Swansea University
Prifysgol Abertawe

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Barriers to Culturally Sensitive Care for Muslim Families: Healthcare Providers' and Social Work Perspectives on the Role of Islamic Faith in Parental End-of-Life Decision-Making for Children

A PhD (Social Work and Social Care) thesis

submitted to Swansea University/ Prifysgol Abertawe

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Submission Date: November 15, 2024

Wordcount: 80980

Abstract:

In this study, the impact of Islamic culture and religious teaching on parents is studied with regard to their ability to care for children who are living with life-threatening illnesses, receiving palliative care, and approaching the end of their lives. Health care providers, prequalified social work students, and Muslim community leaders are also interviewed about their engagement and the support and care they provide Muslims with children suffering from terminal illness and facing imminent death. This study also examines some of the strategies and guidelines used in England and Wales to help shape palliative care services and end-of-life care for children. Specifically, the policy analysis was intended to critically examine health policies concerning children who are at the end of their lives, especially in regard to their culture and religion.

Methodology: In this qualitative study, semi-structured interviews were conducted with healthcare professionals, a mosque leader, and prequalified students. As for the parent participating in the study, a narrative interview was conducted to allow her to talk freely (Fox, 2009).

Findings and conclusion: Although both culture and religion have an impact on families' experiences at the end of a child's life, some cultural values can help families cope with the difficult process of caring for a dying child. The study concluded that culturally sensitive care requires diversity in the workforce, trusting and knowledgeable community members, and interactions between Muslim communities and healthcare organizations.

"*The truest measure of life is not in its length but the fullness in which it is lived*."

By: Maria Housden.
From book: Hannah's gift: Lessons from a Life Fully Lived

Acknowledgement:

First and foremost, all praise to Allah Almighty for giving me the strength, courage, and endurance to complete this PhD study. Without His blessings, this achievement would not have been imaginable.

During my PhD program, I have received help and reinforcement from different people. Firstly, I would like to express my deepest appreciation to both of my supervisors, Dr Tracey Maegusuku-Hewett and Professor Fiona Verity, for their valuable advice, constant support, and patience during my PhD study. My academic research journey has been enriched by their vast knowledge and extensive experience. I couldn’t have asked or imagined having better supervisors. I am extremely grateful for them.

Also, I am grateful and thankful to all those who supported me through the process of obtaining ethical approval, that was one of the major obstacles, that took and extensive effort and time to get it right.

Most importantly, my profound appreciation, gratitude, and love to my parents for providing me with unconditional support and continuous encouragement. For their heart-warming wishes and words when I have almost given up. To my siblings, nieces, and nephews for always believing in my ability and giving me the inspiration and motivation.

Finally, to my colleagues and amazing friends for being there through all the ups and downs, to lift me up, and listen to me expressing my study findings. This accomplishment would not have been possible without them. It is truly about the friends we meet along the way that helps us appreciate the journey.

“It always seems impossible until it’s done" Nelson Mandela

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Chapter 1: Introduction

Introduction:

The greatest fear parents may face when caring for a child with a life-threatening condition is their child's impending death (Liu et al., 2014). Sometimes the hope that their child will survive dwindles or diminishes, which means they have to endure the adversity of seeing their child die, regardless of the efforts they put into saving them (Liu et al., 2014). However, as medical interventions have become more readily available, invasive medical interventions have postponed death, allowing children with life-threatening conditions to live longer (Liu et al., 2014). Palliative care is one of the specialty services that can contribute to enhancing the life of children with life-limiting and life-threatening conditions. Applying palliative care early in paediatric care and paediatric oncology has been recognised because of its benefits in improving quality of life and survival (De Clercq et al., 2019). It may be required for children as early as infancy for a variety of diseases, many of which are rare and genetic in nature (Goldman, 1998). In some instances, they may require palliative care for a long period of time, while in others, they may require it as they grow and for a short period of time (Goldman, 1998). A palliative approach does not necessarily imply the withdrawal of active treatments, but rather, it examines the benefits of interventions for both child patients and their families (Hutchinson et al., 2003).

To consider the interventions, their benefits must be greater than their risks. It is therefore dependent upon the diagnosis of the child as to what type of care they require (Goldman, 1998). Belintxon et al. (2020) emphasized that when developing a treatment plan, generally al patients and their families must be involved in the decision-making process (Belintxon et al., 2020). It is also necessary to take this into consideration when caring for patients from different cultural backgrounds. In this sense, healthcare professionals must have culturally competent skills to tailor their practices to meet the needs of individual patients (Belintxon et al., 2020). Ultimately, to deliver effective culturally competent care, health professionals must always maintain the right attitude to facilitate and enhance their cultural awareness and relevant skills (Belintxon et al., 2020**).**

Having said that, the news that a child has been diagnosed with a life-threatening illness, is being treated with palliative care, and is undergoing end-of-life care is devastating for any parent. They would likely experience fear, anger, anxiety, distress, or even hopelessness in the wake of such news (Ng & Fung, 2023). For forced migrant families, having a child with palliative care needs is burdensome as it adds to their distress and trauma of migration (Clancy et al., 2020). Besides experiencing grief, fear, and loss resulting from their child's diagnosis, they also experience distress because of their migration situation (Clancy et al., 2020). For families of children of Muslim faith particularly, challenge may arise when discussing the life expectancy of their child; namely this is because Muslims believe that the exact timing of death is only determined by Allah (God), and no one is able to predetermine the time of death (Al-Shahri & Al-Khenaizan, 2005). Thus, the lack of understanding of these traditions may create a communication barrier between families of ill children and their healthcare providers. In terms of health services, these families face a number of challenges including limited resources and inadequate support (Clancy et al., 2020).

Background:

Paediatric Palliative Care (PPC)

Paediatric palliative care (PPC) is a multidimensional and multidisciplinary philosophy that has a total approach to caring for children and young people with life-limiting and life-threatening conditions where collaboration is essential between various agencies and health services, including social services and the voluntary sector (Brown & Warr, 2007). A clear distinction is drawn between the terms "life-limiting" and "life-threatening," where the former describes conditions that have no reasonable chance of being cured; even if a child survives, it is unlikely that he or she will live out a normal life (Bergstraesser, 2013). In contrast, life-threatening conditions include those where treatment is feasible, but the outcome is fatal (Boyden et al., 2018). In some cases, an illness begins as life-threatening and turns into a life-limiting condition, such as when a child relapses with diminishing chances of getting better (Sourkes et al., 2005). The palliative care models vary based on the child; some are provided in community settings, while others are provided in hospices or hospitals (Brown & Warr, 2007). Yet, regardless of the setting paediatric palliative care aims to meet the needs of children and their families (Brown & Warr, 2007).

The World Health Organisation (WHO) provides a comprehensive definition of paediatric palliative care, which is a type of care provided to children with life-threatening conditions and their families to improve quality of life. The interventions used in PPC are better to be implemented at early stages of illness in order to reduce pain, treat physical symptoms, and help relieve children and young people of the emotional and psychological burdens associated with life-threatening and life-limiting illnesses (Mitchell et al., 2021; Knapp & Thompson, 2011). The commonly cited definition of paediatric palliative care which is mentioned by the World Health Organisation (WHO) is as follows:

> *"Palliative care for children is the active total care of the child's body, mind and spirit. Also, it involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes." (World Health Organization, 2021, page x.)*

From the WHO's definition above, PPC is a holistic model of care aimed at providing respite care, social support, and meeting the spiritual needs of the child and the family before and after death, and throughout bereavement (Wiener, et al., 2013; Sourkes et al., 2005; Himelstein et al., 2004). Moreover, paediatric palliative care aims to improve the child's quality of life by relieving pain and suffering and providing support to the family, both before and after death (Himelstein et al., 2004). In order to meet the needs of families with children diagnosed with life-limiting or life-threatening conditions, it is suggested that PPC should be readily available to them in all settings, including homes, hospitals, and schools (Klick & Hauer, 2010; Chong & Abdullah, 2017).

