end of life. Many of the family vehemently resist this discussion, because of the cultural notion of openly talking about dying as a sign of giving up on life.

"I try to explain to them [relatives] that I might be dead tomorrow, I tell them, please comply with what I want, but they just shut me up, I have been trying and making efforts…. They think I want to die if I am saying those things."

PR3

The family members seem to deny the likelihood of death even when they have been informed of this by the healthcare professionals. They use religion to blackmail the patient in to not talking about dying.

"In case something happens to me, they will say nothing will happen, nothing will happen. I will say you don't know now oh, nobody knows tomorrow, listen to me please, listen and please comply with what I want, they will just shut me up. I should not say such things. God will not be happy with me. That's what they say."

PR3

In some situations, the patients are dissuaded from talking about death by their family members focus on futile treatment options.

"My brother was advising me about what other treatment options we have [options that do not work], he thinks I am thinking about dying and if I am talking about these things that means I am about to die."

PR3

These ineffective treatment options can be imposed on a patient in the form of emotional blackmail.

"Family pressure can make one go with certain directions. For me, pressure from my family made me do the surgery in the first place. My wife says I am selfish for giving up and not fighting- I want to leave her by herself with the children."

PR5

As seen in the above quote, some family member's position is not only opposing the discussion but also *pressurizing* the patients through coercion or subtle pressure. Emotional manipulation or deception is also used. Family Participants may lie to persuade their ill relative not to express his/her wishes and thus controlling the process of expressing wishes.

"But he keeps insisting that we should remember all he is saying. In fact, I lie to him that I have seen someone who lived several years after having this cancer and something worse. Because I do not want him to think about dying."

FR5

While patients sometimes bow to the family members' pressure, they also use their weight as a means of negotiation when they feel this is needed. For instance, when having to improve their chances of being heard, they also sometimes use emotional or threatening behaviour towards the family members. For instance, one of the patient-participants talked about his experience of using tears to stop his sister from deciding about his care on his behalf. He talked about how he started crying and told his sister to be prepared to carry the burden of his death should he die after being taken to a traditional herbalist instead of the hospital for palliative care as he had requested. He accused the family members of wanting to cause him harm by pursuing futile treatment against his preference.

69

"I told her she will have my blood on her hands if I die at the herbalist, she quickly

accepted to take me back to the hospital."

PR5

This feeling of being antagonised by the family members was quite strong amongst the

patients interviewed. In all but two of the patient interviews, the patients showed anger and

distress at not being able to freely talk about what they wanted to express to their relatives.

For many patients, the need to direct the course of the event seemed necessary for the

conversation around death and preparing for death to happen.

5.4.1.2 Timing as a mechanism for control

Timing refers to making a judgment about when the discussion or expression of wishes and

preferences is best done. It could refer to appropriate scheduling to partake in the

conversation on time before the death of the patient. It could also mean engaging in the

discussion about death at a time when the patients feel ready or are prepared to engage in

such discussions. One patient talked about his experience of having his property stolen by

some of his neighbours while he was in hospital. He believes that by having a conversation

with his wife about what he owns and how he wants his business to be run before becoming

too unwell to manage it by himself, he will prevent outsiders from stealing his belongings

because his wife will know where those possessions are.

"What if I die? Do you know how many things they will steal and take away? So

sometimes I tell them the things I feel I might not be able to tell them later, I want to

do it on time, no matter what happens, that is my goal."

PR5*.*

He also talked about his readiness and feelings that it was the right time to have the conversation.

"But if the mindset is telling one that something might happen, the right time I think is to go with one's guts."

PR5

When one of the participants was asked about when she felt was the right time, and what made her start to express her wishes, she said:

"Nothing doctor, nothing. When it got to the stage when I know I had to talk to people, I talked to my sister."

PR7

The appropriateness of the timing for expression of wishes also relates to the ability to cherish and savour time preciously. That is, the patients think about cutting their losses early and using the little time that they might have, wisely. Some patients related their religious and spiritual beliefs about death and what it means to them and how they ought to react to the possibility of death, including prudent use of time.

"The Almighty created all of us, if it is better to die; it takes one out of the pain. But we should be happy, the fact that one has cancer does not mean they should be stigmatised and be afraid and then not able to talk about your future again. It is just like any other disease, and it might not kill immediately, and if one is unlucky to have it but still have time, then one should take it and use the time wisely."

PR6

The spiritual lives of the patients were evident in their perception of the best time to have the conversation. Patients use the opportunities of memorable spiritual occasions such as religious celebrations that provide an atmosphere of happiness and calmness to express their wishes and preferences.

> *"Yes, maybe. This makes me remember what my younger brother told me. He told me an incident that happened during one of the Eid celebrations before this illness got bad. About three years ago, while he and my dad were preparing the meat for the celebration, my dad talked about death and specified how and where he would like to be buried, he said it jokingly but then we know now."*

FR4

Therefore, time usage and timing appropriately serve as a mechanism of controlling the process of expressing wishes and preferences in such a way as to be heard.

5.4.1.3 Seeking relief as an end target

The end target of controlling the process of expressing wishes and preferences is the derivation of relief or feeling of satisfaction in having the discussion, even though this might not be recognised at the outset by either the patients or the family members. There was a sense of achievement or feeling of satisfaction amongst the patients when they could express their wishes and preferences. Some of them describe the psychological relief from the experience of having the burden of non-discussion lifted off their shoulder and they felt as if their initial efforts were directed towards expressing their wishes and preferences in the first place.

"Honestly, when I talk to my sister about my future, I feel relieved and happier, like a weight off my shoulder. It is just the best thing in this situation for me."

PR6

Moreover, the family members recognise and acknowledge witnessing the patients feeling of accomplishment or reaching a satisfying end.

"After every discussion, I can see the relief in him, at least if he has somebody to talk with, we share ideas about what he is thinking."

FR1.

Although some relief the patients derive from expressing these wishes relates to the ability to impact and take charge of their own life, the satisfaction is also exemplified when facilitating the comfort and good living of the family they will leave behind. For instance, a patient was focused on setting her financial affairs in order not to burden her family after she might have died.

"They know where to find the document for all my properties and what to do with them. So, it is important for me to let my people know what is going on and what to expect when I am finally gone."

PR7

These conversations allow the patients to express their feelings with the hope that the family might gain encouragement and stay strong, continuing to go on after the death of their loved one.

" I really liked it because you discussed something close to my heart that I might not have the opportunity of ever discussing with anyone again, I will feel so much better when I talk about these issues with my children. I think this will make it easier for them when I am gone."

PR7.

This feeling of undying liberation expressed by patients is also acknowledged by family members of terminally ill patients who express their feelings of contentment when speaking to their sick relative about their wishes and preferences especially when they are close to dying. They base their mind-sets on their belief in what happens in the grave and life after death.

"My father keeps on saying, please do not become enemies to each other, that we should remain as friends for the rest of our lives, he said that is what is going to make him happy in his grave, and I believe that. He will be happy that he has used this time to tell us what he wants for us, that is the satisfaction he gets and ... it is a good feeling for me and for my family."

FR3

Besides this sense of personal and shared feeling of fulfilment derived from engaging in the end of life conversations, there is also a higher sense of spiritual/ religious gratification from fulfilling a greater good that is regarded as a privilege given to them by God. Therefore, the family member that can have a conversation with a dying person feels honoured and important.

"I believe that that is one of the reasons that God preserves one after the diagnosis of a terminal illness, to encourage the family members left behind, to let them be strong, they will surely be worse of if the death was sudden."

PR7

"So, I think it is best to have this sort of discussion. I think there is a great pleasure for him and for us to have this sort of discussion while he is still with us."

FR3

The above quotes reflects the acknowledgement of a satisfaction on having the conversation, despite an initial concern about the possible implication of the discussion before engaging in the conversation. It is also an acknowledgement of their struggle, particularly that of the patient, to reach this end:

"Initially, I used to think there was a major disadvantage in it, but now I know it is an opportunity."

FR 6

In summary, patients and family members acknowledge that expressing wishes and preferences during a stressful time such as the diagnosis of terminal illness was complicated due to various barriers, and thus laden with practicalities to overcome those difficulties. As a result, *controlling* as a critical component of *rubbing minds together* allows the reconciliation of values that patients and family members hold firmly. Controlling the process to seek relief

serves a regulatory role in determining the feasibility of expressing end of life wishes and preferences.

5.4.2 Enduring

Enduring refers to the individual and collective show of resilience or putting up with difficulties associated with the diagnosis of a terminal illness and engaging in the conversation around expressing end of life wishes and preferences. It also includes making concession or rethinking of expectations on issues that the patients or the family members previously held as important or of great value. Figure 4 presents an illustration of the component parts and means of *enduring:* adapting, hoping and planning, and thriving.
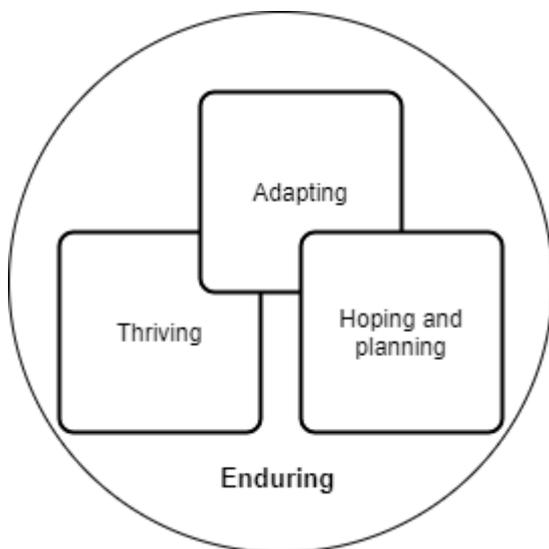
Figure 5. Enduring

5.4.2.1 Adapting

Adapting refers to a change in thinking and behaviour to fit new conditions. The change involves an emotional preparedness or readiness to participate in the communication of wishes and preferences by the patients and the family members after the diagnosis of the serious life-limiting illness. A confused emotional state in the early period precedes a settled point triggered by a specific scenario at some point after the diagnosis of the terminal illness. One of the family member participants expressed his wife's initial reluctance to have any discussion about her illness until she understood that she might die before her children would start secondary school. He described how things changed when she realized that she needed to start making plans to be able to contribute to the upbringing of her children such as deciding who they will live with in the long term.

> *"She is an introvert because of her past and does not talk very much, but when this happened, and I mentioned that the children would stay with my sister … , she seems to have changed and become more dedicated to getting her thoughts and voice out. This is very important to her. I can see that."*
>
> FR2

The adaptive state which outlives the emotional difficulty associated with having discussions about impending death is regarded as an adjustment.

> *"she eventually settles her mind … she adapts to the situation she finds herself."*
>
> *FR2*

The adjusting involved changing priorities to suit the situation at hand and allow for or prevent the expression of wishes and preferences. A patient who was bedridden with terminal cancer articulates how he struggles to express himself with his family because he does not want to cause them emotional stress even though he wants to talk.

"I cannot talk, and there is nothing I can do about it; I have learnt to cope and adjust."

PR7

However, when readjustment does not happen maybe as a result of avoiding reality, participants who wish to participate in discussion feel uncomfortable with the situation.

"My mum avoids my dad, and she is not ready to shift her position, not ready to entertain that possibility, and so she is not able to listen to what he has to say, and my dad is not happy. He is very sad about this."

FR5

However, when patients or relatives adapt by confronting reality, they feel more comfortable with the conversation as they are more able to explore the true nature of the illness.

"I know how bad it is. I made sure we talked about it, I ask the question and tell my children to ask their questions too."

PR5

Facing reality for the patients and their family members is a means of getting back on track and controlling their thinking to focus on what is at hand and getting comfortable with end of life conversations. Furthermore, some patients relate having discussions about their wishes

and preferences to bravery at being able to face the illness head-on with minimal emotions due to how difficult they find engagement with such a conversation.

> "I am not scared of death all. I am more scared of the illness itself that incapacitates me. Once we are dead, it is now a time to rest, the more I try to talk about my wishes, the more comfortable I get with talking about my dying I am not scared at all, (sobbing)— it looks easy right but it was tough."
>
> PR6

Here the patient acknowledges reaching a point of comfort where they can engage in difficult discussions and is ready to move on.

Other strategies used by some family members include normalising the situation or the discussion itself.

> "I just tell him it is just like having a headache, it is normal."
>
> FR 3

They judge that not making the conversation look extraordinary makes it less complicated. For instance, making conversations seem like a standard or natural thing to do by not setting out separate days or time to have the discussion.

> "Of course, we talk at any time. Before like I said it was difficult, we will need to set a date for it. Now it is no more a special discussion. We decide to talk about it whenever. It is easy that way. Easy as we will not have built up all the emotions. If we have a day for this. The whole day will just be ruined. That is why I told you to come any day."

FR6

5.4.2.2 Hoping and planning

Hoping and planning relates to trying to actualise the future based on the suffering and insufficiency of the present; to seek a future path centred around the assumption of a changeable circumstance or situation, despite uncertainties. Hoping acts as a stimulant for planning and planning gives hope. Patients in the terminal phase of their illness demonstrated hope in various ways through: optimism, religiosity and pessimism. These expressions of hope help them in planning.

With optimism, the participants are confident about the future either by hoping that their health condition can improve or believing that having a terminal illness is not the worst possible situation they can be in.

> *"Some people will die in their sleep, they have no illness, no cancer and never wake up, so I am very grateful for this life."*

PR 13

Retaining hope despite challenging situations acts as a catalyst that promotes their expression of wishes and preferences. For instance, a husband expresses how he feels about being hopeful and still planning.

> *"But even if we have this talk, we still believe that she can live, but that does not mean we should not plan. We still believe in planning; we will sit down, rub minds together and talk about what can happen in the future. We will plan for the future and at the same time, be faithful and hopeful that she will live and then we plan." FR2*

For those that depend on their religious beliefs, they acknowledge the role of faith in preparing for the future. The hope of the religious person is in their trust in God from a perspective that makes them accepting of their fate, good or bad. This hope grants them courage and endurance and gives them the strength to go on.

> *"One thing about faith and belief in God is that it cannot be defined, but it helps one to move on – we follow it in whatever direction. Getting better or dying. Whatever will be will be. I go to church every Sunday, and I pray for him."*
>
> *FR6*

With pessimism, the patients assume the worst possible scenario.

> *"I believe there is nothing anybody can do to prolong my life, … although the doctor, the oncologist that saw me in …… gave an assurance that the drug will take a long time, but the drug will melt it, but before I got to him, you know I have been to ……. I have been told it will eventually going to kill me, so I have to reconcile the two statements, it is difficult, but I have decided to take the worst-case scenario"* PR2

Hoping and planning is a means of expressing uncertainty and enduring life with the diagnosis of terminal cancer.

5.4.2.3 Thriving

Expressing a positive attitude with motivation despite the ongoing illness was another mechanism that was utilised in enduring the diagnosis of terminal cancer and expression of wishes and preferences.

"Before his condition became this bad, he mainly tries to get the children together to tell them stories, they seat around him, jumping around and enjoying themselves, you see how happy he is, he tells them story about his life." FR5

"she plays with the children and have fun as if she is not dying, I know it is challenging, being human but she wants her family to thrive and remain joyous. And she is talking to them about dying like she is going to the market."

FR2

This atmosphere of cheerfulness serves as encouragement and a source of strength to the family members in a stressful period. It helps to diffuse the talk around discussion on expressing wishes and preferences.

"My sister can get very emotional at times, but most times she is smiling and encouraging me."

PR1

Similarly, some participants expressed how participation in the research and granting interviews about their wishes and preferences made them feel good about themselves. They see the interview as their way of passing on a message of goodwill to the public. Their message is that of hope and emphasising the leverage expressing wishes and preferences has on families, helping them to thrive after the diagnosis of a terminal illness in a loved one.

"I feel I have let out what I want to say, and I hope it will touch the lives of others as well – it is not all bad news – we can still enjoy life and talk about dying, the diagnosis of cancer does not mean there is no more life."

PR 1

Sometimes, in recognition of the negative emotions that are mostly associated with discussion around dying, some create periods when they deliberately avoid the conversation. When asked about how she sometimes copes with the sadness she feels from having the conversation, one patient-participant said:

"We can't be saying all that bad stuff every day, I will just say today no more talking about dying, we will talk about living, it is a mental challenge, but we do it, we succeed."

PR4

5.4.3 Collaborating

There is a form of partnership between patients and family members that facilitates the process of expressing end of life care wishes and preference. Some patient-participants voice their inability to make unilateral decisions about their hopes and preferences and thus depend on family members' collaboration. These patients feel more confident when they have family members that started their journey of cancer with them. However, both parties self-sacrifice and plan together to be able to collaborate. Therefore, the forces behind collaborating as constructed from this research include: starting together, self-sacrificing and interdependence and this is illustrated in figure 5 below.

Figure 6. Collaborating

5.4.3.1 Starting together as a facilitator of collaborating

Many patients expressed the importance of having family members who have been with them from the beginning of their illness in the process of negotiating to express end of life wishes and preferences. The patients perceive that their family members who have been present from the start are more open and receptive to engaging in the conversations around the possibility of dying. Family members' presence from the beginning, articulated as either the start of the illness or the time when they received their diagnosis, allows them to understand the disease and observe deterioration and the changes that have taken place in the patient's health condition. The family members understanding of the patient's condition increases as they attend hospital admission and appointments with them.

> *"I know everything from the beginning to the end … I was there I saw it with my eyes and I heard it with my ears. I know what to expect."*
>
> FR6

This understanding creates a deeper interaction between the patients and their relatives who are then in a position of starting up the conversation that leads to the discussion around expressing end of life care wishes and preferences.

> *"Those are the kind of things we have been talking about since the first day. Of course, because we know right from the start that he has cancer and they see what is happening, and we can talk at any time. It does not matter who brings it up; sometimes it is him or it is any of us his siblings or even his wife."*
>
> FR 1

The closer interaction then creates an atmosphere of openness. When asked what they had talked about, one patient-participant replied:

> *"That I have not talked about? No there is nothing left, there is nothing left. They know everything about me right from the beginning and what I want, so I am very happy with that."*
>
> PR7

Therefore, the family's presence from diagnosis through the course of a patient's illness allows for collaboration between them.