Moreover, the WHO definition mentioned above suggests that paediatric palliative care better to be introduced at an early stage of the illness in order to improve the children's quality of life, maintain their dignity, and ease their pain and suffering in ways that are culturally appropriate for the child's upbringing and community (Himelstein et al., 2004). By initiating PPC early in the illness trajectory, families will have an opportunity to plan for both their ill child's care and their healthy siblings' needs (Sourkes et al., 2005). Additionally, in situations where it is impossible to cure a child, the early integration of PPC can help to facilitate discussions about the child's impending death (Jalmsell et al., 2013). Also, by involving the multidisciplinary PPC team from the beginning, including chaplains and child-life therapists, families are better supported in dealing with uncertainty and grief (Jones et al., 2011).

Rather than focusing on the imminent death of a child, palliative care aims to improve the quality of life and comfort of patients and their families (Hill & Coyne, 2012). As it is not limited to people whose death is anticipated, paediatric palliative care can be provided at the same time as curative or life-prolonging treatments (Behrman & Field, 2003). Paediatric palliative care is multidisciplinary, involving a team of healthcare providers, including nurses, social workers, and other health professionals, working together with children and their families, to provide palliative care at different stages of illness, not necessarily at the end of life, focusing on continuity of care, regardless of a child's illness (Hill & Coyne, 2012; Pentaris et al., 2018). As a comprehensive approach to care, palliative care aims to alleviate and prevent physical and emotional suffering associated with life-threatening conditions or their treatments (Behrman & Field, 2003) by identifying and treating pain, psychological, and spiritual difficulties as early as possible (Mehta et al., 2009). In this sense, it involves addressing the patient's physical, psychological, social, and spiritual needs (Scott et al., 2022) while administering medical treatments (De Clercq et al., 2019).

As mentioned previously, paediatric palliative care is an active and comprehensive approach to improving not only the quality of life for children with life-limiting conditions, but also that of their families as well. However, the cultures and religions of some families may influence the way they view palliative care and end-of-life care. Therefore, Suleman (2023) suggests that improving the quality of care can be achieved by gaining a deeper understanding of the beliefs, values, and preferences of patients and their families, which will result in an improved relationship between them and their healthcare providers. In addition to improving relationships, understanding the impact different factors have on patients and their families will reduce misunderstandings, tensions, and anxieties during decision-making processes (Suleman, 2023).

Prevalence of children with life-limiting conditions:

The number of children, between the ages of 0 and 19, worldwide with life-threatening or life-limiting conditions was estimated at approximately 21 million (Coombes et al., 2022). A report by Fraser et al. (2020) indicates that the number of children, ages 0 to 19, with life-limiting conditions in England has increased over the past 17 years. In England, the number of children with LLC has increased from 32,975 in 2001/02 to 81,712 in 2017/18 (Fraser et al., 2020). During the period leading up to 2010, the number almost doubled, and the increase continued after 2010, but at a rate of approximately 1.4 times (Fraser et al., 2020). During the past decade (up to 2009/10), there has been an increase in the number of children and young people with LLCs in England, with an estimated increase of 29%, which equates to 40,000 children and young people (Fraser et al., 2020). Scotland, Wales, and Northern Ireland are estimated to have a lower prevalence of children with life-limiting conditions by 2030 than England. As indicated in the report:

> "The estimated future prevalence in 2030 for Scotland (51.0-55.8 per 10,000), Wales (50.8-55.6 per 10,000) and Northern Ireland (52.6-56.5 per 10,000); are lower which may reflect different demographics of the population." (Fraser et al., 2020, p.10.)

Additionally, the report indicates that LLC prevalence is higher in children of Black, Asian, and minority ethnic backgrounds, especially children of Pakistani descent, as compared with children of White descent (Fraser et al., 2020). As the report indicated:

> "Prevalence of LLCs was highest among children of Pakistani origin (103.9 per 10,000) and lowest among children of Chinese origin (32.0 per 10,000) in 2017/18." (Fraser et al., 2020, p.10.)

Among ethnic minorities, conditions like genetic and congenital disorders are more common (Fraser et al., 2020). Moreover, a higher percentage (13%) of children with life-limiting conditions live in areas of high deprivation, while 8% live in areas of less deprivation (Fraser et al., 2020). According to the same report, approximately 2000 of these children with life-limiting conditions will die each year (Fraser et al., 2020). Children and their families will therefore require a different range of services, including professionals, hospitals, communities, and other statutory and voluntary organizations (Fraser et al., 2020). Most of these individuals will require specialist palliative care and hospice care, both facing workforce shortages and financial constraints (Fraser et al., 2020).

The UK has a diverse cultural, ethnic, and linguistic population (Campbell, 2006). From the 2022 report of the Office for National Statistics, data from the 2021 census indicates that 46.2% (27.5 million people) identify as Christians; 6.5% (3.9

million people) identify as Muslims; and 1.7% (1.0 million) identify as Hindus (Roskams, 2022). The number of people identified as Christians has decreased from 59.3% (33.3 million) in 2011, while the number of people identified as Muslims has increased from 4.9% (2.7 million). Specifically, in 2021, the number of Muslims in the United Kingdom (UK) increased from 2.7 million to 3.9 million, representing an increase from 4.9% to 6.5% (Wood & Ransley, 2023). Leong et al. (2016) reported that there are 1.7 billion Muslims in the world, representing 23% of the global population. By 2050, Islam is expected to grow faster than any other religion worldwide (Leong et al., 2016). As demonstrated, the number of children and young people with life-limiting conditions in the UK has been increasing. This increase will place many children at risk of death. Several factors, however, contribute to this prevalence, including ethnicity, geographical region, and socioeconomic deprivation. It is essential that these children and their families have access to a wide range of health care services, including hospitals, hospices, and community amenities, as well as paediatric palliative care specialists, to obtain appropriate and effective care.

Belintxon et al. (2020) argue that this highly diverse and multicultural society is caused by immigration as well as forced migrants, such as refugees and asylum seekers (Clancy et al., 2020). People living in a multicultural society are expected to have a variety of life experiences, beliefs, values, religions, cultures, languages, and healthcare expectations (Wiener et al., 2012). This diversity is reflected in the healthcare system as individuals of diverse ethnicities, faiths, and cultures require services from the National Health Service (NHS) (Suleman, 2023). Thus, several aspects of the healthcare system and delivery could be significantly affected by such diversity (Belintxon et al., 2020). Campbell (2006) noted that health care professionals may face considerable challenges in providing comprehensive physical, psychological, and spiritual care to their patients. Communication and interactions between health care providers and families in paediatric palliative care can be influenced by language barriers, resulting in conflicts, and preventing children and families from receiving palliative care (Pergert et al., 2016). Among the other challenges encountered by healthcare professionals are language barriers, poor health literacy, potential biases, and stereotyping assumptions (Belintxon et al., 2020). Aside from these factors, there may be other challenges within the healthcare institution, such as organizational policies and time constraints (Belintxon et al., 2020). Therefore, for healthcare professionals to be compassionate and provide better support to families of diverse ethnicities, cultural backgrounds, and socioeconomic statuses, they must possess the necessary knowledge and skills to enable patients and their families to cope with such situations (Belintxon et al., 2020; Ng & Fung, 2023). Shoaib et al. (2023) emphasize the need for clinicians to have a deep understanding of cultural and religious sensitivity.

Significance of the study:

As shown, paediatric palliative care is a complex and sensitive area of healthcare. In this area, there is an emphasis on understanding cultural, religious, and familial dynamics. Within this context, providing palliative care to Muslim children may present unique challenges for families and healthcare providers due to the differences in beliefs and traditional practices based on the family's Islamic faith and cultural background. With the growth of Islam worldwide and in the United Kingdom, healthcare professionals are increasingly required to understand and navigate the religious and cultural nuances that may influence the care experiences of Muslim children who may be facing life-threatening and life-limiting illnesses. Even though cultural competence in healthcare is becoming increasingly recognized, however, there is a lack of research specifically examining how healthcare providers perceive barriers encountered when caring for children in palliative care or nearing the end of their lives from Muslim families. The understanding of these barriers is imperative, as it will allow for providing optimal support for children facing life-threatening conditions while providing culturally sensitive care and developing effective care strategies that take into account the values and preferences of Muslim families. To provide parents with realistic and relevant options that are culturally appropriate, and in their child’s best interest, it is imperative to understand the Islamic perspective concerning the primary issues related to the care of terminally ill children. A thorough understanding of the Islamic faith and culture of the child and family is vital to providing them with holistic care that is sensitive to their needs. This study intends to explore the perspectives of healthcare providers caring for children from Muslim families in an attempt to gain a deeper understanding of the challenges and cultural barriers they face. By gaining a greater understanding of these challenges, it is possible to come up with ways to assist Muslim families facing end-of-life decisions in a more effective manner.

This study examines the experiences of healthcare providers in paediatric palliative care in England and Wales when caring for Muslim children and their families. From the perspective of healthcare providers, this study examines factors that influence decision-making at the end of life in an Islamic context. It aims to look at the following research question and research objectives.

Research Question:

How can the Islamic culture and religious teachings impact paediatric palliative care and end-of-life (EOL) decision-making for clinicians, and parents of children with life threatening illness?

Objectives of the study:

- To examine the extent to which faith and culture influence the decision-making process of Muslim parents whose children are diagnosed with life-threatening illnesses.
- To examine whether faith or culture can serve as coping mechanisms for parents and shape their views of their children's conditions.
- To explore the challenges that pre-qualified students and health care providers face in understanding the culture and traditions of their patients in regard to paediatric palliative care and end-of-life care in relation to their Islamic faith and culture.
- To identify and analyse the institutional factors that facilitate or hinder the inclusion of the Islamic faith and culture in paediatric palliative care and end-of-life care.

The thesis consists of six chapters. In Chapter 1, the research background, aims, and objectives are described. Chapter 2 reviews the relevant literature on paediatric palliative care, cultural sensitivity in paediatric palliative care, Islamic views of children's end-of-life care and rituals, and paediatric palliative care policies and principles. Chapter 3 details the research methodology, including data collection and analysis techniques. Chapter 4 presents the key findings of an interview with a Muslim mother. Chapter 5 is divided into two parts (A and B); the first part examines key findings from semi-structured interviews with healthcare professionals and prequalified social work students. Chapter 5b presents findings from a narrative interview conducted with a Muslim parent of a child at end-of-life, suffering from Batten disease. Chapter 6 provides a discussion, implications, conclusions, and future research directions.

Chapter 2: Literature review

Introduction

The following literature review is conducted to give my research a broader context by exploring what has been written about palliative care and end-of-life care for children that are relevant to the study. As a starting point, the literature review explains what paediatric palliative care is, how it operates, and when it is deemed appropriate to incorporate it into patient care. Following this, the chapter will examine the specific challenges and barriers faced by healthcare providers, including communication barriers, cultural misunderstandings, and ethical dilemmas. The review looks at the impact of these barriers on the quality of care provided to Muslim children and their families, as well as possible strategies to overcome them. The Islamic culture and religion are also discussed in relation to illness in general, and children's illness and death specifically, emphasizing the importance of spirituality, family involvement, and rituals when providing care for Muslim children. The last part of the review will consider policies that relate to paediatric palliative care's principles and good practices, as well as how those relate to the cultural and spiritual dimensions of paediatric palliative care in England and Wales.

This study is exploring the impact of the Islamic faith and culture in parents' ability to make decisions about their child with a life-threatening condition. Specifically, it is trying to answer the research question: How can the Islamic culture and religious teachings impact paediatric palliative care (PPC) and end-of-life (EOL) decision-making for clinicians, and parents of children with life threatening illness? The following literature review is conducted to give my research a broader context by exploring what has been written about palliative care and end-of-life care for children in the context of religion and culture generally, and Islamic faith, culture, and end-of-life rituals pertaining to children that are relevant to the study.

Search strategies and sources:

This literature review incorporates a variety of scholarly sources, including peer-reviewed journal articles, books, government reports, and grey literature. The sources were identified by systematic searches of academic databases that included PubMed, MEDLINE, PsycINFO, ASSIA, and Google Scholar. Through Swansea University's library guide, academic databases were accessed. To identify additional sources, the reference lists of relevant articles, reports, and dissertations were scanned. The literature

I looked at mostly consisted of literature reviews, systematic reviews, mixed methods review, and meta-analysis reviews.

Search tools:

Various search tools were used in the search strategy which included the use of: phrase searching, truncation, AND, and OR.

Key terms used in the search:

In this review, the key terms used were:

> "Paediatric Palliative care"; "palliative care"; "dimensions of palliative and paediatric palliative care"; "end-of-life care"; "culture"; "cultural competency"; "cultural sensitivity"; "spirituality"; "spirituality in end-of-life and paediatric palliative care"; "end-of-life decision making"; "religion in end-of-life decision making"; "Islam"; "Islamic views on children's death"; "Islam and end-of-life care"; "barriers in palliative and paediatric palliative care"; "advance care planning"; "perspective of healthcare professionals on paediatric palliative care"; "paediatric palliative care policies'; "communication"; "Muslim children", and "Muslim families" .

2.1: Paediatric palliative care and End-of-life care Definitions and Concepts

Paediatric Palliative Care

The concept of palliative care is not to withdraw active treatment, but rather to assess whether interventions will benefit patients and their families and then proceed with the intervention if the advantages outweigh the burden (Hutchinson et al., 2003). In a qualitative study conducted in Singapore, Chong, Molina, Teo, and Tan (2018) examined the differences in quality of life and outcome between children receiving paediatric palliative care. According to the study results, receiving home-based paediatric palliative care decreased hospital admissions and hospital stays compared to children who did not receive paediatric palliative care (Chong et al., 2018). Additionally, the study has shown that receiving paediatric palliative care can improve children's quality of life by improving aspects of pain and emotion (Chong et al., 2018).

Likewise, Salmani et al. (2018), indicated that infants receiving palliative care are more likely to have shorter stays in the Newborn Intensive Care Unit (NICU) and are less likely to go through painful procedures like using mechanical ventilation with treatments and resuscitation. Parents may also experience positive results such as better adapting to suffering, greater satisfaction with care and quality of life, and more accepting of the do-not-resuscitate (DNR) orders (Salmani et al., 2018). With that being said, clearly the entire family is the centre of care in paediatric palliative care, not only the patient. Therefore, care provision depends on each family, their needs and what they consider important. In other words, families are different in terms of their needs, characteristics, and emotions, making each family's reaction to a child's illness different according to the family's structure, and linked to the child's diagnosis and disease progression (Gurková et al., 2015). The benefits of paediatric palliative care extend beyond the children and their families to the health care system as well. According to Salman et al. (2018), the financial burden on health care systems is reduced, particularly the expenses incurred by curative treatments that may cause suffering in children. In the following part of the literature, end-of-life care will be introduced and discussed further, looking at its definition, how it differs from paediatric palliative care, and the planning families need to do to support them throughout the end-of-life phase of their child's health condition, along with other essential concepts of end-of-life care.

End-of-Life Care

End of life is when a patient is at later stages of an illness, where treatments are no longer effective, and the patient has a short life expectancy of 6 months or less (Hafez et al., 2021). Like PPC, part of end-of-life care is to attend to the psychological, social, and spiritual needs of individuals, which would allow them to cope with end-of-life matters related to ageing, and to deal with death and dying, as well as supporting family and friends through bereavement (Fang et al., 2016). The physical, psychological, and spiritual dimensions of children's palliative care can sometimes be affected by culture; therefore, Rosenberg et al. (2019) assert that culturally sensitive care is essential in end-of-life (Rosenberg et al., 2019).Through palliative and end-of-life care, patients and families are supported (Behrman & Field, 2003), and information about changes in the diagnosis, prognosis are expected to be communicated in a culturally sensitive way, including disclosing the benefits and risks of available treatment options (Behrman & Field, 2003; Grinyer & Barbarachild, 2011).