5.4.3.2 Self-sacrificing as a facilitator of collaboration

Self-sacrificing means intentionally putting others needs before their own need, in the collaborative relationship between the patient and their family members. Both patients and family members prioritize others over themselves in the collaborative effort. For the patients, when expressing their wishes and preferences, they consider the family members' opinion about issues even when they perceive themselves to be in power.

"They do not actually decide for me but, I need to consider their thoughts too, that is important."

PR2

However, they sometimes feel helpless due to being at the receiving end of care for the disabling illness, even when they are unable to change the situation. For example, when patients depend on the family members for emotional support or for practical things such as getting around, they feel embarrassed.

"I do not think so, but sometimes when I think I am adding to their burdens. They have their personal family problems, with their work, their spouse and so on and I then add my own to their burden sometimes I feel guilty about making them cry and worry about me."

PR6

"Also, physically, I cannot say I want to go out without thinking about how this will affect them, it will disrupt their plans as they need to transport me everywhere."

PR5

For this reason, some patients give the utmost importance to safeguarding the emotional interest and physical wellbeing of their relatives when expressing wishes and preferences and as they feel responsible for causing distress. They, therefore, can compensate by sacrificing what they want to happen such as having open discussion even when they acknowledge how important it is to have such a conversation.

"If someone is not strong-minded and you tell them, after everything they have done for you they will start crying, some of my kids cannot handle the discussion, and I know that. They will wonder what this is. That is why I cannot tell them. I know it is important, but I just know that if I say anything, they will be extremely sad and worried. It is quite difficult for me to upset them. I wish I do not have to say anything.

PR7

Conversely, on the part of the family members, they avoid having discussions relating to end of life when they sense that such conversation might bring about emotional distress to the patients. The daughter of a terminally ill man spoke about her mother's reaction to open discussion:

"I think the main thing is that she does not want to see him in pain and difficulty. She is very concerned with him getting comfortable. The suffering is much for him, physical pain and emotional pain. She thinks if she avoids such discussions, then his emotional pain will not increase."

FR4

This situation results in the prevention of open discussion and deception from both sides. Either thinks that the other cannot cope with having the conversation and tries to protect the other from been exposed to the discussion.

However, for those family members who listen and encourage openness, this same need to defend the other person can be the driving force for them. They are sometimes focused on making the other person comfortable irrespective of their position. The brother of a man

with terminal cancer talked about how he tries to listen to his brother despite his distress from it.

> *"We do not want him to suffer in silence, let him tell us what he wants, and we will act accordingly (sobs) it is difficult, but we have to do it."*

> FR1

Self-sacrificing between the patients and the family members was found to be an opportunity for demonstration of dedication and co-operation.

> *"my sister cleans me, cooks for me, stays with me in the hospital, and she is still strong for me, what else can I ask for? I do not give her anything in return, I have not done very much for her, but she is still here, that is how she shows her love and commitment."*

> PR8

Although some persuasion and control is needed for the negotiation in expressing end of life care wishes, the autonomous decision-maker acknowledges their self-insufficiency in making an independent decision. They need to rely on the other person (their family members). The in-control agents collaborate through individual self-sacrifice by positioning the needs of their relatives over their own.

5.4.3.3 Interdependence as a facilitator of collaboration

The patients acknowledge their lack of independence of thought and being able to have clear autonomous choices without their family members. Patients recognise their reliance on the family members' influence on the decision-making process and the lack of individuality. This

interdependence seems to be irrespective of the patient's age, gender and their role in the family. A male university lecturer in his early sixties who had been the primary breadwinner for his immediate and extended family talked about his inability to make a unilateral decision.

"There is no individual decision in anything, and if it was there, then there is no need for me to tell anybody before I make my decisions. So, there is no independence of thought or decision."

PR5

This lack of individuality is like the situation of that of a retired female civil servant with advanced colonic cancer who says her existence is related to and dependent on her relationship with her husband and children. She says she becomes a complete person with the contribution of her family members.

" I think the best thing is to involve your family in everything; I tell them everything. What is the disadvantage in that? I tell them about all my things all the debts I have. I do not know what I can hide from them. The best is just to be open, so you have a free mind. I get easily confused about things, so I need them to get my acts together, they complete me."

PR6

Patients, particularly older ones, rely on their younger family members' involvement in making plans and participation in the expression of wishes and preference. This reliance is due to the cultural expectation that the family members will naturally assist their ill elders in making plans and will support them in their chosen decision. There exists a cultural norm

where young family members inherit from the older ones, particularly children taking over the business of their parents when they die. Therefore, the expectation is that children ought to be the recipients of the expressed wishes and preferences of the parents.

> *"paramount…ehnnn. Because Yoruba people say [says a proverb in the Yoruba language], that is if fire dies it will be covered by dust and if banana dies, another one will raise up, that is the child will do what the parents wanted him/her to do. Uhmmm. When I was in Igboland, all these rich people, before they die they handover what they have and how they want their company to look like when they die to their children … Yes, when they see that they are getting to the end of their life. I know a man that has a big hospital in ……., he begged his children to please listen to him and do what he wants when he dies. And they did it, so he died a happy man. That is all I have to say."*
>
> PR2

Therefore, the young family members who will inherit the properties and take up the responsibility after the patient's death are usually the bearers of the oral communication that their relative wishes to pass on. Some patients see this as a family responsibility that must be followed irrespective of the family's feelings or the possibility of causing family distress.

> *"Even if it causes pain, they should face it and cooperate with me and listen to me, that is their job. That is why I have children. I did my job as a father; they should do theirs."*
>
> PR3

As such, some family members take this role seriously; they feel a sense of responsibility to take up the role of the listener and executor of wishes and preferences.

"When this illness started, I was also not feeling too well, when we knew it was cancer that has no cure, and he had only a few days, my mum was worried. I had to try to get to the hospital to see him, and he wanted to tell me where to find out where all his documents [were], his bank details. Even though I was not feeling too myself. I need[ed] to be there."

FR5

Patient - family member collaborative effort is preferred to a clinician/patient partnership. Being able to depend on family relations as opposed to healthcare professionals gives the patients and the family members a sense of togetherness and feeling of safety. When asked about why his ill brother would choose to speak with him instead of the doctors caring for him, the brother of a patient said:

'' Well, they are not his family; these things are family issues; the doctors have no say about it. He is comfortable to discuss these things with us as a family. One must have someone, I mean my brother should have at least one person he can discuss these issues with, no matter how worried the person will be or not. It is the family members, and it is our responsibility. The most important thing is getting someone reliable and dependable and someone who knows how to keep sensitive information. Who more can be this but we the relatives?"

FR1

Therefore, the existence of a physical barrier between the patients and their family members, such as when they live apart or where there is limited closeness limits discussion.

"We have not always been living together fully … I think that is the major, major problem, a major part of the cause of this problem. We do not connect, so it is difficult for us to have the heart to heart discussions. When I was in the ….., I was always moving from one place to the other. I was getting transferred. They were living with their mum, so we are not close at all."

PR3

The prevailing physical closeness and emotional proximity between the patients and the family members fosters a strong relationship that allows them to be able to express their wishes and converse freely. Conversely, when the patient feels they are not listened to, they complain of distress and unhappiness. For instance, a patient with paralysis from metastatic advanced prostate cancer was crying due to his disappointments in not having his relatives listen to his wishes and preferences.

"Ehhh… hmm what I mean is that I need a reasonable and understanding person, who is ready to listen and understand me. hmmm."

PR 3

Family members' attention to the sick relative is acknowledged to be a source of encouragement and improved patients' tendency to trust and freely express themselves.

"My sister prays along with me and the little help she can give, she encourages me a lot, and I feel strong and I am able to talk to her. I can trust her."

PR6

"We encourage each other; and sometimes we cry together… If we feel bad, he feels

bad too, and he does not want to."

FR4

However, the patients and the family members depend on each other to move on and get

past the sorrow and sadness that comes with discussing such sensitive issues.

"We all very supportive, very supportive of each other, in fact it lightens my heart when

we discuss because I just feel like that is probably the only solution we have for now."

PR5

"My family understands this, and they are in support of what I want, they understand,

they are my pillar of support, and I could not have done it without them. How will I

cope emotionally without them? Impossible they are my strength; we make plans

together, we put our heads together to see what is best."

PR6

"We will sit down, rub minds together and talk about what can happen in the future."

FR1

The above quotes reflect how important the family-patient's collaborative efforts are in the

expression of wishes and preferences in end of life context in the African setting.

5.5 Summary

The constructed grounded theory, *rubbing minds together* is born out of the relationship between the conceptual categories *of controlling to seek relief, enduring* and *collaborating*. The individual components showcase the contextual factors within and between the patients and their family members that contribute to the process of expressing end of life wishes and preferences amongst those with advanced cancer in Nigeria. In keeping with the constructivist grounded theory method that suggests a delayed literature review to further support and substantiate the newly developed grounded theory, the literature review will be presented next.

Chapter 6: Critical Interpretive Synthesis of the literature on end of life communication in Africa

6.1 Introduction

A systematic review of the literature using the critical interpretive synthesis adopted by Dixon-Woods et al. (2006) was conducted in line with the constructivist grounded theory approach that advocates an in-depth sharply focused literature review to strengthen the research argument and improve the credibility of the research (Charmaz, 2014). The critical interpretive synthesis approach is congruent with constructivist epistemology, allowing for multiple and contextual interpretations (Drisko, 2020). The goal is to develop an emerging theoretical model explaining end of life communication between terminally ill patients, their family members and healthcare professionals in Africa. This gives earlier works their due and analyses the most relevant and significant work in relation to end of life communication in Africa. In the discussion chapter that follows (Chapter 7), I explore how the new theory fits in or is positioned into the broader literature. Thus the literature review helps to position the primary research and clarify its contribution to the existing knowledge (Charmaz, 2014) of end of life communication in Africa. As the newly constructed theory reflects the communication between patients and their family members, this critical interpretive synthesis seeks to identify other findings or broader concepts relating to communication in the process of expressing end of life care wishes and preferences in Africa. This interpretive study will be valuable in informing practice and interventions that can improve end of life care delivery to people living in Africa and perhaps to Africans living abroad.

As highlighted by Charmaz (2014), the definitive version of the literature review should fit the specific purpose and argument of the grounded theory research study. The need to ensure congruence between the primary research and the literature review focus informed the

timing of this literature review to after the construction of the focused and theoretical codes. Even though I had conducted a research proposal which required critical engagement with the previous studies around end of life communication, I allowed the 'material to lie fallow' (Charmaz, 2014, p. 307) until I had a constructed an analytic relationship between the categories I constructed from the data. However, despite delaying the formal literature review, I remained conscious to how and when earlier ideas, positions and perceptions entered the research by engaging in constant reflexivity demonstrated through discussions with supervisors and memo writing.

6.2 Aim of the literature review

The aim of the literature review was to construct an explanatory theoretical model on the concept of communication between people with terminal illness, their family and their healthcare professionals.

6.3 Review Methods

6.3.1 Review Question

What is the experience of communication at end of life amongst African patients diagnosed with a terminal illness, their family members and their healthcare professionals?

6.3.2 Review design

This review is based on the premise that there is a limited number of studies focusing on end of life communication in the African context, and these studies will vary in their designs. Therefore, the mid-range theoretical interpretation is grounded in the qualitative and quantitative evidence but provides new insight and a fresh way of understanding. This

analytic process is congruent with the principle of constructivist grounded theory detailed in this thesis.

6.3.3 Key terms

Terminal illness: A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future

End of life care: Care of patients when they are likely to die within the next 12 months. This includes those patients with advanced, progressive, incurable conditions whose death is expected within hours or days.

6.3.4 Search strategy

Medline, PUBMED, CINAHL, PsycINFO, AMED and Academic Search Ultimate databases were searched in September 2019 using a comprehensive search strategy to identify studies on communication in end of life among African cancer patients their family members and healthcare practitioner. Citation tracking using Web of Science and hand-searching of reference lists of all included articles were subsequently conducted to identify additional papers. The literature search was limited to the last 20 years to examine changing and new perspectives.

Database searches

The searches were adapted to each database. MeSH headings and a thesaurus were used in those databases with facilities for them. Boolean operators were used to connect similar and

different terms. The search strategies for each database can be found in the appendix. Terms

used in the search strategies are illustrated below.

Table 4. Search terms

1. Africans: Africa OR West Africa OR South Africa OR Northern Africa) OR Eastern Africa OR Central Africa OR Malawi OR Rwanda OR Ethiopia OR Botswana OR Algeria OR Namibia OR Tunisia OR Egypt OR Cameroon OR Ghana OR Tanzania OR Zambia OR Zimbabwe OR Rwanda OR Congo OR Mozambique OR Mali OR South Africa OR Uganda OR Nigeria OR Subsaharan OR Sub-Saharan Africa OR Kenya OR Ethiopia OR Sudan OR Morocco OR Angola OR Madagascar OR Cote d'Ivoire OR Niger OR Burkina Faso OR Senegal OR Chad OR Somalia OR Guinea OR Benin OR Burundi OR Togo OR Sierra Leone OR Libya OR Liberia OR Central African Republic OR Mauritania OR Gambia OR Gabon OR Guinea- Bissau OR Swaziland OR Equatorial Guinea OR Mauritius OR Djibouti OR Cabo Verde OR Sao Tome & Principe OR Seychelles
2. Terminal illness: terminally ill OR bereave* OR end of life OR terminal care OR palliative care OR palliative* OR advanced cancer OR hospice
#3. Communication: expression of Wish* OR advance* care plan OR advance* directive OR palliative care OR truth disclosure OR medical power of attorney OR advance* statement OR truth telling OR healthcare power of attorney OR discussion OR communication OR breaking bad news.
#4: Patients, family member and healthcare professionals: Patient* OR family caregiver OR family carer* OR family member* OR doctor* OR nurse* OR physician* OR healthcare professional* OR physician-patient relation* OR patient-family relation* OR family-physician relation* OR (MH "Family") OR (MH "Family Relations") OR (MH "Physicians, Family") OR (MH "Professional-Family Relations") OR (MH "Family Conflict")
#5 = #1 AND #2 AND #3 AND #4. This encompasses literature on communication at end of life amongst African patients diagnosed with a terminal illness, their family members and their healthcare professionals.

6.3.5 Selection criteria

- Qualitative, quantitative and mixed method studies.

- Period: 1999-2019.

- Empirical publications in any language reporting empirical data published in peer-reviewed journals.

- Studies focusing on any form of communication between the patient, their family and healthcare professionals.

- Studies focusing on the experience of communication in end of life contexts in relations to ACP, the completion of advance directives or living wills, truth-telling or breaking bad news.

- Studies focusing on facilitators and barriers to end of life communication in any of the above contexts.

- Studies focusing on the adult patient older than 18 years within any end of life care setting.

- Location: Africa

Exclusion Criteria
- Grey literature, newspaper article, editorials, non-peer-reviewed papers articles based on expert opinions.

- Studies focusing on non-life limiting illnesses.

- Studies on paediatric populations.

- Articles on Africans living abroad.

- Articles relating to the evaluation of a tool or programme.

- Articles relating to the inter or intra professional relationships such as referrals.

- Studies directly focusing only on the content of the conversation.

- Studies focusing on the intensive care setting.

6.3.6 Data extraction and data analysis

Identification and selection of studies

Titles of the listed search results were scanned through and abstracts of articles potentially meeting the inclusion criteria were read through. Full text of articles of these abstracts identified as meeting the inclusion criteria were then retrieved and assessed for inclusion.

Data extraction and Analysis

Once identified as meeting the inclusion criteria, familiarity with each article was sustained by reading the full-text multiple times. Then the relevant data were extracted on to a table clearly stating the research aim, the participants, research method and the findings of each study. These extracted findings were in the form of first-order construct, i.e. direct quote from the article and second-order construct i.e. the author interpretations, all from the finding and discussion sections of the included articles. Then, these constructs were matched to each other through constant comparison to develop the synthetic construct. These synthetic constructs or third-order constructs were then related to each other in a refutational synthesis to construct the synthetic argument with attention to the contradictions in the evidence. Thus, the synthetic construct is grounded in the evidence and is a product of the interpretation of the whole evidence. Figure 6 below depicts the critical interpretive synthesis process.