In the case where a child is approaching end-of-life, and curative treatments are no longer options, palliative care is provided, and end-of-life care is incorporated with it, after the patient and family agree to stop curative treatment options and perceive death as a natural and inevitable process (Trotzuk & Gray, 2012). At this stage, in addition to improving the quality of life, PPC includes effective pain and symptom management, communication, decision-making, and end-of-life care (Klick & Hauer, 2010; Hain, Heckford, & McCulloch, 2011). Yet, end-of-life care is not quite the same as palliative care but integrated with it when patients are unable to manage their illness, and death is anticipated (Behrman & Field, 2003). End-of-life care becomes the focus of palliative care and a significant part of children's life and their families due to the support it provides in helping them cope through such a difficult time (Bergsträsser et al., 2017). Lin et al. (2021) conducted a review exploring the impact of paediatric palliative care on end-of-life care and place of death for children and young people. Findings of the review indicated that children and young people receiving palliative care at end of life are less likely to need high-intensity end-of-life care, implying that they have a better quality of life than those not receiving palliative care, in addition to reduced admissions to intensive care units, and having lower chances of dying at a hospital's intensive care unit (Lin et al., 2021).

End-of-life is a challenging time for parents, and some reported that regardless of being aware and informed of their child's deteriorating health status, they feel unprepared for their child's transition from curative treatments to end-of-life care (Hinds et al., 2005). Widger and Wilkins (2004) have denoted that helping parents prepare for the child's death and for care at the time of death can ensure that parents have no regrets and have some positive memories among their unhappy ones. As well, assisting the family, when possible, to have the death occur in the location they wish (home, hospital, regular ward, intensive care unit) can improve the quality of care (Widger & Wilkins, 2004). Thus, having a plan for the end of life when a child has a life-limiting condition could provide a sense of support for the family (Beringer & Heckford, 2014). That being the case, it is suggested in the same study to have a plan laying out options for families and to help them indicate their preferences when it comes to the care delivery, which will assist them in caring and supporting their child (Beringer & Heckford, 2014).

One thing that can be done to support families caring for a child at end of life is doing an Advance Care Plan (ACP), which can be used by healthcare providers as a guide when caring for children at end of life (Jack et al., 2018). Along with discussing treatments and cure options in the ACP, it is suggested to incorporate parallel planning, which is planning for possibilities where health deteriorates, or death occurs (Jack et al., 2018). It is said that ACP is used to assist in improving patient-centred care at the end-of-life because it enables patients to specify their choices, preferences, and their values (Lotz et al., 2017). In a qualitative study by Mitchell and Dale (2015) senior medical staff and nurses determined that one of the benefits of advance care planning is allowing families to express their concerns and wishes for end-of-life care before the child's condition and health worsens. According to Horridge (2015), advance care planning is one of the best practices that give families of children with complex health needs a recorded plan of details of the child's diagnosis, active health concerns, and possible emergencies and complications. Conversely, deaths that occurred without having a previously created ACP resulted in distress for the patient, family, and healthcare providers involved (Mitchell & Dale, 2015).

In essence, when death is anticipated, a great deal of attention is shifted towards end-of-life care where parents are faced by discussions about managing the end stages of their child’s condition and having to make end-of-life decisions that can be included in the ACP, like allowing natural death, the use of life-support technologies, do not resuscitate (DNR), terminal care, and withdrawal of support (Foster et al., 2010; Behrman & Field, 2003). Such conversations include adjusting procedures like removing breathing tubes or modifying symptom management according to physiological changes happening as death approaches (Behrman & Field, 2003). Furthermore, discussions reflecting needs and interest of the patient that involves planning and arranging family activities, like trips, for example, could happen during the provision of end-of-life care where death is expected (Behrman & Field, 2003).

Above all, end-of-life is an emotionally difficult time, not only for the ill child, but also for his or her parents, siblings, family, and healthcare providers who may be dealing with guilt of not being able to meet the expectations of providing a cure (Bates & Kearney, 2015). Therefore, at this point of the illness journey, dying patients and their families have the right to emotional, physical, and spiritual care and support (Hafez et al., 2021). At this critical point, when a child is approaching death, cultural traditions and religious beliefs can impact the conflicts of emotions experienced by parents (Nagel & Clark, 2015). For some, cultural or religious rituals give meaning to life and death and enhance their understanding of the passage from life to death (Koenig & Davies, 2003). Therefore, in subsequent sections of the literature review, culture and religion and their impact on attitude and decisions, especially for Muslim families caring for a terminally ill child would be explored in more detail. A family-centred approach will be discussed in more detail in the next section, emphasizing the importance of the family and the important role it plays when a child is diagnosed with a life-threatening condition.

Family-centred care:

In paediatric care, the family unit is essential as it governs most of the interactions, such as care preferences and the process of clinical decision-making (Rosenberg et al., 2019). Hence, care provided for children in paediatric healthcare is family-centred, implying that delivering care should revolve around the family, respecting and catering to each family individually, rather than looking at the medical staff and health care system as the main focal point of care delivery (Curtis et al., 2016; Fridh & Åkerman, 2020). Mehta et al. (2009) noted that palliative care emphasizes the importance of family involvement in the care process. In this context, family-centred care is one of the principles of paediatric palliative care, along with maintaining symptom management and improving quality of life (Hill and Coyne, 2012). A family-centred approach should be employed throughout the entire process, from the planning stage, to carrying out the care, to evaluating the outcomes (Smith & Coleman, 2010). As patients and their families are going through such a difficult time, palliative care is designed to provide timely and accurate information to assist them in making decisions, as well as assist them in establishing a suitable normality in their lives (Behrman & Field, 2003), thereby allowing them to cope with the situation and address their concerns about the condition of their child (Hill & Coyne, 2012). As a result, they will be able to focus on other aspects of their lives and live to the fullest extent possible (Hill & Coyne, 2012). In the literature review chapter, the principle of family-centred care will be revisited, and discussed from a perspective of paediatric palliative care policies and guiding principle.

Findings from an Australian study conducted by Kristjanson et al. (2006) to determine the need for support and palliative care services for adults with different neurodegenerative disorders indicated that those with tailored palliative care are the most satisfied with the services provided. As for children with life-threatening conditions and their families, it is evident that they are in situations requiring special and specific demands to cater for their unique needs and deliver adequate multidisciplinary care to alleviate their suffering and improve quality of life (Monterosso et al., 2007). The role of the family is a common element that is highly recognised in adults' and children's palliative care; yet family involvement is emphasised more in children's palliative care since the entire family try to adjust to a new reality and that parents are mostly engaged in all aspects of their child's care, including being the proxy decision-makers, representing their child's wishes, embracing the child's care package, and maintaining the well-being of the entire family (Classen, 2012; Price et al., 2005). Interestingly, paediatric clinicians and researchers in a study by Rosenberg et al. (2019), have associated the family unit with culture. Since parents are the proxy decision makers for their children and adolescents with incurable illnesses, deciding on behalf of their children is described by some parents to be one of the most difficult tasks (Foster, Lafond, Reggio, & Hinds, 2010). Hence, in paediatric care, healthcare professionals are required to involve parents and guardians in the care of their children, which includes care procedures and processes of decision making (McConnell et al., 2016). The concept of decision-making and its impact on families will be viewed further in subsequent sections.

Within the context of the family, parental role and responsibility are sometimes shaped by the experience of caring for a terminally ill child at the end-of-life (Bluebond-Langner et al., 2007). As Curtis et al write, parents find their role instantly changes as they become reliant on the medical team to save their child (Curtis et al., 2016). The responsibility to protect and care for a child with a life-threatening illness expands to include the acquisition and use of illness-specific knowledge and skills (Kelly & Kelly, 2013). Additional medical care responsibilities fall upon parents which extends beyond the hospital and include home and school life (Kelly & Kelly, 2013), causing them to be exposed to stressors that include witnessing their child going through pain, fear, and sometimes seeing alarming physical changes happening to their child (Curtis et al., 2016). Other role change stressors are the continuous pressure felt by parents to make critical decisions along with being in hospital environments constantly exposed to machine alarms, interacting with specialty clinicians, and seeing other children with further deteriorating health conditions (Curtis et al., 2016). Evidence from an ethnographic study of childhood cancer experience of British Bangladeshi children and parents showed that parents perceived their role as unsteady, with persistent fear of being perceived as a failure, which prevented them from expressing the difficulties they may encounter (Kelly & Kelly, 2013).

Given what has been said within changes of the parental role and responsibilities, daily tasks become highly demanding and more stressful for parents, specifically when their child's health deteriorates further and reaches a stage of the illness where hope for cure and prolonged survival is decreased (Muckaden et al., 2011), and the care becomes focused on end-of-life (Bergsträsser et al., 2017). As families manage treatment routines (Bluebond-Langner et al.,2007); they may feel the need to prioritize tasks and reorganize roles (Leavitt et al., 1999). Essential changes to daily living can take place, and the sense of safety can be replaced by feelings of isolation, fear, and uncertainty (Foster, Lafond, Reggio, & Hinds, 2010). As Pergert et al. (2016) explore, other parents have indicated that they have experienced loss of control and security; but they consistently try to cope with complex life situations and lengthy periods of psychosocial distress and uncertainty (Pergert et al., 2016). Prior research by Eskola et al. (2017) in Switzerland presented the experience of parents providing end-of-life care for their terminally ill children at home. Parents in the study have demonstrated that caring for a child at home is nonstop, with household errands making it even more challenging, causing parents to be exhausted and at times resulting in physical and mental health issues (Eskola et al., 2017). These health issues can have a long-term impact on parents that can last even for years after they lose their child (Eskola et al., 2017). Hence, parents try to find balance in their life while facing the reality of their child's imminent death. Attaining a balance as indicated by the authors is essential because it allows families to find stability and adjust to a new normal, balancing regular daily activities and adapting to new changes and challenges (Eskola et al., 2017). Also, social support from family, friends, and neighbours is vital because of the positive impact it has on parents (Eskola et al., 2017).

As expressed, due to the importance of the family, it has been frequently highlighted in various literature. One of the reasons is that a child's illness impacts the dynamic of the entire family and can possibly alter roles and responsibilities within each family. The stress parents experience can put a toll on their role, and what is considered normal changes to adapt to their new circumstances. Therefore, finding external sources of support such as from families and friends can have a great positive impact and could help families to better cope with dealing with treatments and hospital visits. It is evident from this review that regardless of the situation of the family, care provided should be family-centred, where parents are involved in the process of decision-making, and most importantly, care is individualised and provided with empathy (Salmani et al., 2018).

Decision-Making:

When a child is diagnosed with a terminal illness, parents find themselves in a distressing position where they must decide on serious and risky matters that include integrating palliative care, treatment options, and sometimes deciding whether to try experimental medical interventions (Kearney & Byrne, 2011). It has been clearly illustrated throughout the literature that the process of decision-making is one of the most important aspects of care in paediatric palliative and end-of-life care, as it goes beyond the type of medications and assessing benefits and risks (Carroll et al., 2012). Actions requiring decision-making usually emerge from complex and evolving medical circumstances consisting of overwhelming information leading to considerable uncertainty (Kearney & Byrne, 2011).

Specific decisions they must make can involve nutrition and hydration and issuing a do-not-resuscitate (DNR) or do-not-intubate orders (Carroll et al., 2012). Whereas at end-of-life, the focus of decisions become more on treatment options aiming to relieve the child's suffering or improve quality of life rather than finding a cure (Larcher et al., 2015; Sullivan et al., 2015); decisions range from withholding or withdrawing life-sustaining interventions, to deciding on a place of care or death, if it is at home, hospital, or hospice (Medeiros et al., 2020; Carroll et al., 2012). Overall, at end-of-life individuals caring for children with life-threatening conditions sometimes are confronted with making massive choices like withholding treatment that are possibly not initiated, withdrawing treatments that have already started, or putting some limits on the treatments (Larcher et al., 2015).

As evident in the literature reviewed, in addition to being the protectors, parents also see themselves as advocates for their children. Advocating can take the form of treatment choices, while protecting is in assessing the risks of the options (Bluebond-Langner et al., 2017). Depending on the child's condition, therapies intended to prolong life may cause more pain and distress rather than restoring health (Larcher et al., 2015). In conditions like cancer, there is a possibility of treatments to fail, even if they are available (Medeiros et al., 2020). Whereas in other circumstances, like Batten disease, parents are forced to make decisions when there are no curative options available, and the child is expected to die before reaching adulthood (Medeiros et al., 2020). Therefore, families might be confronted with a dilemma as to whether or not to choose life-sustaining treatments for their children (Larcher et al., 2015). Thus, parents must do a thorough assessment to evaluate the advantages and disadvantages of further treatment options (Kars et al., 2011). In making such judgments, parents of children with life-threatening conditions encounter decision-making challenges (Medeiros et al., 2020) and are confronted with the need to weigh their child's quality of life against the slight hope of survival (Nagel & Clark, 2015). In an interpretative qualitative study for Dutch parents in the Netherlands, Kars et al. (2011), have found that some parents have felt torn between two treatment decisions, either do something, or do nothing. Doing nothing for certain parents is perceived as losing hope and allowing their child to die (Kars et al., 2011). On the other hand, doing something is viewed as not giving up, at least to their children (Kars et al., 2011). Regardless of the outcome, if positive or harmful, resulting in the child's suffering, not only parents, but also health care professionals would have to live with the decision made (Bluebond-Langner et al., 2017).

It has been pointed out that parents make decisions elicited on what is deemed best for the child's quality of life. In other words, all the decisions made or sought by parents are strongly based on doing their utmost to be good parents (Foster et al., 2010). As Foster et al. write, according to some parents, being a good parent constitutes having their child's best interest; striving to prevent or minimise suffering; protecting the child; represent the child at times when discussing issues with health care members; and being always with their child regardless of the circumstances (Foster et al., 2010). For parents, feeling as if they acted in their child's best interest may prevent negative emotional effects, such as guilt, resulting from their decision (Sullivan et al., 2015). Thereby, being involved in end-of-life decision making is considered a fundamental parental responsibility linked to doing what is right rather than following their parental desire to prolong a child's life (Sullivan et al., 2015).

Despite the variation in desires and levels of engagement, parents generally prefer to be involved in the process of making decisions about their child's end-of-life (Sullivan et al., 2015). Sullivan et al. carried out a qualitative study of 25 bereaved parents, exploring their perspectives, parental involvement, and overall experiences of making decisions for their child at the end-of-life (2015). The study has resulted in three different types of decision-making roles: self-determined, guided, and acquiescent role (Sullivan et al., 2015). Self-determined parents make decisions based on the information provided by their child's doctors, the information they have researched on their own, from their acquired knowledge, or their experiences with their child (Sullivan et al., 2015). Guided decision-makers are similar to self-determined, but their decisions are guided and shaped by health providers recommendations and opinions (Sullivan et al., 2015). On the other hand, some parents were obliged to have a submissive role where they were unable to be the primary decision-makers due to their child's stage of illness. In other words, parents whose children have reached later stages of the illness, deciding on life-sustaining medical treatments become ineffective, and the child’s death is imminent (Sullivan et al., 2015).

Regardless of the difficulties, medical decisions will always be negotiated by parents because the expertise of a health practitioner in the medical field does not mean parents must accept everything as they have the need to further protect their child (Bluebond-Langner et al., 2007). Occasionally, in multicultural settings, for example, individuals may hold conflicting perceptions because of differences in views and values, making it challenging for parents and care providers to reach an agreement on what action is in the child's best interest (Westra et al., 2009). In the next part of the literature, barriers to paediatric palliative care in a multicultural health setting would be discussed in more detail, mainly barriers posed by diversity, including communication barriers in a diverse society.

2.2: Paediatric palliative care policies and guidelines

This part of the study looks in depth at some of the policies and guidelines impacting palliative care services for children with life-limiting conditions in the UK, and Wales particularly. The chapter will start broadly with a definition of health policy, then go into defining health policy analysis, before defining the difference between policies and guidelines. Then it will examine the role of the government in designing and implementing policies. Followed by a breakdown of important policies, strategies, and guidelines in the care of children and young people with life-limiting conditions.