Familiarisation with the papers	•First order constructs are read and identified (Table 5) •Second order constructs are read and identified (Table 5)
Identifying the synthetic constructs	•Third order constructs (synthetic) are developed (Table 5)
Refutational synthesis	•Consideration of the contradictions and flaws in the evidence (Narrative of the constructs)
Line of argument	•An overarching sythesising argument is constructed (Figure 8)

Figure 7. Depicting the critical interpretive synthesis process

6.4 Results of the review

The PRISMA figure (Figure 7) describes the study selection process. The electronic and hand searches yielded 2462 records. Of these 14 articles met the inclusion criteria and were therefore included. Studies included 8 qualitative and 6 quantitative studies and the publication dates ranged from 2003 to 2018. The studies were from South Africa, Kenya, Uganda, Tanzania, Nigeria, Ethiopia, Egypt, Islamic Republic of Mauritania, and the Democratic Republic of Congo.
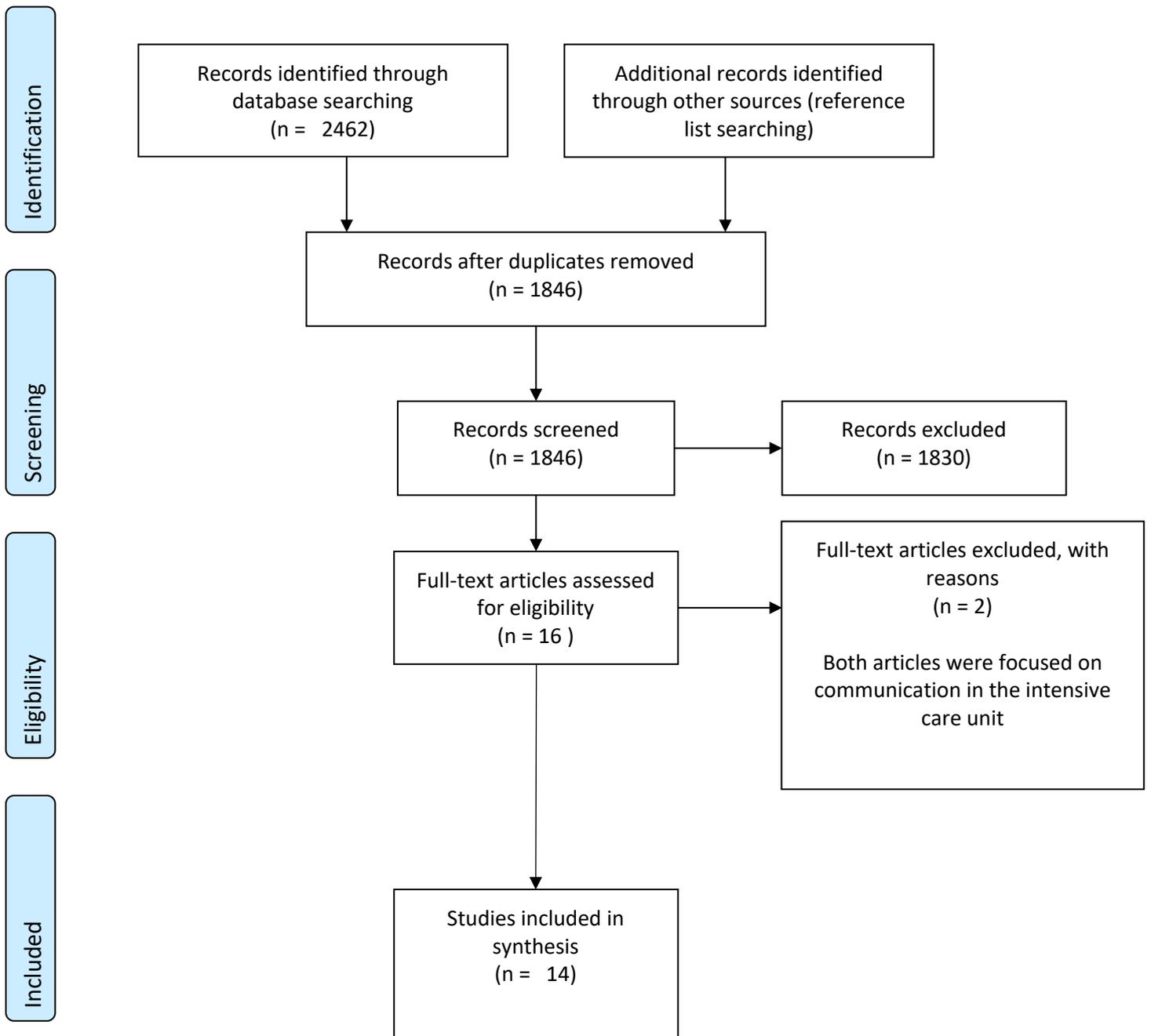
Figure 8. PRISMA flow diagram of study selection

6.4.1 Overview of the included studies

Table 5. General overview of included studies

Author(year)country	Study aim	Participants	Method	Third order constructs	First and second order constructs
Harris et al. (2003) Northern Tanzania	To report on the issues related to the disclosure of cancer diagnoses and prognoses.	37 Healthcare providers in Northern Tanzania Setting: A medical centre: a research and teaching facility.	A combination of ethnographic and other qualitative approaches such as participant observation, intensive and semi structured interviews, informal interviews and the review of key documents.	• Professionalism • Familial decision-making authority	The use of therapeutic privilege: i.e. clinicians withholding information from competent patients justified by lack of therapeutic resources, stigma associated with the illness or avoidance of loss of hope. The central role of the family in end of life decision is emphasized. Tanzanian trained doctors behave differently from foreign trained doctors.
Selman et al. (2009) South Africa and Uganda	To explore the information needs of patients and caregivers attending palliative care services and identify the areas in which patients and caregivers consider that they need more information, and understand their past experiences of communicating with healthcare staff.	90 patients and 38 family caregivers enrolled in palliative care services.	Qualitative approach Setting: Four palliative care services in South Africa and one in Uganda.	• Professionalism • Familial decision-making authority • Illness understanding	Patient's and family's expectation of accurate and timely information Information improving family discussion and improved self-satisfaction from emotional support Information needs centred around diagnosis and prognosis.
Nwankwo and Ezeome (2011) Nigeria	To ascertain the perceptions of the physicians on truth-telling for cancer diagnosis and prognosis.	228 physicians between Jan and April 2010.	A cross sectional quantitative study Setting: A university hospital in South Eastern Nigeria.	• Professionalism	Clinicians' practices of truth telling at end of life directly related to their level of training in palliative care.
Harding et al. (2014) Uganda and Kenya	This study aimed to measure the intensity of multidimensional problems (physical, psychological,	210 adults with advanced malignant disease	A cross sectional quantitative study Setting: One hospice in	• Professionalism	Information to plan for the future was a major problem

	social, and spiritual) among advanced cancer patients in Kenya and Uganda.		Uganda and two hospices in Kenya.		Emphasis on the non-physical need of patients with progressive life limiting illness
Alsirafy et al. (2016) Egypt	To explore the attitude of Egyptian family caregivers of cancer patients toward cancer diagnosis.	288 FCs of cancer patients. 53% of the FC's had patients who was receiving palliative care.	Prospective study (Quantitative descriptive study) Setting: 2 Egyptian cancer care services.	• Illness understanding	Family members' personal preferences to disclosure reflects on their practices of disclosure to their family. Family members of patients with full awareness of diagnosis stand by their decision to tell. Family members' rural residence and low level of education directly linked to non-disclosure practices.
Ganca et al. (2016) South Africa	To explore communication skills and practices of medical practitioners when conveying a poor prognosis to patients and families, and to identify their communication skills, needs and understanding of palliative care.	14 practicing doctors in oncology, internal medicine, medical emergency and neurosurgery.	Exploratory qualitative study using a grounded theory approach Setting: A tertiary hospital in Western Cape Province South Africa.	• Professionalism • Maintaining relationships • Illness understanding	Lack of professionals' formal training in end of life discussion and non-abandonment of patients improves the process of open communication. End of life improves the process of healthcare professionals' concerns about damaging their relationship with patients when breaking bad news. Involvement of patients and family members throughout the disease trajectory improves open communication.
Ayers et al. (2017) Ethiopia	To investigate how palliative care staff communicated with dying patients and their family members.	Five palliative care staff, four patients and six family caregivers.	Focused ethnography (qualitative) Setting: A palliative care setting offering a range of services including home care and in-patient care.	• Maintaining relationships • Familial decision-making authority	Family members trivializing the diagnosis and prognosis with the aim of protecting patients from strong emotions, and healthcare professionals evading difficult conversation to maintain relationship with patients and family members. Family members act as constraints to healthcare professionals' dedication to openness and honesty.

Githiagi and Swartz (2017) Kenya	To examine the content and contexts of family end of life conversations and decisions.	4 focused group Bereaved women family cancer caregivers living and working in Nairobi.	Interpretative phenomenological analysis Setting: local hospice, personal contact and referral from participants living and working in Nairobi.	• Maintaining relationships • Familial decision-making authority	Fear of stirring up emotional distress in patients prevents open discussion Mutual attempts at protection between patients and their family members. Emphasis of the family member's critical role in end of life discussion.
Lofandjola et al. (2017) Democratic republic of Congo	To illustrate in the perceptions of families on the care of patients suffering from advanced cancer and to identify the possible aids provided by the healthcare services.	Family members caring for patients with advanced illness. 6 focus groups of 8 members each.	A qualitative study Setting: Patients hospitalised in 6 hospitals across in Kinshasa, Democratic Republic of Congo.	• Illness understanding • Maintaining relationships	Healthcare professional's practice of communication in informal language diminishes patients and family's understanding of the illness. Patients' feeling of guilt of being a burden to family members and the family member's participation in end of life discussion is seen as asocial duty and contributes to the patient's morale.
Lewis et al. 2017) (Tanzania)	To explore the views of nursing staff and medical professionals on providing palliative and end of life care to hospital inpatients in Tanzania.	31 healthcare workers in the adult medicine (18) or paediatric ward (13).	Qualitative method- Setting: A tertiary referral centre in Tanzania.	• Professionalism • Illness understanding • Maintaining relationships	Clinicians acknowledgement of their role in improving patients and family members understanding and acceptance of diagnosis and prognosis and breaking bad news as a professional and personal failure. Clinicians late recognition of death prevents open communication. Patients dying while being treated as a demonstration of love by the family members.
Omondi et al. (2017) Kenya	To determine the proportion of terminally ill patients with advance directive and to identify the factors that influence advance directive completion in a hospital.	Records of 216 terminally ill patients	Quantitative descriptive: Retrospective survey of available records Setting: A university hospital	• Professionalism • Illness understanding • Familial decision-making authority	Palliative care specialist review of patients improves completion of Advance directive Socio economic deprivation and low level of education linked to poor understanding of illness. Advance directive document are made after patients' discussion with their family members.

Shen et al. (2018) South Africa	To investigate the understanding of south African patients with advanced cancer of their illness, EOL care preferences and communication.	221 Patients with advanced cancer and their informal unpaid caregivers.	Quantitative descriptive study Setting: A palliative care centre in Soweto, South Africa.	• Maintaining relationships • Illness understanding	Patients preference for care related to their intention to relieve their family of immense pressure relating to giving end –of-life care Patient's lack of terminal illness acknowledgement and socioeconomic deprivation relates to poor understanding of illness.
Yennurajalingam et al. (2018) conducted internationally across 11 countries including South Africa	To determine the frequency and predictors of passive decisional control preferences among advanced cancer patients and determine the concordance between actual decision-making and decisional control preferences and its association with patient satisfaction.	Patients with advanced cancer. South African were 96 of the total 1490 patients (6.4%) and the data was presented by country.	Cross-sectional survey Setting: Palliative care centres.	• Illness understanding • Familial decision-making authority	In comparison to United States, South Africans are less likely to choose passive decisional preferences. Predictor of passive decisional preferences include low educational status and poor performance status. Shared decision making with family more likely than shared decision making with physicians.
Fearon et al. (2019) Islamic Republic of Mauritania	To explore whether the principles of palliative care are congruent with the perspectives of health professionals, families and communities.	33 rural health professionals 12 bereaved family members and 31 respected community leaders.	Qualitative research.	• Professionalism • Illness understanding • Maintaining relationships	Healthcare professionals lack of acknowledgement of terminal illness, resulting in their lack of clarity and openness. Healthcare professional seeking to protect their relationship with the community by not disclosing bad news: breaking bad news leads to loss of trust.

Assessment of quality

In keeping with the recommendation of critical interpretive synthesis, primary research papers deemed to be relevant to communication between patients, family members and their healthcare professionals were prioritised irrespective of their methodology. The process of critiquing the literature began with using the Mixed Method Appraisal Tool MMAT (Pluye et al., 2011) designed to appraise qualitative, quantitative and mixed method papers. The tool was used to identify serious flaws, but the final decision on inclusion or exclusion was made based on the relevance of the individual research to the developing theory. No paper was excluded based on their quality assessment.

Table 6. Quality assessment of qualitative studies

Qualitative studies	Clear research question	Relevance of data to research question	Relevance of data source to the research question	Relevance of data analysis to the research question	Contextual consideration	Reflexivity
Harris et al. 2003	Y	Y	Y	Y	Y	N
Selman et al. 2009	Y	Y	Y	Y	Y	N
Ganca et al. 2016	Y	Y	Y	Y	Y	N
Ayers et al. 2017	Y	Y	Y	Y	Y	N
Githiagi and Swartz 2017	Y	Y	Y	Y	Y	N
Lafandjola et al. 2017	Y	Y	Y	Y	Y	N
Lewis et al. 2017	Y	Y	Y	Y	Y	N
Fearon et al. 2019	Y	Y	Y	Y	Y	N

Table 7. Quality assessment of quantitative studies

Quantitative studies	Clear research question	Relevance of data to research question	Relevant sampling strategy	Appropriate population representative-ness	Appropriate measurement	Acceptable response rate <60%
Nwankwo and Ezeome 2011	Y	Y	Y	Y	Y	Y
Harding et al. 2014	Y	Y	Y	Y	Y	Can't tell
Alsirafy et al. 2016	Y	Y	Y	Y	Y	Can't tell
Omondi et al. 2017	Y	Y	Y	Y	Y	Y
Shen et al. 2018	Y	Y	Y	Y	Y	Can't tell
Yennurajalingam et al. 2018	Y	Y	Y	Y	Y	Y

6.5 Narrative of the synthetic constructs/refutational synthesis

The following four concepts were constructed from the literature review.

6.5.1 End of life professionalism

The construct of professionalism in end of life contexts refers to the clinician's possession of a set of internalised strengths and values when taking care of the patients nearing the end of their life and their family members. Professionalism in an end of life context involves directing clinicians' efforts towards the fundamental ethos of palliative care which includes the holistic assessment of the patient and the active management of their physical and existential symptoms (Lewis et al., 2017). Even though the quest for a cure is abandoned, the provision

of care is not (Lewis et al., 2017). Lewis et al. (2017) note that healthcare professionals acknowledge their role in guiding patients through the process of accepting their diagnosis and prognosis from a state of denial, and psychological counselling is regarded as a part of their professional role aside the management of physical symptoms. The health-care professionals conceptualise that reaching a state of acceptance helped the patient to achieve a dignified death and eased the process of family bereavement before and after the demise of the terminally ill patient (Lewis et al., 2017). For instance, knowing what to expect and how to manage it helped improve the patient's quality of life as they gained a sense of inner peace from being informed, and having a frank discussion was a form of emotional support (Selman et al., 2009). Consequently, the non-abandonment of the patient and the reassurance of continuity of care eases the process of open and truthful communication (Ganca et al., 2016). Thus, professionalism in end of life care involves respect for truth-telling and exchange of accurate information about the status of the patients, goals of care and provision of options to them (Ganca et al., 2016).

Conversely, the literature suggests that healthcare professionals that are poorly trained in physician-patient communication can be uncomfortable with their role (Fearon et al., 2019). Ganca et al (2016) observe that palliative care training of South African doctors in oncology, internal medicine, medical emergency or neurosurgery improves healthcare professionals' confidence when communicating with terminally ill patients and their family members. Likewise, Nwankwo and Ezeome (2011) note that physicians' education on breaking bad news links to their truth-telling practices. He observes that exposure to some form of training, such as seminars or other academic activities in palliative care improves the clinician's ease with breaking bad news, and their appreciation of truthful disclosure of advanced incurable

cancer. Unsurprisingly, palliative care specialist review of patients is proven to improve the completion of advance directives (Omondi et al., 2017) . Therefore, Ganca et al. (2016) proposed that all healthcare professionals, irrespective of their areas of specialisation ought to be trained in palliative care/ end of life care.

However deliberate misinformation or holding back information by the clinicians from the patients and their family members was also noted. As a case in point, Harris et al. (2003) detailed how clinicians use what he describes as therapeutic privilege to excuse the withholding of relevant health information from the competent patient when this is considered to be in the best interest of the patient as perceived by the doctor. Such practical justification includes the lack of sufficient health resources or therapeutic options for the patient's illness and the stigma associated with a cancer diagnosis. However, this argument for withholding diagnosis and prognosis seems indefensible as the patients and their relatives acknowledge that the information they get is fundamental to any further choices they might have (Selman et al., 2009). In addition, patient and family member respondents being cared for in palliative care specialist centres report feeling invisible; being misinformed (Harding et al., 2014) or being informed insensitively about their prognosis (Selman et al., 2009). Others complain of getting inadequate information needed for them to plan for their future (Harding et al., 2014). For the patients and their family members, expectations of a competent healthcare professional include accurate and timely information communicated with due care (Selman et al). As such, professionalism could be of limited value when the healthcare professional adheres to values and beliefs that might disagree with open truth-telling delivered empathetically. Therefore, when the multidimensional nature of professionalism in palliative care that goes beyond the physical relief of symptoms is not focused on, patients

assessing palliative care from qualified professionals might complain of a lack of satisfaction in the care they receive (Harding et al., 2014).

6.5.2 Familial decision-making authority

Familial decision-making authority refers to the central role of family members and family dynamics when determining the context and content of end of life communication. In the African context, family members have a dominant role in communication involving the care of patients with incurable cancer and end of life communication is mainly an informal process between the patients and the family members (Githaiga and Swartz, 2017). In addition, decision making through joint consensus between the family members is the expectation (Githaiga and Swartz 2017). Healthcare professionals use familial harmony, the robust family ties that exist in African culture and that minimise the chances of conflict of interest between patients and family members, especially elderly people, as a justification for divulging information to the family members instead of the patient (Harris et al., 2003). It should be noted that, the issue of individual autonomy or concern about a breach of confidentiality, for example, healthcare professionals discussing a patient's information with family members without the consent of the patient, was not recognised as an issue by the patient-participants, in the primary research articles included in this study.

Harris et al. (2003) report that all the Tanzanian physicians interviewed either concede to the family's decision to withhold disclosure entirely from the patient or rely on them for assistance in disclosure. While this surrendering to familial wishes might seem out-dated with improving end of life care, another study conducted more than a decade later, had a similar finding. The Githaiga and Swartz study conducted in 2017 among bereaved women family

cancer caregivers living and working in the Kenyan capital of Nairobi emphasised the relational nature of end of life discussions. Family members influence the timing and nature of end of life communication. They observed that family members prompt terminally ill patients to write down their wills or were responsible for writing the will. In a situation where there is no written will or advance directive, family members are responsible for making end of life care decisions, including determining disclosure or non-disclosure.