Health Policy

In some ways, health policy is a plan of action that creates laws, practice guidelines, and guiding principles to aid in easing suffering, improving healthcare, and preventing disease (Cheung et al., 2010). Consequently, health policy provides evidence-based guidelines for clinicians and other health care providers to assist them in making suitable decisions when it comes to patient care; such decisions include preventive care, acute, chronic, and end-of-life care (Engelman et al., 2019). Health policy does not only impact health services, as it affects all parties involved in delivering health care services, such as organisations, institutions, clinical practices, and the overall funding arrangements (Engelman et al., 2019).

In order to combat some of the most pressing health problems of today, such as obesity, it is essential to understand how health policy interacts with health (Buse et al, 2012). There are many factors that affect health status, including but not limited to medical treatments and services offered through the healthcare system. Environmental factors, poverty levels, and educational levels could all play a role. As a result, various policies such as economic policies or taxes on specific products such as cigarettes or alcohol may have an impact on the health behaviours of people (Buse et al., 2012).

Health Policy Analysis:

Health policy analysis is one of the fundamental aspects of health policy (Gilson, Orgill, Shroff, & World Health Organization, 2018). According to Walt et al. (2008), health policy analysis is a multifaceted approach that explains the collaboration between institutions bringing together interests and ideas throughout the policy process. Also, another structural importance of health policy analysis lies in looking at the forces behind making policies; this includes the politics behind policy change, the individuals or groups steering the process of developing and implementing policies (Gilson, Orgill, Shroff, & World Health Organization, 2018). The process of policy analysis involves reviewing aspects of current and previous policies, including their development and results (Collins, 2005).

Health policy analysis plays a crucial role in the construction and changing of existing public policies by breaking them down and examining the best practices, ensuring they complement the latest research evidence and promote health and wellbeing (Engelman et al., 2019). In addition, health policy analysis is beneficial in examining the failures and successes of past policies. Consequently, policies can be modified, and future policies planned and implemented (Walt et al., 2008). Therefore, health policy analysis contributes greatly to improving the health system by providing insight into current practices and taking actions to make ultimate changes.

There are various mechanisms that can be used to analyse policy and determine its characteristics, the way it was developed, and evaluate its outcome (Collins, 2005). In this study, Walt and Gilson's framework will be applied to look in depth at various policies, strategies, and guidelines affecting children and young people with life-limiting conditions receiving palliative care or end-of-life care. Walt and Gilson's framework is a health policy triangle created in 1994 to make it easier to analyse health policies (O'Brien et al., 2020). Instead of putting the emphasis solely on the content without giving the other crucial components much consideration, the framework was created to assist in looking at other aspects of policies, such as context, the process of the policy, and those who contributed to its creation (O'Brien et al., 2020).

Since this study is centred on the impact of Islamic faith and culture on children and young people and their families' ability to make decisions at such a critical time (end of life), the focus on the policies and strategies will be mainly on aspects of care that are relevant to culture and religion as elements of palliative and end of life care and essential to children and their families possibly impacting the process of decision-making about treatment and care options. Mainly, the policies and guidelines related to children with life-limiting conditions to be discussed include: National Service Framework for Children, Young People and Maternity Services in Wales; End of life care for infants, children and young people with life-limiting conditions: planning and management (NICE guideline); All Wales Paediatric Advance Care Plan (PAC-PLAN) Policy for Patients under 18 years of age with life-threatening or life-limiting illness.

The National Service Framework (NSF):

The National Service Framework (NSF) for children in Wales is an important strategy for the development of paediatric services and palliative care for children and young people in Wales. It has provided standards not only for children and young people, but also for mothers. The elements of the health policy triangle will be used to discuss the NSF further, and how it incorporates culture and religion for children with life-limiting conditions (which in the document are included with children with disabilities).

The Welsh Assembly Government created the National Service Framework (NSF) for Children, Young People, and Maternity Services in Wales in 2004 as part of its policy to prioritize children's health and well-being (Essex et al., 2004). According to Lachman and Vickers (2004), Kennedy and Laming were the most influential reports on children's services that guided the development of the NSF. There were several recommendations in the Kennedy Report aimed at improving the National Health Service (NHS), emphasizing patient-centred care (Kennedy, 2001). Those recommendations were based on a comprehensive examination of the quality of services provided at Bristol Royal Infirmary after the death of a number of children following open-heart surgery. Thus, the

NSF was created based on some of the outcomes of the Kennedy report, but in terms of the needs of children and young people and their families in Wales. Among the standards that are on the NSF are access to services, child and family-centred care and quality of services. Also promoting health and well-being; safeguarding; parenting; and transitions to adult services are the other standards that are intended to improve the services of children, and young people and their mothers. There are also several standards included within the NSF in order to ensure that the NHS is providing mothers and children with quality health care (Lachman & Vickers, 2004).

During the period between 1984 and 1995, Bristol Royal Infirmary failed to provide adequate care for children undergoing open-heart surgery, leading to having the highest mortality rate in England for paediatric cardiology (Bridgeman, 2002). It was not so much incompetent surgeons as it was organizational factors, along with problems with teamwork, ineffective management, and a lack of critical evaluation that led to poor quality of care (Bridgeman, 2002). Therefore, the chances of these children surviving would have increased if they had been treated elsewhere than Bristol Royal Infirmary (Dyer, 2001). Hence, the Kennedy report focused on some structural factors at Bristol Royal Infirmary that were believed to be responsible for the deaths of several children following heart operations between 1991 and 1995.

At the time of the Kennedy report's publication, the NHS lacked services that were dedicated specifically to the needs of children (Kennedy, 2001). Consequently, one of the proposed changes included customizing services and addressing the unique physical and emotional needs of children differently than adults (Kennedy, 2001). The relationship between patients and healthcare professionals must also be improved as part of improving the quality of services in the NHS (Kennedy, 2001). As outlined in the Kennedy report, establishing trust between patients and health care providers as well as building trust between the NHS and the public requires openness and honesty (Kennedy, 2001). Another aspect of children's care that was criticized in the Kennedy report was access to services, which the NSF took into account when designing services and developing standards of care. As patient-centred care was a major focus of the Kennedy report, it emphasised that patients' perspectives must be taken into account when making changes, whether in the formulation of policies, the development of services, or the delivery of services (Kennedy, 2001). Providing information that is age-appropriate and culturally sensitive was stressed in the NSF as a means of involving children in decision-making and allowing them to make informed choices about their care (Essex, 2004). Since the

Welsh Assembly Government puts a high priority on providing services for children and young people, it encourages their involvement at all levels of decision-making (Essex et al., 2004).

With the NSF, the Welsh Assembly Government strives to improve the quality of services provided to children, young people, and mothers. At the time of writing the NSF document, the Welsh Assembly Government recognized the value of collaborative work and made it one of its priorities to assist in improving the quality of services for children and young people. Thus, the key actions of the NSF were carried out by different organisations, such as NHS Trusts, Health Boards, or Local Authorities, to ensure services were being delivered effectively, and to meet the needs of children and young people and their families (Essex et al., 2004).

The NSF for Children in Wales was developed in collaboration with seven External Working Groups (EWGs) that included experts and key stakeholders in relevant children's services. Participants in the project included groups concerned with improving health and wellbeing for children and young people, maternity care, mental health, and psychological wellbeing for children and young people (Essex et al., 2004). Additionally, there were groups that worked with children and young people with disabilities, children and young people with special needs, children and young people with acute and chronic illnesses, and a group in medicine (Essex et al., 2004). Further, the Children's NSF was a joint policy initiative in which NHS was also involved and supported the Welsh Assembly Government's vision and aim of improving the health and well-being of children and young people in Wales in accordance with UNHCR (Essex et al., 2004). The role of the NHS was in commissioning services at two different levels: one, at the local level, through Local Health Boards (LHBs) and the other at the national level, through Health Commission Wales (HCW). Additionally, the perspective of children and young people, as well as their carers or parents, was explored as part of the inclusion of those most affected by the services provided (Essex et al., 2004).

The National Service Framework (NSF) by the Welsh Assembly Government (2004), examined standards of care that are relevant for disabled children and those with acute or chronic illnesses. The NSF gave a comprehensive interpretation of the care standards based on evidence, providing a list of specific measurable key actions, with a clear indication of the organizations responsible for delivering them. Although the NSF does not include standards specific to caring for children at end of life, or those receiving palliative care, it still incorporates these children under disabled children standards. They have defined children with life-limiting conditions as disabled because it is how the Association for Children with life-threatening and Terminal conditions (ACT)/ Royal College of Paediatrics and Child Health (RCPCH) defined children or young people with a life-limiting condition (Essex et al., 2004).

The NSF is one of the few documents that clearly and explicitly presented ethnicity, socioeconomic status, and geographical location as factors possibly restricting the provision of quality care for children and young people. Therefore, the development of the framework reflects the Welsh Government's commitment to prioritizing services for children and young people, by emphasising the need to carry a holistic assessment to capture all these aspects. The assessment should draw attention to available services that are beneficial to children and their families, which will improve their quality of life since the services are customised. In addition to the required services, barriers preventing effective delivery of services, factors inhibiting access to a good quality of life, as well as agencies that are able to tackle these barriers should be included in the assessment. The assessment must be repeated continuously to monitor the changing needs of children and their families.

Given that the NSF was guided by the UN Convention on the Rights of the Child 1989 (UNCRC), just like all the Welsh Assembly Government's work with children (Essex et al., 2004), most of the standards and key actions are relevant to Articles of the UNCRC. For example, one of the areas highlighted in the NSF document that align with the UNCRC, Article 12 is providing information and support, and participation in decision making. At all levels of service delivery children and young people should be involved in making decisions and that their views should be respected.

> "*Children have the right to have a say in any decision that affects their lives. Children (including those with communication needs) must be enabled to participate in decisions about services which affect them." (Essex et al., 2004, Page 82)*

This is related to Article 12 of the UNCRC which states:

> *"(respect for the views of the child) Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right always applies, for example during immigration proceedings, housing decisions or the child's day-to-day home life." (UNICEF, 2012)*

The Essex et al. (2004) acknowledged in the NSF that disabled children, and their families face many physical and social barriers that hinder their participation and involvement in all aspects of society.

> *"Article 23 (children with a disability): A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families."* (UNICEF, 2012)

Quality of life for disabled children is another concern addressed in the NSF. In that regard, it was mentioned that impairments are not the only thing limiting children with disabilities, as there are other factors like negative attitudes, and disabling environment, not catering to their needs (Essex et al., 2004). Other factors impacting the quality of life incorporate unequal access to education, communication barriers, lack of employment opportunities, and housing care. Therefore, children with disabilities can sometimes require a range of services beyond health care, including assistance from social services and voluntary organizations (Essex et al., 2004). These required services include healthcare, education, social services, as well as assistance with accommodations, transportation, and leisure activities (Essex et al., 2004). Therefore, the NSF stressed that cooperation between services is crucial to delivering efficient care for disabled children and their families (Essex et al., 2004). Even though cooperation between services was highlighted, and it was one in which the entire document was established, there was no mention to the involvement of religious groups or the need to involve minority group members to aid in the improvement of services and environment for children with disabilities.

It is evident throughout the NSF document that religion, culture, and language, are considered important aspects when providing care for children and young people. To ensure that, as was mentioned in the NSF, an assessment is needed to address the needs of disabled children, and accordingly, receive services that take into consideration their culture, language, and viewpoints (Essex et al., 2004). It was clearly stated in the NSF document, especially for disabled children that:

> *"Services designed to maximise the development of a disabled child should include Provision of services which respect's each child's views, language and culture" (Essex et al., 2004, page 80).*

While the NSF acknowledges faith, culture, and language as part of caring for children and young people, the group involved in developing the NSF did not include chaplaincy services. Incorporating all religious groups into policy may be challenging for the NHS due to the diversity of religious groups. However, organizations dedicated to caring for children with life-limiting conditions, such as Together for Short Lives, have developed guidelines that consider the major world religions. Also, Public Health England have guidelines specific for spirituality and religion when caring for people at end of life.

All Wales Palliative Care Standards

The *All-Wales Palliative Care Standards for Children and Young People's Specialised Healthcare Services* was developed by the Welsh Assembly Government in 2008 as part of a broader initiative to enhance specialised healthcare services for children and young people in Wales (Hart, 2008). These standards apply to individuals aged 0 to 18 who require specialised services and align with the Welsh Assembly Government's healthcare framework, which encompasses four key areas: 'The Patient Experience,' 'Clinical Outcomes,' 'Healthcare Governance,' and 'Public Health' (Hart, 2008). By setting out structured guidelines, these standards aim to support the NHS and associated organisations in delivering timely, high-quality, and effective care.

The first document, All Wales Universal Standards, outlined key actions for all specialised services for children and young people. As new service-specific criteria emerged and key actions were identified, the document gradually evolved into separate updated documents. The evolved standards do not contradict the Universal Standards and must be used in tandem (Hart, 2008). Like the National Service Framework (2004), the all-Wales standards documents are part of the Welsh Assembly's initiative to improve health services and quality of care for children and young people. Consequently, the specialized standards that were developed in the All-Wales documents (Hart, 2008) are built on the existing ones from the Children's NSF and enhance the initiated improvements in the delivery of services for children and young people (Hart, 2008). It is also recommended that the Children and Young People's Specialised Services Standards be used in conjunction with the Universal and Specific Parts of the National Service Framework for Children, Young People and Maternity Services in Wales (Essex et al., 2004).

Actors and Content of the document:

Palliative care encompasses medical, social, emotional, and spiritual dimensions, which necessitate a tailored approach for children and young people (Hartt, 2008). Unlike adult palliative care, paediatric palliative care must accommodate a broader range of conditions and diverse needs. Recognising this, the Palliative Care External Working Group (EWG)—comprising professionals involved in paediatric palliative care—developed the standards to provide clear guidance for both healthcare professionals and other stakeholders working with these children.

There six standards specific for palliative care for children and young people included 'access to palliative care services'; 'staffing of palliative care services'; 'facilities for palliative care Services' (including equipment); 'care of the child and family'; 'communication'; and 'education and training' (Hart, 2008). Despite their specificity, these standards remain rooted in the broader *Universal Standards*, ensuring a cohesive and comprehensive approach to healthcare for young patients.

Access to Palliative Care Services:

A fundamental component of palliative care, access to services must be seamless, ensuring all children and young people receive high-quality, multidisciplinary care (Hart, 2008). Key actions to improve accessibility include establishing a 24-hour telephone support system not only for children and families but also for healthcare professionals seeking specialist advice (Hart, 2008). This ensures timely interventions and support regardless of the time or location.

Staffing of Palliative Care Services:

Delivering effective paediatric palliative care requires a well-trained multidisciplinary team with adequate resources (Hart, 2008). The standards mandate that such teams establish robust links with relevant support services, including chaplaincy and spiritual care, to provide holistic support to children and families. A child-centred, family-inclusive approach is emphasised, ensuring services are delivered in an accessible and person-centred manner. Rooted in the Universal Standards and the NSF framework, these standards ensure consistency while addressing the unique needs of paediatric palliative care. By prioritising accessibility, multidisciplinary collaboration, and a child-centred approach, the framework supports the delivery of high-quality, specialised care that meets both medical and holistic needs of children and their families.***All Wales Paediatric Advance Care Plan (PAC-PLAN) Policy for Patients under 18 years of age with life-threatening or life-limiting illness***

The Paediatric Advance Care Plan (PAC-Plan) policy is designed to establish ethical and legal guidelines for decision-making at the end of life for children with life-limiting and life-threatening conditions. This policy plays a vital role in ensuring dignity, appropriate medical intervention, and the involvement of key stakeholders. While it provides a strong foundation, there are areas that highlight both its strengths and opportunities for improvement (NHS Wales, 2016).