Family members are invited to act as surrogate decision makers (Githaiga and Swartz, 2017), and discussions concerning poor prognosis and bad news are made with family members rather than patients and the family's guidance on how much information is to be delivered is favoured even when patients possess the capacity to make their own decisions (Harris et al., 2003, Lewis et al., 2017). According to Ayers et al. (2017), clinicians could be constrained from complete openness by family members even when they (the healthcare professional) tried to create an atmosphere of honesty in communication, and ultimately deferred to the demands for non-disclosure by the family members. Patients also rely on family members for information regarding clarity when there is inadequate information or no information from the healthcare professional; they serve as a key provider of information to the patient (Selman et al., 2009). Omondi et al. (2017) observed that advance directive documents by patients were in most cases heavily reliant on discussion with their family members as opposed to an individualistic or a balanced mutualistic approach to advance directive completion. Thus, the attitude of family members to communication could significantly affect end of life discussions.

6.5.3 Illness understanding

The implication of illness understanding on the communication behaviour of the patients, family members and healthcare professionals is explored. Underlying the problem associated with getting appropriate information, issues relating to communication practices centre around illness understanding, for example, the acknowledgement of death and dying. Even though the recognition of life-threatening illness and end of life is a central concept for palliative care, some patients, family members and even healthcare professionals caring for people nearing the end of their life refuse to acknowledge this notion (Fearon et al., 2019). Fearon et al. (2019) report that some clinicians hold views that diverged from palliative care orthodoxy by believing predicting death is a show of arrogance and foolishness as God exclusively controls death. Some other clinicians believe that being a doctor precludes them from being able to accept or acknowledge the imminence of death as it is viewed as an admission of both professional and personal failure (Lewis et al., 2017). Furthermore, the lack of clarity on who should receive palliative care and when palliative care ought to start in the disease trajectory was found to be a barrier to good end of life communication by clinicians (Fearon et al., 2019, Lewis et al., 2017). However, the challenge of illness understanding, resulting from late recognition of death, might not depend solely on clinicians but can also reflect the patient's willingness to get involved in their own care.

For instance, the literature suggests that patients might be satisfied with a low level of involvement. In a study with South African palliative care patients in a socioeconomically deprived urban black population a high (76.9%) preference for not wanting to know their prognosis even when their clinicians were aware was demonstrated (Shen et al., 2018). Also, there was a low (5.9%) level of self-reported understanding of terminal illness and only 2.3 %

of patients reported that their clinicians discussed their prognosis (Shen et al., 2018). Interestingly, a comparable study amongst predominantly well educated, high and middle-class black populations in a hospital-based palliative care unit in Nairobi Kenya (Omondi et al., 2017) reports a different finding observing a 41.2% completion rate of an advance directive document amongst terminally ill patients. Based on these two studies there is an indication that socioeconomic status is of significance in the determination of patient understanding of their illness and end of life. The high completion rate noted in the latter study which was significantly associated with discussion with a healthcare professional suggests that people of low socioeconomic status might be prone to a non-discussion approach in end of life communication. This is corroborated by (Omondi et al., 2017) study where they found that social deprivation and low levels of education are associated with non-disclosure and passive decision making in the advanced cancer setting.

Apart from socioeconomic position, the prevailing cultural practices in societies were also found to be a barrier to illness understanding. For instance, the cultural behaviour labelling discussions around death and dying a taboo prevents honest discussion (Lewis et al., 2017). Family members need to navigate between the cultural expectation of avoiding conversation around death and dying and a pragmatic need to have a practical discussion as their terminally-ill relatives near their end of life (Githaiga and Swartz, 2017). The responsibility of participation in end of life decisions lies with the family members and is seen as a societal duty (Lofandjola et al., 2017). Patients in the African continent tend to be more open with their family members than with their healthcare practitioners. This was noted by Yennurajalingham et al. (2018) who observed that shared decision preferences of patients with their family members were more likely than shared decision making with physicians.

Yennurajalingham et al. (2018) found that while France and Jordan are more likely to choose passive decisional preferences a high proportion of patients in South Africa are less likely to be passive in their own decision making in comparison to the USA. However, the Yennurajalingham et al. (2018) study included South African participants with a high level of education which may not be representative of most African people. Interestingly, the authors grouped diverse countries with different economies such as India, France and Jordan together as favouring passive decisional preferences over active participation in decision making. The possible explanations they gave for this were the prevailing culture, the healthcare system or other unknown factors. These findings show the potential errors associated with generalisation and indicate a need for individualisation when exploring the construct of end of life communication practices.

6.5.4 Maintaining relationships

Patients, family members and healthcare professionals seek to maintain a relationship and protect each other's emotions. This is the primary justification for or against open communication. Githaiga and Swartz (2017) found that family members sometimes understood that having discussions with patients about their impending death improved family relations during and after the death of the patient. In addition, the initiation of conversations by family members with the terminally ill patient could be viewed as a show of support and solidarity with patients, that facilitates a dignified death (Githaiga and Swartz, 2017, Lofandjola et al., 2017). These studies also report terminally ill patients' concern for their family members' emotional wellbeing, using the conversation to advise them to seek bereavement counselling and push for family unity and togetherness after their demise.

Conversely, in one study, the priority placed over the protection of the patient's emotional well-being and fear of stirring up emotional distress during communication informed the clinician's decision for disclosing information to family members before the patients (Githaiga and Swartz, 2017). Some healthcare professionals' concern about their relationship with the patients and family members in the community (Fearon et al., 2019) means they will evade difficult conversations to avoid losing face (Ayers et al., 2017). They believe that provoking emotional responses in family and in the patient damages the patient–clinician relationship and trust, in the context of a prior clinical relationship (Ganca et al., 2016). Also family members will trivialise the diagnosis and especially the prognosis so as not to upset the patient and cause a negative emotional reaction (Ayers et al., 2017). They believe that helping patients to avoid strong emotions helps them to cope with their illness.

This collusion between healthcare professionals and family members that is intended to actively manage the patient's emotions by not allowing them to know the actual reality of things, and the enormous concern for keeping a positive attitude runs the risk of causing harm (Lewis et al., 2017). This is particularly relevant when emotional protection is prioritised over symptom management (Lewis et al., 2017) such as protecting the patients even when it is detrimental to their comfort. For example, Shen et al. (2018) report that most patients prefer dying at home but those preferring to die in the hospital, perhaps do so to help relieve family members of the enormous pressure put on them especially in the context of socioeconomic deprivation. Family members are expected to carry on the burden of caring for the patient when they are at home and thus patients may feel guilty for having used up family resources (Lofandjola et al., 2017).

Although dying in hospital also involves a financial burden that patients and family might not be able to afford, taking terminally ill patients to the hospital is a demonstration of care by the family members (Lewis et al., 2017). However, seeking palliative care rather than active treatment could be viewed by outsiders as a show of greed; not wanting to spend money in search of a cure (Fearon et al., 2019), which is something to be avoided. Clinicians are also not excluded from this way of thinking as Fearon et al. (2019) report. In addition, a clinician's conceptualisation of a good death may be viewed as one that happens while the patient is having an intravenous infusion, as this is a sign that all has been done to save the patient's life. However, some patients for their own part may wish to avoid accruing debts for their remaining family members and choose to decline certain treatments to minimise the family's financial burden. Therefore, the mutual relationship between those involved in end of life discussion (patient, family members and healthcare professionals) was found to be important not only for an individual's benefit or comfort in the end of life process. All concerned are able to focus on their mutual relationship and shared advantage over individual benefit (Fearon et al., 2019).

6.6 Discussion

6.6.1 The communication empowering model

The output of critical interpretive synthesis is a synthesising argument in the form of a coherent theoretical framework comprising of constructs and the relationship between them (Dixon-Woods et al., 2006). Through the constant comparative analysis of the extracted data from a methodologically diverse body of literature, a conceptual theory on end of life communication between patients, their family members and healthcare professionals in the African setting was constructed. The communication empowering model (Figure 8) emerged

as the overarching theoretical framework that explains the issues and underlying concerns of end of life communication between clinicians, family members and patients with advanced cancer in the African countries. The conceptual model comprises of four interlinked conceptual tetrads as shown the diagram below; end of life professionalism, familial decision-making authority, Illness understanding and maintaining relationship.
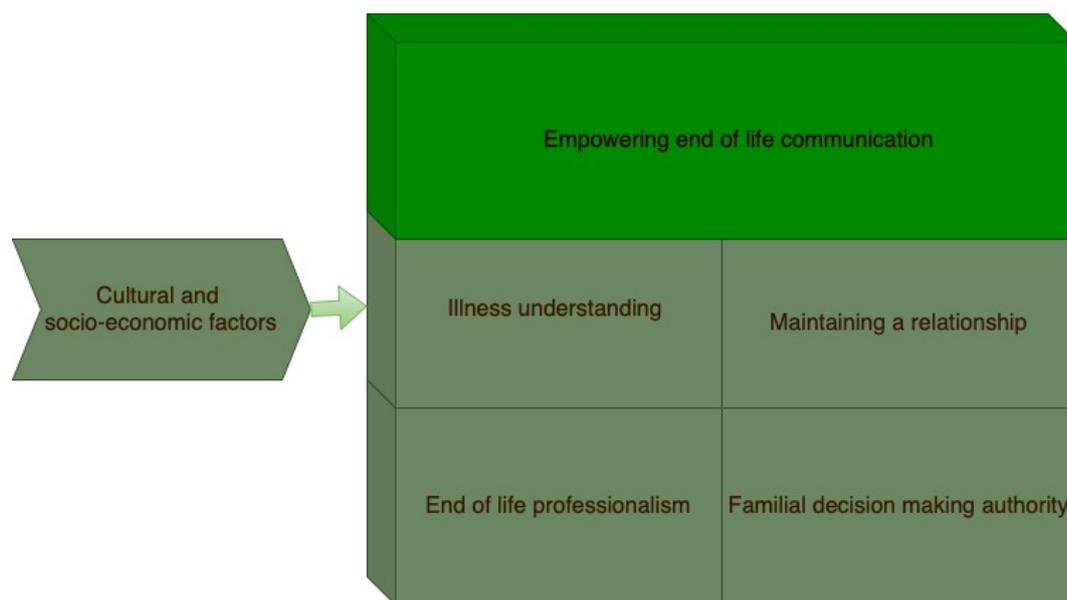
Figure 9. The Communication Empowering model

While the definition of these individual concept might exist, the description of each construct has been developed from the studies themselves and are not formal definitions. The synthesising argument in the communication empowering model has implications for practice. The model suggests that attention to end of life professionalism, familial decision-making authority, illness understanding and maintaining a relationship gives the patients, their family members and healthcare professionals the confidence and competence to participate in end of life communication. There is a progressive relationship between the concepts, with new concepts building upon prior ones. Like building blocks, end of life professionalism and familial decision-making authority form the base, while illness

understanding and maintaining a relationship form the second layer. When all the pieces of the building blocks are in place at the right level, the patient, family members and healthcare professionals are empowered in end of life communication. Thus, affirming some, at the expense of others hinders the empowerment of end of life communication for all concerned.

One of the most important aspects of this model of end of life communication for the African context is the influence of end of life professionalism. End of life professionalism, as described by the empowerment model, involves healthcare professional's dedication to the palliative care tenet of comprehensive management of the patient and their family members. Professional training and competence in palliative care translate to their level of confidence in end of life communication and truth-telling practices (Ganca et al., 2016). Furthermore, healthcare professionals' recognition and acknowledgement of death and dying in the terminally ill patient contribute to their professionalism. When professionals are equipped to be able to support patients and their family members, they can influence patient's and family's illness understanding. For instance, well-trained palliative care clinicians can support patients with the right information and adhere to openness and truth-telling. As Omondi et al. (2017), noted, healthcare professionals' commitment to communication improves completion of advance directives and therefore, an empowered end of life communication.

The other important component of the empowering model is the recognition and acknowledgement of familial decision-making authority. This review suggests that when healthcare professionals recognise the family members' role in end of life communication, there is reduced friction, thus fostering a desirable positive relationship for all concerned. As family members serve the role of intermediaries between patients and healthcare professionals, it will be reasonable to conclude that a key to improving end of life care

communication is the empowerment of family members. The African cultural emphasis on family presence in end of life communication is empowering when the healthcare professionals can depend on family members to communicate accurate information to patients. This improves the patients' illness understanding (Githaiga and Swartz, 2017). That is, when the central role of the family member is recognised, and utilised, healthcare professionals can help equip them to be able to better function in this role. Githaiga and Swartz (2017) also note that family members perceive that family communication in the end of life improves interaction between one another.

Other non-clinician factors such as cultural and socioeconomic factors can, however, affect communication empowerment. Based on this model, these factors are not dependent on end of life professionalism or the acknowledgement of familial decision-making authority. For instance, there is a cultural tendency to discourage open end of life communication that affects patients' and family members' level of illness understanding. Therefore, in as much that as the culture and socioeconomic status of people might be difficult to change, focusing on other modifiable subtle factors, such as end of life professionalism, illness understanding, familial decision-making authority and maintaining a relationship can help improve end of life communication in Africa.

6.7 Summary of the communication empowering model

This critical interpretive synthesis review suggests that communication patterns between the patients, family members and healthcare professionals towards the end of life in the African context can be empowered through improving healthcare training and acknowledging the central role that family members play in decision making. These two strategies may improve the information that patients and their family members receive and thus their understanding

of death and dying. They can also influence the relationship between the patients, family members and healthcare professionals. Therefore, a plan of care that is consistent with the patients' values and preferences can be reached with a focus on these issues. As the socioeconomic and cultural factors might be unmodifiable, changing the level of healthcare professional readiness for end of life care and accepting the significant position of the family members in these circumstances might be the key to improving end of life communication in the African cancer context.

6.8 Differences and similarities between the theory of *rubbing minds together* and communication empowering model

The communication empowering model substantiates the novel theory of *rubbing minds together* in the expression of end of life care wishes and preferences in the African setting, as shown in figure 9. Familial decision-making authority described as one of the bedrocks of the communication empowering model reflects the significant position family members hold. Several articles (Ayers et al., 2017, Githaiga and Swartz, 2017, Lewis et al., 2017, Lewis et al., 2018) included in the critical interpretive review highlight the unique African socio-cultural context where end of life care mostly occurs as home-based care and or family-member reliant care and family members are expected to serve as informal carer givers. However, apart from being responsible for most care, family members play a significant role in decision making, and end of life discussions are negotiated at the familial level.
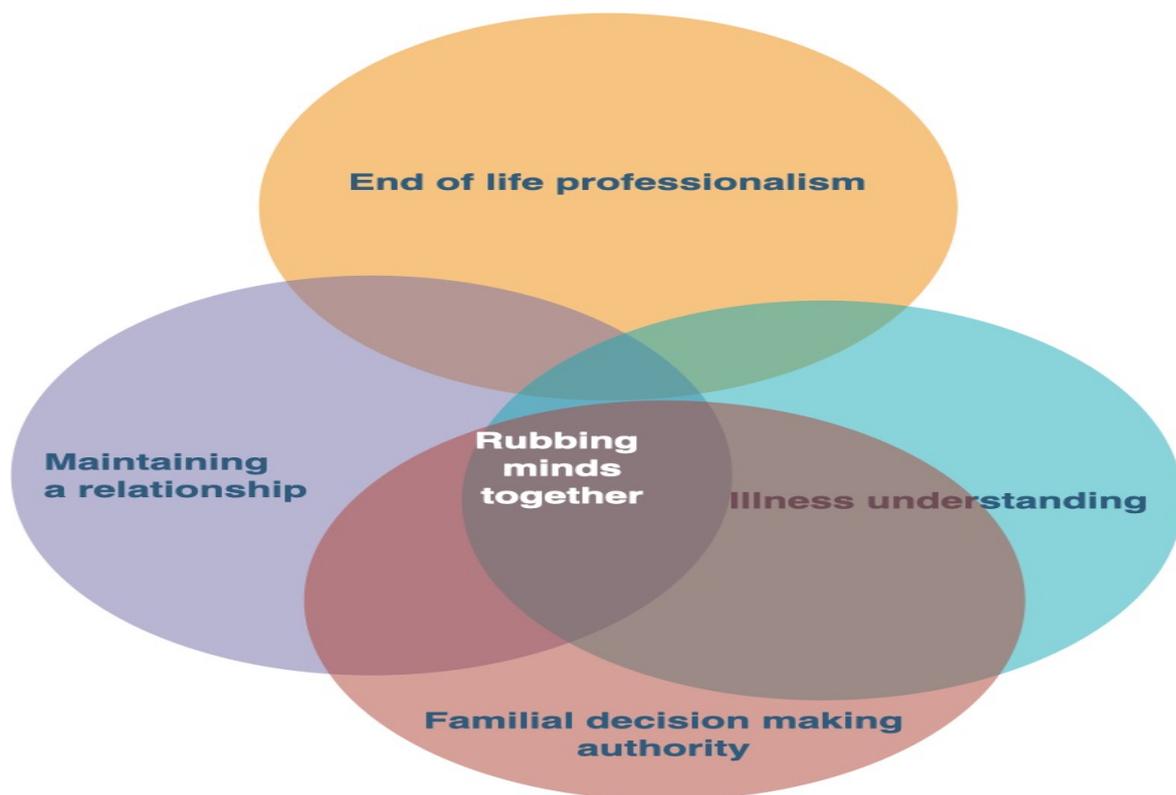
Figure 9: Relationship between the theory of rubbing minds together and the communication empowering model

Githaiga and Swartz (2017) in their interpretive phenomenological study conducted amongst bereaved family caregivers in Nairobi Kenya, reported on the effect of family dynamics on the nature, timing and the decision to initiate end of life conversations. In this study, bereaved family members retrospectively reflected on the negative impact their lack of participation in the expression of end of life care wishes and preferences had on their dead relatives' dignity. Not facilitating or supporting their dead relative's expression of wishes and preferences was viewed as a deterrent to open conversation. In addition, healthcare professionals in Tanzania identified differences between their expectation and that of the family members as a source of dispute that stands as a barrier to end of life care delivery (Lewis et al. (2018) . Thus, family members are important agents in end of life communication.

However, the extant literature does not provide ample insight into the patient's perception of their role in end of life communication. The dominant participant group in the articles included in the critical interpretive synthesis may explain the lack of emphasis on the patient's own story, as these studies were focused on family members and healthcare professionals' views. The novel theory of *rubbing minds together* adds clarity. It brings in the patient's and family members' perspective of the process of expressing end of life care wishes and preferences and reflects their respective roles in the process. The theory of *rubbing minds together* explains the need for the willing participation of family members or patients who are motivated and willing to get actively involved, for end of life discussion to take place. The theoretical development of *rubbing minds together* implies a dynamic interaction between patients and their family members before an expression of wishes and preferences can occur. However, extant literature assumes patients to be passive recipients of end of life communication.

To explain this point, looking at the literature review, of the fourteen studies that met the inclusion criteria, only five of them included patient-participants. Furthermore, only three included both patients and family members. Selman et al. (2009) and Harding et al. (2014) focused on the needs of their participants concerning communication. In Ayers et al. (2017), the patient and family member participants were passive respondents as the focus of the study was on how the healthcare staff communicated with patients and their relatives rather than the patients' action and interactions. Shen et al. (2018) and Yennurajalingam et al. (2018) conducted quantitative surveys of understanding and practices, respectively, without aiming to understand or explore subjective reasoning behind such understanding or practices. None of these studies tried to explain the process by which patients engage or not in the expression

of end of life care wishes and preferences. The theory of *rubbing minds together* recognises the level of control that patients have in the process of expressing wishes and preferences. Controlling to seek relief shows the extent of patient motivation for expressing their wishes and preferences and how they work towards achieving them.

As shown in figure 9, the other central pillar of the communication empowering model; end of life professionalism, is conspicuously missing in the theory of *rubbing minds together.* Again, this can be explained by the difference in participant groups between the new study and extant literature. Furthermore, Selman et al. (2009), who included patients and their family members in their research, report that they perceive information as a significant unmet need. Furthermore, Ganca et al. (2016) and Lofandjola et al. (2017) identify well-trained end of life care healthcare professionals as a support system in end of life communication. Fearon et al. (2019) report on the negative impact of the absence of patient-centred communication, healthcare professional practice of non-disclosure and their lack of end of life acknowledgement on end of life communication. Lewis et al. (2018) emphasise the critical role healthcare professionals hold in facilitating the state of acceptance where patients come to terms with their diagnosis. The newly developed theory of *rubbing minds together* emphasises that patients and family members require a personal adjustment that is dependent on the information they get from their clinicians, in order to express end of life care wishes and preferences. However, there is the need to have further research on the role of end of life professionalism in the expression of end of life care wishes and preferences.

The newly constructed theory of *rubbing minds together* provides theoretical relevance to patients and their family members' perception of their own needs. For instance, their illness understanding and need to maintain a relationship, as depicted in the literature review

finding. The new theory of *rubbing minds together* explains that when family members and patients have similar illness understanding, they have better and more in-depth interaction. The concept of collaboration in my grounded theory study and maintaining a relationship in the critical interpretive synthesis are similar and underscore the relational nature of end of life communication. Moreover, the socio-cultural impact of relational autonomy on end of life communication is evident in the grounded theory and the critical interpretive model. Studies in the critical interpretive synthesis come from across various setting and multiple countries, therefore reinforcing the findings from my new theory by strengthening my argument and adding credibility to the work.

6.9 Strengths and limitation of the review

To my knowledge, this study is the first interpretative synthesis examining end of life communication in the African context. This critical interpretive synthesis review structured the synthetic constructs relating to the data into a synthesising argument that explains important factors involved in end of life communication in the African setting. The findings are relevant in informing interventions that are focused on improving end of life communication in the context of an under-resourced, multicultural Africa. Critical interpretive synthesis offers an innovative way of interpreting the evidence to produce new insight and fresh ways of understanding and allows for the synthesis of diverse literature types with differing methodologies. The interpretive nature of the study lends itself to the construction of new interpretations that go beyond individual text, however, it is not a mere aggregation of the evidence as the analysis offers new insight into the available evidence.

Although, the lack of reproducibility of the review analysis and results can be seen as a limitation, critical interpretive synthesis is not intended to be reproducible or exhaustive; thus, different researchers analysing the same data could arrive at different theoretical models. The analysis and interpretation is however grounded in the data offering credibility to the research. The critical interpretive synthesis is limited by the quality of the studies, especially as methodological quality is not usually utilised in the inclusion/exclusion criteria, except for fatally flawed research articles. The focus of interpretive research is prioritising papers that appear to be relevant to the research. For this review, no article was excluded for being seriously flawed. The critical interpretive synthesis was chosen because its methods is closely linked to the constant comparison and theoretical conceptualisation that takes place in grounded theory. Furthermore, delaying the literature helps to 'defend the constructed finding' (Charmaz, 2014, p. 305) and reinforces the rigour of the grounded theory study.

With a constructivist mind, I appreciate that my personal preconceptions and perceptions as a medical doctor with experience in end of life care could be present in the work and could be viewed as a limitation. However, I actively engaged with and reflected on the research process; thus my awareness heightened the credibility of the conclusions. My documentation of the search strategy, close engagement with the included literature and the writing of the narrative and the discussion of the synthesising arguments offers transparency and credibility to the work. The flexibility and creativity of the constructivist approach has been challenging for me as an emerging researcher who had needed to shift from a positivist way of thinking to a constructivist paradigm that I now value. The direct influence of my research skills on the output of this research is a potential limitation of this study. I have however developed and

fine-tuned my research skills through active participation in the research journey and regular reflection on feedback from well experienced and skilled supervisors

6.10 Conclusion

The communication empowering model (figure 8): the new theoretical conceptualisation derived from the interpretation and analysis of extant literature provides potential insight and vividness into extant literature through induction and interpretation. This is particularly useful here where past literature is used to support and substantiate the newly developed grounded theory of *rubbing minds together*. The context of this model specifically relates to the end of life communication among patients with advanced cancer and their family members in the African setting and showcase the importance familial decision making authority in end of care.

Chapter 7: Discussion of the theoretical model of *rubbing minds together* and relations to existing literature

7.1 Introduction

This study is the first to explore the process of expressing wishes and preferences amongst patients and family members in the Nigerian setting with an emphasis on their perspectives and experiences. In this study, *rubbing minds together* is the constructed grounded theory. It is an abstract understanding and explication of the process of expressing end of life wishes and preferences and it shows the relationship between the constructed conceptual categories directly derived from the data. Through *controlling to seek relief, enduring* and *collaborating,* the patients *rub minds together* with the family members to express their end of life wishes and preferences. *Controlling to seek relief* reflects the African patient's quest for self-reliance in a family-centric society. At the same time, *collaborating* is the acknowledgement of interrelationship with family members and the relational nature of their autonomy. Although these two appear to be opposing actions, the theory of *rubbing minds together* proposes that controlling to seek relief is not exclusive. Its coexistence with collaborative efforts and *enduring* that focuses on the patient's and family's strength helps to achieve expression of wishes and preference. Therefore, an integrative perspective that recognises *controlling to seek relief*, a *collaborating* between the patients and family members and *enduring* to communicate, facilitates the process of the expression of end of life care wishes and preferences in the African context.

This constructivist grounded theory of *rubbing minds together* recognises the relational nature of expression of end of life care wishes and preferences in the Nigerian setting. This discussion will show the novelty of the theory and how it relates to previous research conducted in Africa. The critical interpretive synthesis contribution to the theory is the

identification of the conditions facilitating the expression of wishes and preferences; familial-decision making authority on *controlling to seek relief*; the acknowledgement of the role of illness understanding and end of life professionalism on *enduring*; and the need for maintaining a relationship on *collaboration*. However, the critical interpretive synthesis on its own does not explain the process involved in the expression of end of life wishes and preferences. The patient-participants' and family members' experience on this issue has not been explored in previous research but is the focus of the current study. Therefore, the findings are crucial as they help to fill in a knowledge gap and bring to focus the process of expressing end of life care wishes and preferences based on the perception and experiences of the patients and family members.

7.2 Relationship to the literature

7.2.1 Controlling to seek relief

The theoretical understanding of 'control' over familial influence emerging for this study is similar to the autonomy proposed by Houska and Loucka (2019). They presented the quest for autonomy at the end of life as simple self-determination to take charge, which differs from the general Western interpretation of autonomy as independent rational decision making, with the exclusion of other people's interest. The implication of this simple self-determination is the patient's comprehension of their own emotional and social context, including the people they have relations with and the role these people play in their lives. Houska and Loucka (2019) however, go further to identify that the patient's feelings for their family can 'compromise' autonomy and self-confidence in the ability to participate in end of life discussions. Results from the current study validate this conceptual model of self-determination to take charge. For example, patient-participants wanted to control their own

life. The patients also acknowledge that the family members position can be different from theirs. However, this current finding further establishes that the effort of taking charge is strengthened by the patient's ability to influence and be an active participant in their family members' lives. This current study shows that the patients work through the challenges that they face from their relationships with their families without letting go of their family member's contributions and comforts. Therefore, the patient establishes control to seek relief for themselves and family members while expressing their wishes and preferences within a family context.

African patients' autonomy and self-determination are closely linked to their strong desire for the involvement of those closest and dearest to them in their end of life care discussions (Collins et al., 2018). A systematic integrative review linked this familial preference to the longstanding mistrust of the American health system amongst African Americans (Sanders et al., 2016). Although limited data exist on end of life decision making in Africa, this novel research documented terminally ill patients' preference for family involvement in end of life care issues over their healthcare professionals. End of life conversations are informal discussions between the patients and their family members (Githaiga and Swartz, 2017) with the patient-participants in my study expecting that the family members would act on their behalf if they become unwell even when they have not been given prior permission to do so. This finding is comparable to the heavy family presence in end of life care observed in Mediterranean Europe (Gysels et al., 2012) and it confirms the decision-making authority of family members in traditional African settings (Githaiga and Swartz, 2017). I argue that the patient's dependence on their family members is embedded in the African patient's socio-cultural identity and is not in conflict with the demand for control to seek relief, autonomy

and self-reliance. This line of discussion will be explored further when discussing *collaboration* as a component of *rubbing minds together.*

A systematic review and meta-ethnography on patients' perspective of dignity, autonomy and control at the end of life (Rodriguez-prat et al., 2016) confirms that patients' sense of autonomy and ability to control overlaps with their perceived dignity. This current study suggests that patients desire for self-determination and having control over the dying process through their expression of wishes and preferences is a pursuit of self-worth and self-satisfaction that is situated within a family unit. Patients expressed the feeling of psychological relief at being able to express their wishes and preferences to their family members. Unfortunately, there is inadequate information from extant research regarding this issue as it relates to patients in Africa. Studies closely linked to the issue of expressing end of life care wishes and preferences report on ACP. However, previous studies on the process of ACP have focused on patients and family members in Western countries, and no study was found to focus on the experiences of expressing wishes and preferences among the African patient population, in the more formal and documented ACP sense. However, similar to the findings of this current research, a multi-country study designed to determine patients decisional control preferences found that African patients preferred shared decision making with their family members as opposed to with their physicians (Yennurajalingham et al., 2018). Stanford et al. (2013) also report on the perceived relevance of formal ACP in South African populations and found that there is a strong wish by healthy participants to involve people in ACP, with whom they have strong kinship ties.

The challenge to end of life communication posed by family members is well documented in the literature (Clayton et al., 2005b), more so amongst African populations (Kagawa- Singer

and Blackhall, 2001). Similarly, I observed that even though the family members have a critical role to play in the patient's sense of autonomy and control, they sometimes try to shield them from having an end of life discussion. As family members can act as a significant barrier to a patient's free expression of their wishes and preferences, it is crucial to understand the reason or reasoning behind this. This study shows that *controlling to seek relief* could be instinctive for Nigerian patients due to the need to take charge of their own lives and that of their loved ones. For instance, findings from this present study show that the patient's commitment to take control is not only due to their concern for their own welfare, but also the wellbeing of their family in the bereavement period and beyond. This protectiveness can be attributed to firmly held cultural values about the need to protect their loved ones from harm caused by perceived potential suffering. Stanford et al. (2013) report that some South African general populations were in favour of ACP due to its potential for uniting family members.

Conversely, end of life care planning can be a source of family concern and a threat to the patient's sense of control. Participants in my study struggle against a strong cultural belief about openly discussing death and dying. This stigma associated with conversations about dying is comparable to the social stigma observed in some cultural societies in Asia where speaking of death is viewed as inciting it (Love et al., 2020). Love et al. (2020) acknowledge the prevailing cultural practices that view discussion around death and dying and expressing end of life care wishes as a taboo. Similar reports have been found in the Western population where patients and their caregivers showed resistance to participation in end of life care due to the stigma associated with palliative care (Zimmerman et al., 2016, Collins et al., 2017). Nevertheless, avoidance of palliative care observed in these studies does not reflect the

general openness in Western countries to a discussion around the terminal nature of advanced incurable cancer.

Some Nigerian values might promote openness in end of life discussion though. This present study reports that in certain circumstances another cultural norm of preparation for death and putting affairs in order, before dying, can be a driving force for patients' desire to express their wishes and preferences. Sneesby et al. (2011) report that the African cultural animosity towards open discussion around end of life care particularly relates to death in a young person and when an older person is dying the process is celebrated, and open discussion is the cultural norm in this situation. This current study did not observe any age variation of discussion expectation among the respondents, perhaps because the age range of the participants was relatively similar. What was observed in this study, is that terminally ill patients are firm believers in open discussion with their family members while most of the family members are against this, and this can result in conflict.

Lin et al. (2020) note that despite the conflict potential of end of life discussions, patients and family members see an opportunity for dialogue that fosters the relationship they desire. Throughout the study, it was evident that that the patients derived some psychological relief from the pleasure of having family conversations. This resonates with the traditional African conviction that at the point of death a human being becomes a supernatural being who will not die until they have been visited by a relative who is close to their hearts (Kanu et al., 2018). Unsurprisingly, when dying patients have an intimate and authentic conversation with their family members, a sense of closure and completion is achieved (Keeley and Yingling, 2007), adding to the patients' sense of control.

The above section of the discussion highlights the unique difficulties patients in the study faced in communicating with their loved ones and the significance of this problem. Patients viewed seeking relief as an ability to take control or take charge of their lives while also supporting their loved ones. It emphasises the patient's desire for a type of autonomy that acknowledges family validation and support, despite apparent differences in opinion. Therefore, the concept of *controlling to seek relief* here fills a gap in the literature. Furthermore, the study reports on the need for further research in ACP interventions for cancer patients who are from family-centric societies like Nigeria and do not view themselves as independent beings. The discussion around *controlling to seek relief* in relation to previous studies has been concluded. Next, *enduring* and the discussion in relation to the existing literature is presented.

7.2.2 Enduring

Enduring as a conceptual component of *rubbing minds together,* involves the persistence and perseverance experienced by the patients and the family members. The conceptual category reflects how the participants persist in continuing with end of life conversations despite the distress and difficulties they faced. Wittenberg et al. (2017) in the USA demonstrated the stressful impact of communication within the family environment on the family member's quality of life when dealing with a patient's life-threatening illness. Studies included in the critical interpretive review demonstrate the impact of illness understanding and end of life professionalism on communication behaviour. This present study builds on this, confirming that non-adaptive communication patterns or behaviour after the diagnosis of terminal cancer create tension between the patients and the family members. The participants in this current study discuss how they deal with the uncertainty, complexity and emotional stress

surrounding the end of life that can inhibit them from having a conversation.

All the patients interviewed acknowledged the emotional and practical difficulties they go through. Furthermore, all but one appreciated the need for adjustment to the way they communicate as a reaction to the situation in which they found themselves. The patient makes behavioural and emotional adaptations or preparation that affect participation in communication, such as changing priorities, confronting reality or normalising. The normalising here involves not making the conversation seem unusual but recognising it as a natural thing to do, thereby perceiving the situation as ordinary. It also means redefining a new normal by coming to terms with the situation (Duggleby et al., 2017). This act of normalising is in opposition to that noted by Horne et al. (2012) who found that white British patients with lung cancer and their family members were focused on maintaining integrity by carrying on as normal without having an end of life discussion while facing death. The author however recognised that a longitudinal study with interviews over the patient's course of illness may show different perceptions or changes warranting the need for further research.

This issue with timing has long been observed in the work of the Swiss psychiatrist, Kubler-Ross et al. (1972), on death and dying who proposed the five psychological stages of grief that patients go through after the diagnosis of a terminal illness. The last stage of grief described as acceptance is vital in the grief process and is regarded as a time of adjustment and readjustment, where good days outnumbers bad days. The current study's finding was similar, identifying a developmental process from a state where the patient-participants are unable to freely express themselves to a point where they feel more confident in their readiness to participate in the conversation as the illness becomes terminal. Although Kubler-Ross has explained that the stages from denial to acceptance are neither sequential nor

mandatory, the findings of this research suggest a progressive pattern from distress to less grief. In this present study, there is an acknowledgement of the evoked emotional distress evoked by the situation, but also the transition into a more settled state, allowing for open communication. This adaptation recognises the notion that resolution of grief coincides with the acceptance of loss and that an enhanced degree of acceptance is associated with less suffering and emotional distress (Prigerson and Maciejewski, 2008).

Furthermore, the patients and family members in this study describe the critical importance of hope when facing a serious life-threatening illness. Patients report that their decision to express their wishes and plans is not at odds with their ability to maintain hope. This finding is consistent with existing literature which has long emphasised the importance of maintaining a sense of hope (Clayton et al., 2005a). Also, this research confirms that honouring hope, including hope for the cure of incurable cancer, is not synonymous with denial and does not challenge clear and truthful communication resulting in the planning for the end of life. However, emotional distress might be unavoidable for these patients despite striving to maintain hope as a means of *enduring* the stressful situation they are going through.

This current study also notes that hoping and planning is dependent on individual readiness for acceptance based on an emotional, psychological or spiritual state that acknowledges the need for expression of end of life wishes and preferences. However, other factors facilitating or undermining readiness to express end of life wishes and preferences have been observed in the literature. Nwankwo and Ezeome (2011) report that inadequate clinician training in Nigerian settings affects the preparation of patients and family members for the acceptance of imminent death. Incongruities between a patient's preferences and clinicians' perception

about truth-telling (Huang et al., 2015), un-acknowledgement of death and dying, the reluctance of the healthcare professionals to have the discussion or initiate the topic (Hiscock et al., 2016), and inadequate information sharing (Selman et al., 2009) are amongst such factors. Some patient and family member participants in this current study expressed despair in finding out about the terminal nature of their illness through their palliative care clinicians after being referred for such care. Their primary clinicians originally managing their illness were not forthcoming with such information. Another study found that the majority of Nigerian physicians do not tell the truth about poor prognosis or give survival estimates; leaving patients uninformed (Nwankwo and Ezeome, 2011).

African patients are likely to rely on family members for end of life care information, for the construction of end of life care wishes and preferences (Ekore and Lanre-Abass, 2016, Githaiga and Swartz, 2017) and for implementing them (Ekore and Lanre-Abass, 2016). Ironically, however, family members have little or no information to work with and are ill-prepared for dealing with the patient's end of life issues (Selman et al., 2009). Although the need for more information is not unique to the African population, African patients' and family members' unmet needs are distinctive. Due to the poor pervasive inadequacies in palliative care/end of life care and poor levels of healthcare professional training in a large West African country like Nigeria, difficult conversations with patients and their family members occur rarely. Medical training in most of Africa does not include palliative care in the curricula, despite clinicians' plea for more training in palliative care and end of life communication (Nwankwo and Ezeome, 2011). Inadequate training and healthcare professionals' lack of confidence in the provision of end of life care results in maladaptive reactions and poor communication patterns. Therefore, poor illness understanding and lack

of competence of the healthcare professionals in end of life communication compromise the *enduring* that patients and family members require to be able to participate in expressing wishes and preferences.

The above discussion on the *enduring* component of *rubbing minds together* brings to focus the personal development that the patients and their family members endure, through *adapting, hoping and planning* and *thriving* to be able to participate in the process of expressing wishes and preferences. The discussion on *collaboration* and its relationship with existing literature is elaborated next.

7.2.3 Collaborating

Collaboration between terminally ill patients and their family members in Africa is essential for many reasons. The family members have the most substantial ties with the patients (Harris et al., 2003) and are often the primary caregivers for their terminally ill relative in the hospital or outside the hospital (Lofandjola et al., 2017). Besides, family members influence the timing and nature of the end of life conversation and play a central role in decision making (Githaiga and Swartz, 2017). Finally, there is a cultural significance in the family member's help in voicing the patient's wishes and preferences as opposed to patient's completing an ACP document (Ekore and Lanre-Abass, 2016). Therefore, family members serve as a means of achieving optimal end of life care.

Despite the potential benefits of positive family interactions, research shows that clinicians still doubt the motives of family members particularly those of African origin living in the West (Rhodes et al., 2015, Kramer et al., 2010). Despite the genuineness of this fear, this present study, like previous studies shows that family collaboration is vital for quality end of life

communication. Fletcher et al. (2012) note that the family unit constitutes the most critical social context within which coping with illness occurs. That patients value the contribution of family members with whom they have a current relationship has also been noted (Stanford et al., 2013). However, some patients in this current study report that close family members try to assert undue control by making decisions that compromised their wishes and preferences, negating the spirit of collaboration.

Nevertheless, most recognisably, terminally ill patients in this empirical study report being strengthened by their family members. For instance, the participants in this study note that communication was more natural with family members with whom they have strong interaction and who were present right from the beginning of the illness. Furthermore, patient-participants reported that a family member's act of listening and complying accordingly with their wishes and preference was a show of dedication that gave them comfort and reassurance. This finding is significant as familial collaborative efforts could be utilised to improve end of life communication. As a case in point, research across various family-centric societies has consistently observed that clinicians' view informing family members about a bad prognosis before the patient as a culturally acceptable practice (Hahne et al., 2020, Harris et al., 2003). This finding should not conflict with the patient's wish to have full disclosure. Rather, there is a need for the family's influence to be recognised and put to use, rather than sidestepped, in order to facilitate open communication.

Alsirafy et al. (2017) in their work on disclosure preferences of family caregivers of Egyptian cancer patients, observed that family member's personal preferences on disclosure reflect on their practices of openness with their terminally ill relatives. They also found that family members' belief that the patient was unaware of his/her diagnosis predicted their negative

attitude towards full disclosure to the patient. Therefore, against the backdrop of familial authority, it seems that it is more important than ever to have family involvement in preserving or restoring the African terminally ill patient's autonomy. Consequently, communication skills training tailored towards patient participation in family decision making that could help improve end of life communication is imperative (Hahne et al., 2020). An addition or an alternative is the prioritisation of education for healthcare professionals in palliative/end of life care and understanding. An improved illness understanding by family members will indirectly improve mutual support and openness within the family unit. The resultant positive effect on collaboration improves end of life communication.

Before going further, however, it is essential to acknowledge that even though the family members' presence in the end of life discussion might mean competition for control with the patients, for most of the patient-participants in this study the relationship is not necessarily at their expense. It is not a domineering relationship that seeks to overcome or abuse the powerless patient but a relationship between people who depend on each other. Fine and Glendinning (2005) criticised the segregation of the worlds of the care receiver from those who care for them. They note that 'inequality of power is compatible with both justice and caring if the relationship does not become one of domination' (Fine and Glendinning, 2005, p. 613). Likewise, for the patient-participants in this study, the perception is that the inequality of power is insignificant when the relationship between them and their family members is built on mutual trust and responsibility. They both expect that either is trying to protect the other, and they recognise that their sense of responsibility means fulfilling each other's needs. Despite family members distress in caring for the ill patient at the end of life,

caregiving is seen as a filial obligation and reciprocatory care necessary for creating compassionate communities (Salifu et al., 2021)

In this study, I found that patients and family member's self-sacrifice and prioritise each other's need over and above their own desires. The patient-participants in my study were devoted to their family members. However, this might be viewed as not a wise thing to do in other settings, especially in an end of life context where formal ACP is meant to prioritise the wishes and preferences of the dying person. Conversely, the family member participants in this study clarified that they had decided to support or oppose the end of life conversations based on the perceived best interest of their ill relatives. These findings support prior research that observed 'symbiotic niceness' (Li, 2004) between patients, family members and their healthcare professionals even among diverse populations (Li, 2004, Yoo et al., 2010). In the African studies, maintaining a relationship and protecting each other's emotions were primary justifications for or against open communication (Lofandjola et al., 2017, Githaiga and Swartz, 2017). That is, people are defined by their interactions with and responsibility towards their loved ones, and the relationship with and welfare of their relatives may be more significant than the interests of their individual self in isolation.

Research notes that for the Africans included in their studies, family disharmony is a strong predictor of end of life conflict (Kramer et al., 2010) and family dysfunction was positively associated with greater use of life-sustaining treatment in the final moments of life (Winter and Parks, 2008). But extreme dedication to family unity might be counterproductive. For instance, the patient-participants in this present study sometimes chose to protect their family's emotions rather than openly expressing their wishes and preferences. Participants sometimes value maintained or improved family relations and unity, especially during the

period of terminal illness and bereavement, even when it means deception and avoidance of discussion that is perceived to cause distress. However, the concern about causing distress might be an unfounded fear. Research from countries known to avoid open conversation about cancer has found that open information has no significant adverse effect on psychological wellbeing (Wang et al., 2014) and honesty and openness can significantly reduce uncertainty and anxiety when dealing with terminal cancer (Kao et al., 2013). The clinical implication of the above is that enhanced patient-family understanding of end of life care could improve collaborative efforts. This could perhaps improve the expression of end of life care wishes even when not in the formal sense of ACP as conceptualised in Western countries.

While there is an ambivalence in acknowledging dependency as a healthy, necessary social condition, independence is regarded as the ideal in Western culture (Fine and Glendinning, 2005, Weicht, 2010). For example, LeFebvre and Franke (2013) in a cross-country comparative case study on decision-making between a sample population of students from the USA (individualistic culture) and sample student population from Ghana (collectivist culture), equated the independence of the American sample to rationality in decision making and viewed the dependence of the Ghanaian students as problematic. Although terminally ill patients in this current Nigerian study sometimes felt guilty about being dependent on their family members, the family members accept the responsibility as a moral obligation that is expected and acceptable. The Nigerian patient-participants recognised this moral responsibility that the family members bear and are sometimes reluctant in denying them this duty. For instance, Jegede and Adegoke (2016) in their study among a predominantly Yoruba-ethnic group in Nigeria, note that involvement in decision making is a communal

moral responsibility. They found that respondents irrespective of their age group and religious background believe that individuals cannot make decisions on their own but should rely heavily on the advice of family members. Therefore, collaboration is viewed as an essential virtue that facilitates the expression of wishes and preferences.

Furthermore, Gorodnichenko and Roland (2012) note a difference in the self-perception of people from individualist countries such as the US, UK, Canada, and Sweden to people in collectivist cultures, such as Africans, East Asians and Native Americans. They report that people from collectivist society seek to know themselves through the evaluation of others while people from individualistic societies discover themselves through inner introspection. This suggests that there is a mould of cultural and moral obligation in collectivist cultures that extends beyond helping patients go through difficult times, relaying information to the clinicians or providing long term care. The patients give family members' preferences significant consideration during decision making. The African collectivist value promotes dependence, which is similar to the healthy dependence described by Feeney (2007), wherein healthy functioning of the self is dependent on the human need for connection. Thus, dependence and collaboration in the expression of wishes and preferences ought not to be viewed as a cultural constraint that will always be harmful to the patient.

Aside from the collectivist nature of African relations, under-resourced healthcare systems also contribute to the heavy family interdependence. The prevalent socio-economic situation means that patients generally depend on their family members for their healthcare costs. This reliance on family funds makes independent decision making a difficult and rather an unachievable possibility, as resources influence choices and patients consider family financial security when deciding on their care options. Evidence, however, suggests that financial

interdependence is connected to a unique cultural identity. Family members' acceptance of the socio-economic burden is not only out of necessity, but also a moral responsibility to the patient (Lewis et al., 2017). Furthermore, in the US context, African Americans' moral caregiving obligation is conceived and maintained within a religious framework (Mattis and Jagers, 2001), which recognises the family as the medium for religious and spiritual growth. Therefore, the moral, socio-economic, and religious cultural interaction are all intertwined and inseparable creating the distinctive African patient–family values that influence how the expression of wishes and preferences is perceived and experienced towards the end of life. Consequently, healthcare professionals ought to reflect on these multi-factorial values and understand the central place of collaboration between patient and their family members in the expression of wishes and preferences in end of life.

7.3 Contribution to knowledge

Grounded theory is about constructing a new theory. *Rubbing minds together* is an original and novel contribution to knowledge from the Nigerian advanced cancer context. It brings to focus the relational nature of expressing wishes and end of life preferences in the Nigerian advanced cancer setting using first-hand information. It also represents the only existing theoretical framework for the process involved in expressing end of life wishes and preferences in the African cancer context. To my knowledge, studies focusing on evaluating the relevance of formal ACP in Africa is on healthy populations (Stanford et al., 2013). African studies have not prioritised understanding the process of realising or relinquishing expression of the end of life care wishes and preferences. Studies reporting processes of ACP have focused on Caucasians of Western origin or Africans living abroad whose socio-economic situation differs from that of people living in Africa. Also, due to the possibility of ethnic and

cultural dilution by Western ideology (Song and Gutierrez, 2015), the acceptability and transferability of ACP theories derived from Africans living abroad to people living in Africa are unclear.

Also, this research has addressed the gap in knowledge created by the dearth of qualitative information around end of life communication in Africa and especially West Africa. Of the eight qualitative articles from Africa that were found to focus on end of life communication amongst patients with advanced cancer, their family members and healthcare professionals included in the literature review of my thesis, none were conducted in West Africa. As recognised, end of life and end of life communication is value-laden and complex, thus qualitative research has the potential to add new and unique contributions that are not easily quantified or known to be important in advance of research work (Koenig et al., 2003). The subjective experience of patients and their family members provides a unique insight into the communication patterns and processes that can inform clinical practice, policy and research

7.4 Implications for Clinical Practice and Research

The most relevant clinical implication of this study is the need for clinicians working in Nigerian or African settings to recognise and utilise the relational nature of expressing wishes and preferences in the delivery of end of life care. A stereotypical view of patients as passive care recipients and viewing the involvement of family members in decision making with suspicion might potentially create a climate of mistrust between the patient, family and healthcare professional. This distrust might impact on end of life communication. Therefore, clinicians should be adequately trained in end of life communication. Having cultural sensitivity and acknowledging the possibility of patients genuinely welcoming "intrusion" from their family members in their decision-making process and in their expressing of wishes

and preferences is important. This is especially relevant in Nigerian or other African clinical settings where the medical training leans towards a Western ideology of bioethics or when the clinicians are foreign trained. For instance, Harris et al. (2003) show the effect of cross-cultural differences in the approach to disclosure between clinicians trained in Tanzania and those trained abroad even when working with the same Tanzanian population. Furthermore, even though the implications for clinical practice relate explicitly to clinicians working in Nigeria, the findings have implication for clinicians working similar care settings in Africa or Asia. Even though the views and experiences of Africans living in Nigeria or Africa might not be the same as those of people living abroad, these findings may also have some relevance in other multi-cultural societies like modern Britain and the US.

Even when clinicians are unfamiliar with the patient's family values, respect for their patient's dignity requires that they are open to trusting and abiding by the patient's own evaluation of their family situation. Consequently, maintaining patient dignity for people of African origin might necessitate the inclusion, engagement and education of family members on the end of life issues. Healthcare professionals should be trained and encouraged to have open communication and interaction with patients and family members on their expectation of care, hopes for the future and views on communicating details of illness and its prognosis. Empowering family members will enable healthcare professionals to better support their patient's expression of end of life care wishes and preferences. Healthcare professionals who listen to the family's concerns, acknowledge their involvement, give attention to cultural and spiritual beliefs and respect their reasoning will help recognise areas of misinformation or misunderstanding that need attention. The above will provide a strong foundation for meeting the needs of patients and their relatives.

Finally, as a follow-up to the findings from this study, more empirical research and theory-driven interventional studies focusing on how African healthcare professionals can engage the patients and family members in end of life discussion that will facilitate the expression of end of life care wishes and preferences is required. Development and improvement of communication practices are essential to significantly improve the delivery of culturally sensitive goal concordant care significantly.

7.5 Limitations and strengths of the study

Findings from this study should be interpreted in light of some limitations. First, the theory constructed might not be representative of all advanced cancer contexts. The findings relating to the theory were drawn from fourteen participants experiencing advanced cancer or caring for a patient with advanced cancer, and had access to a hospital-based palliative care service in Nigeria. Furthermore, this study firmly lies within an interpretative tradition that views the data and its analysis as a construction of the researcher and the researched. The findings are contextually in a specific time, place and situation. The constructed theory depends on the researcher's interaction with the research process and her interpretive decisions, 'it does not and cannot stand outside of it' (Charmaz, 2014). The researcher's position based on her bias, experience and world view cannot be positioned outside of the constructed theory. This has been acknowledged through reflexivity throughout the research process. Furthermore, generalisability is not a concern in qualitative research (Bryman, 2012) as the interviewees are not meant to be a representative of the entire population. Rather case by case transferability will be more relevant here (Lincoln and Guba, 1985). This work has provided an explicit connection to the cultural and social context in which the analysed data were collected.

Secondly, this study excluded healthcare professional participants for logistic reasons. Realistically gaining access to these already stressed and busy palliative care clinicians within the context of a PhD influenced the decision to exclude them from the research. Recruiting healthcare professionals as participants could take far longer than anticipated, needing extra time and resources. However, these people could have informed the debate about end of life communication especially in the advanced cancer stages or final days of life where the process of communication between the family members and the healthcare professionals could be valuable to the development and improvement of evidence-based communication pattern and procedures. Lastly, due to the focus of the research, most of the included patients and family members in the study are likely to be those who are inclined to having an open conversation about end of life communication. Patients and relatives who are not interested or are averse to open communication would have self-excluded.

The strength of the research includes rigorous adherence to the grounded theory method that facilitates the construction of a theory grounded in data. The writing of the thesis demonstrates groundedness in the data through the usage of direct quotations from the participants. This gives strong logical links between the gathered data and research claims. The resultant theory is a co-construction of rich data collected from the experiences of participants and my reflective participation in the data collection and analysis process. The research was conducted and theory constructed by myself, a Nigerian who has sensitivity to the Nigerian issues and peculiarities having lived in the country and worked within the Nigerian health system. Additionally, the tape recordings of interviews, detailed transcript and researcher memos obtained throughout the research process provide evidence to the credibility of the research findings.

The findings of this research provide valuable insight for clinicians working with African patients with advanced cancer. This study shows how the patients' communication process with their family members evolves through the terminal stage of the patient's illness. The rich descriptive theory captures the basic psychosocial terrain that offers new insight into the processes involved in the expression of wishes and preferences in the Nigerian advanced cancer setting. While the theoretical model of *rubbing minds together* is constructed explicitly from patients with advanced cancer and their family members in the Nigerian palliative care setting, the theory may apply to other African settings. Even though it would be problematic to generalise this finding to the whole of Africa, as doing so is an assumption that Africa is monolithic, however, the papers included from the literature review broaden the transferability of the research findings. The diversity of African advanced cancer settings in the papers included in the literature review familial decision-making authority to be key components of end of life communication. This suggests that *rubbing minds together* may also be present across other African palliative care settings. Additionally, the discussion around the relational nature of end of life communication conducted in this study of family-oriented people, suggests that the grounded theory constructed might be relevant to other people diagnosed with a life-limiting illnesses in other collectivist societies.

7.6 My Position in the Research Process

Mruck and Mey (2019) emphasise the need for self-reflexivity in any empirical research. This is particularly important for me as a constructivist researcher-clinician who has clinical experience in the substantive area in which I conducted the research. Having worked in the research setting, I undoubtedly have an insider perspective that offers me the opportunity for a deeper understanding and theoretical sensitivity to the context in which the research

was conducted. Theoretical sensitivity facilitates analytic precision; and the construction of analytic codes that have a clear empirical origin (Charmaz, 2014). Conversely, sharing similar cultural views with the researched could potentially obscure my view to some of the elaborations and directions during data collection and analysis (Teh and Lek, 2018). Therefore, it was important for me to constantly reflect on how and where some of my assumptions and views might affect my interpretation of the respondent's words.

For instance, I initially failed to appreciate the implication of *rubbing minds together*. I came up with *negotiating* between patients and their family members to be the emerging theoretical model and a plausible explanation for what was taking place. However, through introspective reflexivity and memo writing, I identified *rubbing minds together* as the contextual explanation for what was going on. Even though a couple of the respondents used *to rub minds together* when describing how they engage in expressing wishes and preferences, the commonality of the expression for people in my country meant the concept was initially lost to me. However, I recognise my influence on the constructed theory and understand that my use of words might be dissimilar to the words that might be chosen by another researcher undertaking the same research.

Mruck and Mey (2019) note that a single researcher usually finds it difficult to reflect on their presumptions and re-interpretations without external support. I engaged in reflexive discussion with my supervisors and reflected on my supervision feedbacks throughout the research process. This was especially useful at critical times when my personal experience had decisive effects on the research process. For instance, my uncle unfortunately suffering from and dying from advanced cancer during the data collection and data analysis stage of my research made me anticipate and recognize how my experience would shape what I was

hearing from the research respondents. My co-constructive interaction with the study participants necessitated situating myself socially and emotionally in relation to each respondent's circumstances (Mauthner and Doucet, 2003).

7.7 Conclusion

With this constructivist study, I have made an important contribution to knowledge. I have addressed the distinct lack of evidence-based explanation for the basic social processes involved in the expression of end of life wishes and preferences in the African setting, specifically in Nigeria. The central message of the thesis is that the process of expressing end of life wishes and preferences by patients with advanced cancer and their family members involves *rubbing minds together.* This grounded theory has been constructed based on the perceptions and first-hand experiences of study participants, in the context of a growing number of people with advanced cancer in the African setting. These people live in a geographical location where palliative care, that may be their only feasible care option, remains mostly inaccessible. This grounded theory study puts into context a specific population that has a unique socio-cultural background where relational autonomy is more valued in comparison to individual autonomy that forms the basis for the existing Western-oriented ACP processes.

This research has given a voice to an underrepresented population and has extended the understanding of ACP as it might relate to this specific setting. This new awareness should inform practice. With appropriate adaptation to the existing formal ACP, there is a need for a carefully developed ACP that is relevant to the population that it serves. Perhaps, giving less focus to an ACP model that emphasises completion of a document by patients, drawing attention to improved communication and encouraging family participation in end of life

conversations will prove more impactful in these cultural contexts. *Rubbing minds together* may have something to offer back to the further development of advanced conversations in some Western settings offering a counterpoint to document driven approaches to care.

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Appendix

Appendix A: Recruitment Email to Clinicians

Dear Prof/ Dr/Mr/ Mrs / Miss

I would like to let you know about a research study that may be of interest to your patient and/ or their family members and ask you to consider referring your patient for possible participation. I will also request that you inform your patients who meet the inclusion criteria that their family members who are interested in the research could also participate.

This study is for my Ph.D. in Palliative Care at Lancaster University, Lancaster, United Kingdom. The purpose of the study is to increase understanding about expressing wishes and preferences amongst cancer patients and their family members after a diagnosis of cancer. It is expected that interviews from these participants will be a valuable resource in the understanding of expression of wishes amongst these people. Eligible and interested participants will be expected to partake in a one-on-one 45- 60-minute' interview with me the sole researcher, where issues concerning their views and/or experiences of expressing end of life wishes will be explored. In addition, patients will be urged to discuss the research with their family members who are interested in participating in the research.

However, I will like to make it clear that patient participation is not a requirement for the family member participation or vice versa. In addition, interview sessions will be conducted separately, that is no two people will be interviewed at the same time. Nevertheless, exceptions can be made for patients who will feel more secure having a family member around.

I kindly request that you assist in recruiting participants from your practice after using your clinical acumen to assess patients level of competence to give informed consent.

Patients that meet the following criteria may be eligible:

1. Adult (>18 years) cancer patients with any form of advanced stage cancer (Stage 3 and 4).

2. Patients who are aware of their disease and its prognosis, and have been told more than four weeks prior to the recruitment period.

3. Patients who are competent to give informed consent as judged by your clinical acumen.

4. All potential participants should be able to communicate in either English or Yoruba

Family members that meets the following criteria may be eligible:

1. Adult (>18 years) family caregivers of cancer patients as identified in 1 and 2 above
2. Family caregivers who are aware and have been aware of their ill family member's diagnosis and prognosis for more than four weeks prior to the recruitment period.
3. All potential participants should be able to communicate in either English or Yoruba.
4. Family members competent to give informed consent by being able to make their own choice after being provided with all the relevant information and asking relevant questions.

I look forward to speaking with patients and/or family members in your practice who may be interested in participating in this study. Please feel free to contact me with any questions, or have your patients contact me themselves, using the contact information provided below.

Considering the focus of the study, there is a possibility that participants might recognize the benefits of expressing their end of life care wishes and preferences and having discussions with yourself if they have not yet done so. I will encourage keen participants to bring up discussions with yourself.

Thank you for your time and consideration.

Attached to this Email is a copy of the participant information sheet for both patient and family member, expression of interest form for both patient and family member and consent form contained in the participant information pack.

Yours faithfully,
 Dr. Lateefah Oloyede
Email address: l.oloyede@lancaster.ac.uk
Telephone number: +2348034784884
Supervisors
DR. NANCY PRESTON

Email address: n.j.preston@lancaster.ac.uk

Telephone number: +44(0)1524 592802

DR MARY TURNER

Email address: j.m.turner@lancaster.ac.uk

Telephone number: +44(0)1524 594148

Lancaster University logo to appear here

A Research On Expression of Wishes and Preferences in Cancer Patients and their family members

My name is Lateefah Oloyede, I am conducting this research as a Ph.D. student at Lancaster University, Lancaster, United Kingdom

What is the research about?

The purpose of this research is to gain an understanding of the expression of wishes and preferences about future care after the diagnosis of cancer. This will relate to discussions you have had or yet to have with your family members and health professionals. It will involve you participating in one or more interview(s) with the researcher.

Why have you been approached?

You have been approached because we want to know how patients diagnosed with cancer feel about future care and we would like you to share your experiences, views, and thoughts concerning being involved in discussions regarding expressing future care plans to others such as family members and healthcare professionals. However, this research will involve both patients diagnosed with cancer and their family members and this material is meant to give information about the research. Your participation is not a prerequisite for your family member's participation in the research, either or both of you can choose to participate or not to.

Do I have to take part?

No, it is completely up to you to decide whether or not you partake. Before you decide I would like you to understand why the research is being done and what it involves for you. Also please feel free to ask any questions about being a part of the study.

What will I have to do if I take part?

If you decide to take part in this study, with your permission, I will ask you some questions about you, your/ illness, your thoughts or experiences of expressing future care plans to others such as your family members or healthcare professionals in a one-to-one interview. If your family member also agrees to participate they will be interviewed separately. However, exceptions can be made for those that will feel more comfortable having a family member

with them. This interview will be in any safe place of your choice and will be audio recorded on a handheld device.

Will my data be identifiable?

Your name will be kept confidential and will be stored separately from the interview data. All personal details that can be used to identify you will not be included in the report or publication.

The original data recording will be deleted once the research has been completed and examined. A transcribed copy of audio recordings will be electronically stored on a password protected secure computer only accessible to me and a backup will be electronically archived on Lancaster University online file store. These will only be accessible to me and my supervisor (s). All hard copies will be destroyed once the research has been examined and submitted.

The backup on the Lancaster University electronic file store will be archived for 10 years after the submission of the final report. The scanned consent form will also be stored in a secured electronic location for this period.

Any other sheet or document containing identifiable information such as your name or address will be destroyed after the research unless you want to be contacted after the research for a report summary.

However, if what you say in the interview makes me think that you someone else is at a significant risk of harm, I will have to inform the appropriate member of staff or department but will let you know about this if possible.

What will happen to the results?

Findings of the study will be produced in my thesis/project and will be submitted for oral or poster presentations at academic conferences in various organizations locally, nationally or internationally. It will also be submitted for publication in various peer-reviewed journals and will be disseminated amongst colleagues and the general public via twitter.

What is the possibility of discomfort and risks?

There is a possibility that you might be distressed talking about thoughts and experience related to your illness. You have the right to either withdraw from the interview, not to answer a specific question or postpone it for some time if you are upset. Even after participation, you have up two weeks to decide if you want to withdraw your interview and all efforts will be made to remove your interview. If you experience any distress after the

interview you are encouraged to inform me or get in contact with any of the resources provided at the end of this information sheet.

Are there any benefits

Although some people might find having such discussions a way of letting out inner feelings, there are no direct benefits in partaking in the study. As the study aims to improve understanding of the concept, expressing wishes for future care, it is hoped that it will help improve the care of patients diagnosed with cancer in the future.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the University 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 either the researcher: Name: Lateefah Oloyede

Email address: l.oloyede@lancaster.ac.uk

Researcher telephone number: +2348034784884

OR Supervisors

Dr. Nancy Preston

Email address: n.j.preston@lancaster.ac.uk

Telephone number: +44(0)1524592802

Dr. Mary Turner

Email address: j.m.turner@lancater.ac.uk

Telephone number: +44(0)1524 594148

Complaints

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 Bruce Hollingsworth

Tel: (01524) 594151

Email: b.hollingsworth@lancaster.ac.uk

Head of the department

Division of health Research

Lancaster University

Lancaster

LA1 4YG

If you wish to speak to someone outside of the Ph.D. Doctorate Programme, you may also contact:

Professor Roger Pickup

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. **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 in this project or in the future, the following resources may be of assistance:

1. Your local Palliative Care Nurses.
2. Care Organization, Public enlightenment (COPE)

   Contact: 39B Adeniyi Jones Avenue, Ikeja, Lagos, Nigeria

   +2347018000004, +234 8137109164

   info@copebreastcancer.org, cope@yahoo.com

3. MAMA cancer foundation of Nigeria

    Nagogo road, off Rabah road, Kaduna, Nigeria

+2348023550515, +23462243608

mamacancerfoundation@yahoo.com

4. Breast Cancer Association of Nigeria (BRECAN)

    18, Akinyemi way, off E- GT Bank

    Ring road, Ibadan, Nigeria.

    +2348033331211

    brecan97@yahoo.com

Lancaster University logo to appear here

A Research On Expression of Wishes and Preferences in Cancer Patients and their family

members

My name is Lateefah Oloyede, I am conducting this research as a Ph.D. student at Lancaster University, Lancaster, United Kingdom

What is the research about?

The purpose of this research is to gain an understanding of the expression of wishes and preferences about future care after the diagnosis of cancer. This will relate to discussions you have had or yet to have with your family member diagnosed with cancer. It will involve you participating in one or more interview(s) with the researcher.

Why have you been approached?

You have been approached because we want to know how family members of patients diagnosed with cancer feel about having a discussion around future care with their ill family member and we would like you to share your experiences, views, and thoughts concerning being involved in this discussions. However, this research will involve both patients diagnosed with cancer and their family members and this material is meant to give information about the research. Your participation is not dependent on your family member diagnosed with cancer's participation in the research or vice versa, either or both of you can choose to participate or not to.

Do I have to take part?

No, it is completely up to you to decide whether or not you partake. Before you decide I would like you to understand why the research is being done and what it involves for you. Also please feel free to ask any questions about being a part of the study.

What will I have to do if I take part?

If you decide to take part in this study, with your permission, I will ask you some questions about you, your family member that is diagnosed with cancer, your thoughts or experiences of being involved in a discussion about future care with your family member diagnosed with cancer in a one-to-one interview. If your family member also agrees to participate they will be interviewed separately. However, if you prefer to be interviewed together, exceptions can be made for those that will feel more comfortable having a family member with them. This

interview will be in any safe place of your choice and will be audio recorded on a handheld device

Will my data be identifiable?

Your name will be kept confidential and will be stored separately from the interview data. All personal details that can be used to identify you will not be included in the report or publication.

The original data recording will be deleted once the research has been completed and examined. A transcribed copy of audio recordings will be electronically stored on a password protected secure computer only accessible to me and a backup will be electronically archived on Lancaster University online file store. These will only be accessible to me and my supervisor (s). All hard copies will be destroyed once the research has been examined and submitted.

The backup on the Lancaster University electronic file store will be archived for 10 years after the submission of the final report. The scanned consent form will also be stored in a secured electronic location for this period.

Any other sheet or document containing identifiable information such as your name or address will be destroyed after the research unless you want to be contacted after the research for a report summary.

However, if what you say in the interview makes me think that you someone else is at a significant risk of harm, I will have to inform the appropriate member of staff or department but will let you know about this if possible.

What will happen to the results?

Findings of the study will be produced in my thesis/project and will be submitted for oral or poster presentations at academic conferences in various organizations locally, nationally or internationally. It can also be submitted for publication in various peer-reviewed journals.

What is the possibility of discomfort and risks?

There is a possibility that you might be distressed talking about thoughts and experience related to your illness. You have the right to either withdraw from the interview, not to answer a specific question or postpone it for some time if you are upset. Even after participation, you have up two weeks to decide if you want to withdraw your interview and all efforts will be made to remove your interview. If you experience any distress after the interview you are encouraged to inform me or get in contact with any of the resources provided at the end of this information sheet.

Are there any benefits

Although some people might find having such discussions a way of letting out inner feelings, there are no direct benefits in partaking in the study. As the study aims to improve understanding of the concept, expressing wishes for future care, it is hoped that it will help improve the care of patients diagnosed with cancer and that of their family members in the future.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the University 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 either the researcher:

Name: Lateefah Oloyede

Email address: l.oloyede@lancaster.ac.uk

Researcher telephone number: +2348034784884

OR Supervisors

Dr. Nancy Preston

Email address: n.j.preston@lancaster.ac.uk

Telephone number: +44(0)1524592802

Dr. Mary Turner

Email address: j.m.turner@lancater.ac.uk

Telephone number: +44(0)1524 594148

Complaints

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 Bruce Hollingsworth

Tel: (01524) 594151

Email: b.hollingsworth@lancaster.ac.uk

Head of department

Division of health Research

Lancaster University

Lancaster

LA1 4YG

If you wish to speak to someone outside of the Ph.D. Doctorate Programme, you may also

contact:

Professor Roger Pickup

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.
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Resources in the event of distress

Should you feel distressed either as a result of taking part in this project or in the future, the

following resources may be of assistance:

1. - Your Palliative Care Nurses.

2.   Care Organization, Public enlightenment (COPE)

     Contact: 39B Adeniyi Jones Avenue, Ikeja, Lagos, Nigeria

     +2347018000004, +234 8137109164

     info@copebreastcancer.org, cope@yahoo.com

3. MAMA cancer foundation of Nigeria

     Nagogo road, off Rabah road, Kaduna, Nigeria

+2348023550515, +23462243608

mamacancerfoundation@yahoo.com

4. Breast Cancer Association of Nigeria (BRECAN)

   18, Akinyemi way, off E- GT Bank

   Ring road, Ibadan, Nigeria.

   +2348033331211

   brecan97@yahoo.com

Appendix D: Expression of Interest Form for patient

A Research On Expression of Wishes and Preferences in Cancer Patients and family members

I have read and understood the research information sheet.

I am interested in participating in this study as I have been diagnosed with cancer.

Please, either return this form to the confidential box in the head of units' office, call the researcher on the number below or if you wish to be contacted, leave your contact details with your clinician. The researcher will be in contact with you to discuss the research, answer any question you may have about the research, and whether you will like to take part.

Kindly, provide the following information, but only details you are happy to share

Name:

Contact number(s):

Carers number:

Email:

Home address:

Researcher contact details: Department of Medicine, University of Ilorin Teaching Hospital, Ilorin, Nigeria

Name: Lateefah Oloyede

Email address: Lateefah.oloyede@yahoo.com

Researcher telephone number: +2348034784884

Lancaster University logo to appear here

A Research On Expression of Wishes and Preferences in Cancer Patients and family members

I have read and understood the research information sheet.

I am interested in participating in this study as I am a family member of a person diagnosed with cancer.

Please, either return this form to the confidential box in the head of units' office, call the researcher on the number below or if you wish to be contacted, leave your contact details with the clinician caring for your family member diagnosed with cancer. The researcher will be in contact with you to discuss the research, answer any question you may have about the research, and whether you will like to take part.

Kindly, provide the following information, but only details you are happy to share

Name:
Contact number(s):
Carers number:
Email:
Home address:
Researcher contact details: Department of Medicine, University of Ilorin Teaching Hospital, Ilorin, Nigeria

Name: Lateefah Oloyede. Email address: Lateefah.oloyede@yahoo.com: Researcher telephone number: +2348034784884

A Research On Expression of Wishes and Preferences in Cancer Patients and family caregivers

You are being asked to participate in a research aimed at explaining the concept of expressing wishes for future care.

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 my interview will be audio recorded and then made into an anonymized written transcript.	
4. I understand that audio recordings will be kept until the research project has been examined.	
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected. I understand that the interview data can only be withdrawn up to two weeks after the interview, after this point the data will remain in the study.	
6. I understand that once my data have been anonymized and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up until two weeks after the interview.	
7. I understand that the information from my interview will be pooled with other participants' responses, anonymized and may be published.	
8. I consent to information and quotations from my interview being used in reports, conferences and training events.	
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor.	
10. I agree that the audio recordings of the interviews may be stored securely to enable the researcher to continue analysis of the study data in future projects.	
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished	
12. I consent to take part in the above study.	

Name of Participant: _____   Signature: _____Date: _____
Name of Researcher: _____   Signature: _____Date: _____

Lancaster University

Applicant: Lateefah Oloyede
Supervisors: Nancy Preston and Mary Turner
Department: Health Research
FHMREC Reference: FHMREC16120

13 June 2017

Dear Lateefah

Re: The expression of end of life care wishes and preferences among cancer patients and family caregivers: a grounded theory approach

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 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Diane Harris

Dr Diane Hopkins

Research Integrity and Governance Officer, Secretary to FHMREC.

UNIVERSITY OF ILORIN TEACHING HOSPITAL

Chairman:
MRS. OLAJUMOKE ANIFOWOSHE
L.L.B. (HONS) ACIArb

Chief Medical Director:
PROF. A.W.O. OLATINWO
MBBS. FWACS, MBA, AMNIM

Chairman Medical Advisory Committee:
DR. B. S. ALABI
MBBS. FWACS, FMCORL
Cert. Health Inf. Mgt.

Director of Administration:
DR. (MRS.) Y.C. AYO-BELLO FHAN
B.Sc., MPH (Oklahoma, USA) Ph.D (Ilorin)

Old Jebba Road, Oke-Ose,
P.M.B. 1459, Ilorin,
Kwara State, Nigeria.

E-mails:
- unithilorin1980@yahoo.com
- info@uith.org

Telephones:
- 08055763942
- 08037301311

UITH/CAT/189/19 ᴮ/313

UITH ERC Protocol Number: ERC PIN/2017/04/0554
UITH ERC Approval Number: ERC PAN/2017/05/1681

Date: 17/05/2017

THE EXPRESSION OF END-OF-LIFE CARE WISHES AND PREFERENCES AMONG CANCER PATIENTS AND FAMILY CAREGIVERS: A GROUNDED THEORY APPROACH

UITH Ethical Research Committee (ERC) assigned number: NHREC/02/05/2010
Name of Applicant/Principal Investigator: DR. LATEEFAH ABIODUN OLOYEDE
Address of Applicant: Faculty of Health and Medicine, Lancaster University, UK
Date of receipt of application: 27/04/2017
Type of Review: Full Committee Review
Date of full Committee Decision on the Research: 17/05/2017
Date of full Committee Approval: 17/05/2017

Notice of Full Committee Approval

I am pleased to inform you that the research described in the submitted protocol, the consent forms and other participant information materials have been reviewed by the UITH Ethical Review Committee (ERC) and given full Committee approval.

This approval dates from 17/05/2017 to 16/05/2018. You are requested to inform the committee at the commencement of the research to enable it appoint its representative who will ensure compliance with the approved protocol. If there is delay in starting the research, please inform the ERC so that the dates of approval can be adjusted accordingly.
Note that no participant accrual or activity related to this research may be conducted outside these dates.

The UITH ERC requires you to comply with all the institutional guidelines and regulations and ensure that all adverse events are reported promptly to the ERC.
No changes are allowed in the research without prior approval by the ERC. Please note that the ERC reserves the right to conduct monitoring/oversight visit to your research site without prior notification.

Notwithstanding above, we will not be responsible for any misconduct on the part of the researcher in the course of carrying out the research.

Thank you

PROF. (MRS) F.G. ADEPOJU MBBS, MSC, FMCOPH, FWASC, FICS, MNIM
Chairman, UITH Ethics Review Committee. (ERC)

26th October 2017

Not being listened to

Patient participants describes frustration of expressing participant wishes, they felt being disregarded by their family members. Family members tending not to want to discuss the issues by using tactic such as dismissing patient's worries or outrightly not willing to listen even when prompted to do so by the patients.

This seems to be linked to a not having a discussant such as that described by Lara- she describes being a widow and having no one to talk with. Olu talked about not having access to his son that he can discuss with.

17th November 2017

After my last supervision meetings, it has become clear that majority of my coding are quite abstract and I myself find it difficult to be able to directly connect the codes to the transcript. My plan is to recode all the data form the beginning and use my previous coding as a learning experience for constructivist coding and using NVivo.

.....

20th December 2017

Not so useless an experience after all!

Initially I thought of using Strauss C' s because I thought it will make my life easy and I would be able to link back the research question with the codes I was generating without the worry of going out of tangent like I previously did but I was going to try to make sure that the codes were fitting the c's and not the other way round to be able to avoid fixing data as Glasser noticed. However, when I started, I realized that not all the codes fit in to the neat categories and I might need to force some to fit in.

I have this decided that the only way this could work was for me to put the questions right in front of me while coding check that each code I have written down goes in the direction of the research question and I do not need to code those lines where the participants were talking about something else. This seems to be making sense thus far.

Reflexivity

During my last coding session, I think I did not really think about how I was impacting on the codes I was generating. Although I thought I was detached enough, but on rechecking codes I realised I have so much of myself in the codes than I thought. Although -' grounded theorist code for possibilities rather than ensuring accuracy' pg. 120,. Thus, I compared incidents with incident to define the code and its properties

Relishing in an enabling relationship -- *Factor that favours expressing wishes*

Initially this was "being comfortable with a close observer" that is deriving comfort in having a close discussant who knows patient's history. But this did not really reflect the message.

I changed its to deriving confidence to talk by expressing to expressing to a close relative - This reflects that the respondent's (Olu) expresses feeling of being comfortable to discuss his end of life wishes with a family member (his wife) that has been present since the beginning of the illness understands why he (the patient) wants to express this wishes even though she might not agree with what he says she still listens and . This is compared with Lara' experience of being able to get encouragement and strength from her sister as she speaks with her about her wishes for her family.

Deriving relief in expressing wishes-- *Factor that favours expressing wishes*

Segun talked about being out of pain after expressing wishes, while Olu described the pain of not being able to express himself to his family who are not interested in listening to him as the worst of his pain

Facing one's own immortality--- *Derived or perceived benefit of expressing wishes*

Expressing wishes about the ending despite the pain associated with discussing one's own death. Segun talked about learning to bear the pain and face the reality of dying so that he can make plans for his family. Lara talked about how she feels that expressing her wishes is the same thing as telling someone else that she is going to die soon, she also talked about the emotional difficulty of discussing about her wishes but she is till forced to discuss because she wants to make plans for her kids.

Making Choices---*Adjustments made in expressing wishes*

The respondents made some decisions in the process of expressing or not expressing wishes

Avoiding the immature ones - Segun talked about not talking to his daughter because she is immature, and Lara says she dislikes talking to her daughter because she is still a child.
Being selective: Segun talked extensively on how he chooses who to discuss with based on how they react to his discussion Others suggested being wise and older is a plus. others include - actively giving importance to planning

Not being listened to ----- *Factors against EW.*

Contending with family avoidance: Challenges related to family members not wanting to be involved in discussions where patients seek to express their wishes. This includes: 1. Being shut up 2 being denied a discussion 3. Family evading discussion and family rejection

Being Autonomous----*Derived or perceived benefit of expressing wishes*

Describes participating in planning as a reason of expressing end of life care wishes. The participant describes expressing wishes as their own involvement (autonomy) or opportunity to be able to make plans for themselves and their dependents by expressing wishes

3/5/18

Family looking out for the patient. family hiding their emotions and the patients expecting them to sacrifice? As if they are not the one being hit the most, they are not the one dying. Enduring to express hiding emotions to be able to discuss. Comforting the family and being comforted: comforting each other- preparing the family: making them comfortable

16/6/18

Looking at some of the codes, some are family member's emotions, thought and actions while some are their perception of patients thought, views and perceptions. I am not so clear how I will have to separate these. It is becoming clearer that I need to separated family member codes from patient codes. In the meantime, I might lump it all together bought I might need to group patient's codes with relative's perception of their views, thoughts and reasons behind their actions.

19/6/18

From the interview process and the codes, it is obvious that the relational aspect of the concept of expressing wishes is emerging and thus should it be interpreted as such?

Adjusting to situations:
This relates to the emotional preparedness or readiness to participate in expression of W&P. It occurs at the point when they acknowledge the inevitability of EOL, and It influences how patients get to the point of expressing wishes and how family members receive this.

Adapting- This code applies to both patients and family members. The respondents talked about how they or their family members get to the point of expressing wishes. For instance, when Shola (F) was asked about the qualities of his wife that makes her able to freely express her wishes he responded. "She adapts to situation she finds herself "meaning she understands the situation and acts accordingly. Segun (P) also commented "painful. And there is nothing I can do about it, I have learnt to cope with it and adjust do you understand? I have learnt to bear it "when commenting on the emotional difficulty associated with talking about ones impending death and preparing for it. This is contrary to what one of the respondents (Gbemi F) described when she talked about her Mum not adjusting to the fact that her father is going to die and thus living in denial.

Settling one's mind

Shola (F) describes the process it takes his wife from knowing that she is dying when she is able to have EOL discussion with him. He talks about her confused emotional state when she heard about the diagnosis and then making plans for the future when she will have settled her mind".

Controlling emotions. Shola (F) relates the facts that his wife is strong and sensible, understand that she is dying and there is nothing she can do about it other than to be sensible and control her emotions and be able to discuss her future freely. I had other codes such as 'being sensible' and 'staying in control' in this code category but moved them to the unsure list as I am not sure those relates to this code, they are about? characteristics that makes the person to be able to be able to express their w&p. I might still merge all these codes together.

Not getting straightforwardness This was initially avoiding/ being avoided. It is a description of not getting the honest and full explanation of what is going on and this then prevents the patients from knowing they need to make plans-

This was an overarching code in the interviews, emotional baggage affected expressing wishes in so many ways. Patients wanting to protect family members and Family members avoiding discussion to avoid upsetting patients.

Appendix J: Categorical code book

Name	Description	Files	References
Collaborating		**10**	**157**
Attaining understanding	Comprehending the disease ___> (to use Vivo code) Understanding the disease- > to make it more broad to accommodate the other codes ? Do I need to change this to something more meaningful? Being able to understand what is going on or getting involved in what is going on leading to free expression of W&P.	6	17
Family getting involved	Clinicians encouraging family members to get involved	1	1
Family lacking understanding of illness	Not understanding that death is near	1	2
Relying on facts	Making decision to discuss based on facts	1	1
seeking more information	Looking for ways to get more information to be able to support the next step	1	1
Seeking understanding	Seeking acceptance of what is happening	1	3
Wishing for understanding	Resting the discussion on the shoulder of a listener	3	4
wishing for a serious person	As an attribute of who to discuss with	2	3
Wishing for understanding despite nonacceptance		1	1
Being actively discouraged	Family members stopping or disrupting discussion that can lead to expression of EOL W&P.	3	8
Discouraging expressing wishes F	Family discouraging patient from initiating end of life discussion and dismissing their expression.	2	3
Dismissing expression P&F	Dismissing all the patient's expression of wishes, claiming it is not necessary as the patient isn't dying. This has been merged in to discouraging expression	2	2
Getting resistance	Family members resisting the expression of wishes	1	2

Name	Description	Files	References
Lying to dissuade		1	1
Benefitting closeness	Deriving comfort in closeness in a way that facilitates discussion	1	1
Characteristics	This characteristic -code makes its effect of expressing wishes and preferences looking static and not an ongoing behaviour that affects patient's decision to express their wishes. Change to possessing enabling characteristic- what if they are not enabling but discouraging towards expressing wishes. Should I link this with "controlling the process" as they are characteristics that controls the process and also how family members engage with the process of expressing future care wishes and pref.	0	0
Being selfless	Attribute that makes the patient want to express wishes- take care of family even after his death	1	2
Sacrificing for family F	Attribute given to patients who care for family more that self	1	1
Showing compassion	Family's perception of patient's actions	1	1
Showing dedication	Family's perception of patient's characteristic? Significance?	1	1
considering the past	Mental thought of family members when considering patients unexpressed wishes. Dwelling into their pasts and thin king about what they will want	2	2
Expecting family cooperation	Having expectations- Patients or families expecting certain things from each other in order to facilitate or deter free expression of W&P.	3	6
Allowing assumption of responsibility	Playing out an assumption that family members ought to help patients - to be their comfort zone, to listen to have they have to say and help achieve their expressed wishes	1	1
Expecting cooperation	Giving importance to family cooperation	1	2
Expecting strength from family	Expectation on the family to face their fears	1	1
Needing to be strong	Family members needing to be strong for patient	1	1
Needing to have the discussion		1	1
Family pressure		1	7

Name	Description	Files	References
Being at family members mercy	Being forced to let family members make decision due to their financial power	1	1
Controlling the process	**Selecting discussant: Making choices. _> Controlling discussion This describes making choices in the process of expressing wishes as a conscious practical activity in expressing wishes- It is not only about controlling the discussion per se but controlling the process of expressing wishes. This can relate to maintaining autonomy**	**10**	**103**
Avoiding being saddened P	Being saddened by discussions. Strong negative emotions related to having discussion with people	4	5
Avoiding cultural inappropriateness	Avoiding talks that is viewed as culturally inappropriate. Discussing end of life with parents	1	1
Deriving relief in expressing wishes	Initially - "Seeking relief in expressing wishes" Receiving Psychological gains? This explains the psychological gains associated with expressing wishes. It is deriving relief because it is an end point after expressing wishes even if that was not the initial plan. Might need to merge deriving relief in expression with deriving psychological relief. as they mean the same thing. Isn't it?	6	15
Deriving emotional relief in planning P	Planning for oneself and the family. Deriving happiness, comfort in planning P	2	4
Deriving psychological relieve from discussion P		3	4
Deriving relief in expressing	Family- observing the relief patients feel in expressing wishes.	1	1
Getting opportunity to open up	Patient happy about the opportunity to discus	1	1
Letting it out P	Expressing feelings	1	2
Obtaining mutual pleasure	This is about deriving fulfilment by having the conversation and being able to better understand the patient.	1	1
Transiting worry P	Getting comfortable with discussion	1	1
Expressing wishes covertly P		2	8
Jokingly expressing wishes		2	3

Name	Description	Files	References
Expressing wishes indirectly P		1	3
Feeling ignored by the clinicians	Family members feeling left out by clinicians who treat the patients	1	1
Hiding information from family	Expressing wishes indirectly	1	1
Initiating discussion P	Bringing up end of life discussion with family	4	6
Leaving parts out P		1	1
Leaving people out	Leaving certain people out of the discussion in so as to avoid emotional distress during g the discussion	1	1
Negotiating with emotions	Patients getting what they want through their show of emotions	1	2
Not getting straightforwardness	Avoiding - being avoided; This relates to the deliberate act of avoiding the discussion by either parties.	2	6
Getting indirectness from clinicians P	Lara talked about not getting clear message or information from the clinicians; this might affect adjustment to be able to express wishes? Explore further in next interviews	1	2
Misconceiving F	Not getting the true extent of the disease	1	2
Not being clear F	Being avoided: Friends avoiding family member	1	1
Persisting in expression F		1	2
Pleading to be heard	Begging family members to have discussions	1	7
Making unfruitful efforts		1	2
Using interview to motivate family discussions	Encoring them to Interview encouraging future talks	1	4
Putting plans in place	Family members assisting g the patients to execute their plans	1	1
Refusing		3	6
Refusing to accept		3	4

Name	Description	Files	References
Enduring	**Both patient and family members naturally needed to adjust or modify their thinking to be able to start expressing wishes or listening to the expressed wishes. The participants could not talk about expressing wishes without talking about how they transitioned from not being able to have the discussion or being worried or scared of having the discussion to it being a sore point where they have to go through to be able to express their wishes or for the family members to be able to listen to the discussions.**	**10**	**69**
Adjusting to the situation	This relates to the emotional preparation and readiness for expressing W&P at a point in time after acknowledging the inevitability of EOL. Should I change this to being able to adjust to the situation.	7	19
Adapting to the situation	Family's perception of patient's way of adjusting to a situation that is beyond his/her control and therefore patients expressing wishes by acknowledging the need to adjust to the situation	3	4
adapting to the situation		1	1
Balancing emotions	Maintaining emotional stability order to make rational decision Stabilizing emotions	1	1
Being sensible	Attributing patient's actions to be able to adjust to the situation of acknowledging the end of life and then move on to sensibility	1	2
Controlling emotions	This was initially - Staying focused: Family's perception of patients handles the need to discuss-? Not getting carried away. I have changed this to controlling emotions as it's a more fitting code. Controlling emotions is a way that the respondents adjust emotionally to the situation that she has found herself and is able to move on to expressing wishes.	1	1
Moving on	Nvivo code - This illustrates getting past the initial very difficult experience of starting discussion around Ex W&P.	1	1
Not adjusting to the situation	Holding back on discussion because she is not ready to open her mind to the possibility that her husband is dying	1	1
recognising impending death	Factor encouraging discussions	2	3

Name	Description	Files	References
Reconsidering decision	Changing from a decision to discuss/ not to discuss to the other	1	1
Reconsidering	Deciding to discuss based on re consideration of facts	1	1
Settling one's mind		1	1
Talking about the next step	IS this related to moving on from the initial shock.	1	1
Thinking about the future		1	1
Balancing between planning and being hopeful	This relates to the participants going forward with making plans and expressing wishes about the future but still hoping that things can get better. This is like a forward and backward movement. But is it really backward? Does being hopeful for the best makes them go ahead with planning. For some participants being hopeful means getting better and for some getting comfortable and for some hoping dying is better. So is it ? Using hope to sustain the need to plan. Not sure of how to code it	3	6
Believing in planning F		1	1
Getting prepared	Preparing for the worst case scenario	1	1
Planning while being hopeful	Balancing?	1	2
Staying in control- F	Family members perspective of patients actions	1	1
Being uneasy with discussion	Feeling of uneasiness with having discussion. This relates to personal feeling or imposed feeling due to family behaviour or perceptions	4	7
Being uncomfortable- uncomfortable with the discussion P		3	5
Disliking discussing future care plans	This is not really disliking the end of life discussion in itself but disliking it because of the family reaction to the discussion	1	1
Disliking end of life discussion	Avoiding dying discussions- this code is more like disliking end of life discussion but planning despite the discomfort- (When the whole context of that code in read)even though they are uncomfortable with having the discussion they still go ahead with it . Due to a greater good?	1	1