One of the fundamental principles emphasized in the policy is Advance Care Planning (ACP), a critical component of paediatric palliative and end-of-life care. ACP is consistently recognized in various government-issued reports and documents, such as the National Service Framework (NSF) (Essex et al., 2004) and the Sugar Report. The PAC-Plan highlights ACP as essential for children with life-limiting or life-threatening conditions and recommends early discussions, ensuring a smooth transition from curative to palliative care(NHS Wales, 2016). Additionally, the policy advocates for palliative care to be integrated alongside curative treatments from the time of diagnosis. Moreover, the policy points to the importance of considering language and interpreter needs when developing ACP and reaching decisions (NHS Wales, 2016).

Although the policy underscores the importance of early planning to enable healthcare teams to facilitate end-of-life decisions for families, it acknowledges that each family's readiness for ACP varies, and some may never engage in formal planning (NHS Wales, 2016). Accordingly, ACP discussions may unfold over weeks or months, often requiring multiple meetings to reach a consensus. Throughout this process, effective communication, emotional support, and psychological services are crucial in ensuring families feel supported and informed (NHS Wales, 2016).

Strengths and limitations of the PAC-Plan Policy

A key strength of the PAC-Plan is its ethical and legal framework for caring for children with life-threatening or life-limiting conditions. It prioritizes dignity and respect in decision-making, aligning with the United Nations Convention on the Rights of the Child (UNCRC). By reinforcing these principles, the policy ensures that medical decisions uphold the child's best interests (NHS Wales, 2016). Another major strength is its holistic and individualized approach to end-of-life care. The policy ensures that care is patient-centred, considering not just medical needs but also the emotional, social, and psychological well-being of both the child and their family (NHS Wales, 2016).

Additionally, it emphasizes multi-agency collaboration, encouraging coordination between General Practitioners (GPs), community nurses, social services, police, bereavement services, and other stakeholders to minimize gaps in care (NHS Wales, 2016).

The PAC-Plan also provides clear guidance on advance discussions regarding medical interventions, such as resuscitation and mechanical ventilation. By ensuring that families are well-informed, the policy supports them through the decision-making process (NHS Wales, 2016). Moreover, it recognizes that care decisions should remain dynamic, evolving as the child's condition and prognosis change. Another strength of the policy is its support for healthcare professionals. It includes guidance that provides legal and professional clarity, reducing clinical risk and potential litigation (NHS Wales, 2016). The policy ensures that healthcare teams receive training, support, and legal protection when making difficult end-of-life decisions. Additionally, the policy demonstrates a commitment to quality improvement by implementing monitoring and auditing mechanisms, ensuring that paediatric palliative care services undergo continuous assessment and improvement (NHS Wales, 2016).

Despite the PAC-Plan policy emphasis on early ACP discussions, in practice, these discussions are sometimes delayed as different families experience different reactions. A child's prognosis can also affect the timing of the initiation of an advance care plan (NHS Wales, 2016). While the policy acknowledges the importance of respecting cultural and religious values, it does not specify how to manage conflicts when medical recommendations differ from familial or religious beliefs. Strengthening this aspect would enhance inclusivity and reduce ethical conflicts in care planning.

The policy highlights the need for holistic care and multi-agency involvement; however, chaplaincy and religious organizations are not emphasized as part of these multi-agency efforts (NHS Wales, 2016). Additionally, there are no recommendations on how such involvement should be sustained. While the policy states that healthcare professionals and staff will be made aware of it through training, it does not specify any additional training opportunities for healthcare providers to enhance best practices in key areas, such as cultural sensitivity (NHS Wales, 2016). This omission raises concerns about whether children's and families' cultural and psychosocial needs will be adequately met.

The Sugar Report:

The Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services (2008), commonly known as the Sugar Report, is a significant document addressing both adult and paediatric palliative care in Wales. This report evaluates the services provided for children and young people, identifies gaps in provision, and offers recommendations for improvement. Key findings in the report include, underscoring the necessity of a holistic approach in children's palliative care (Palliative Care Planning Group Wales, 2008). It highlights that palliative care must not only address physical symptoms but also consider the developmental, emotional, and cognitive needs of children. Given the complexity of long-term conditions, the report recommends that care should be child-centred, family-focused, and flexible to meet individual needs effectively. Another thing is that the report identified a significant gap is the insufficient support at community and home levels (Palliative Care Planning Group Wales, 2008). Many families struggle with the demands of palliative care, necessitating enhanced services in these settings. The report stresses the need for increased respite care to provide relief for families caring for children with life-limiting conditions (Palliative Care Planning Group Wales, 2008).

Moreover, the report emphasizes the critical role of a multidisciplinary team (MDT) in delivering effective palliative care. The MDT is responsible for ensuring holistic care, supporting families, and enabling children to receive end-of-life care in their preferred setting where possible (Palliative Care Planning Group Wales, 2008). However, logistical challenges often make fulfilling these preferences difficult. Additionally, the report notes one of the areas in which children's palliative care differs from adult services, which is the need to support healthy siblings. Parents caring for a child with a life-threatening condition may require additional assistance in managing the needs of their other children (Palliative Care Planning Group Wales, 2008). The Sugar Report acknowledges this as an essential aspect of paediatric palliative care. Consequently, to ensure high-quality care, the report advocates for enhanced education and training for healthcare professionals (Palliative Care Planning Group Wales, 2008). This would help practitioners develop a better understanding of paediatric palliative care complexities and deliver more compassionate and effective care (Palliative Care Planning Group Wales, 2008).

Limitations of the Report

While the report acknowledges the importance of spiritual and emotional support in adult palliative care, it does not adequately address the role of spirituality in children's palliative care. Adult palliative care services recognize chaplaincy and spiritual care as core components, yet there is a notable lack of funding and resources for such support in children's services. This omission highlights a gap in providing truly holistic care for young patients and their families. Furthermore, as medical advancements have led to children with life-limiting conditions living longer, there is a growing need for appropriate transitional care into adult services. The Sugar Report identifies that many adolescents face difficulties in transitioning, as adult palliative care services are often unsuitable for their needs. This gap underscores the necessity for a more structured transition pathway to ensure continuity and quality of care.

The Sugar Report (Palliative Care Planning Group Wales, 2008) provides a comprehensive assessment of children's palliative care in Wales, highlighting key recommendations to improve service provision. Its emphasis on holistic, child-centred care, multidisciplinary teamwork, and enhanced community support is commendable. However, its failure to address spiritual care for children and transitional care challenges represents areas requiring further attention. Moving forward, addressing these gaps would ensure a more inclusive and effective palliative care framework for children and young people in Wales.

NICE Guidelines:

The National Institute for Health and Care Excellence (NICE) (2016) guidelines provide comprehensive recommendations on the planning and management of end-of-life and palliative care for infants, children, and young people up to the age of 17. These guidelines specifically focus on children and young people with life-limiting conditions, excluding those who die unexpectedly, such as in accidental deaths (NICE, 2016). The intended audience includes healthcare professionals, social workers, chaplains, educators, commissioners, and other providers who play a role in delivering holistic care (NICE, 2016). A central aim is to enhance quality of life by integrating physical, social, emotional, and spiritual support into care planning. As well as encouraging the involvement of children, young people, and their families in decisions about their care and improve the support that is available to them throughout their lives.

The NICE (2016) guidelines emphasize various critical areas of care including communication, care planning and support, symptom management, care at home, service delivery, and care as the child approaches death and after death. In such a difficult time, managing distressful symptoms, deciding on the preferred place for care, and realizing that death may occur in days or even hours become crucial aspects of caring for children and young people (NICE, 2016). These guidelines also provide guidance on practical, emotional, social, psychological, religious, spiritual, and cultural support and interventions. Each of these is an essential element that must be considered throughout the care process.

The major themes within the NICE guidelines (2016) that will be discussed include communication, Advance Care Planning (ACP), service delivery, the importance of spirituality and religion, a child- and family-centred care approach, and comprehensive support for children and their families. These themes are not exclusive to the NICE guidelines, as they are also commonly referenced in relation to children's care and end-of-life care in other policies and documents, such as the NSF.

Effective communication and collaborative decision-making.

As agreed, communication is essential in many aspects of people's lives. When it comes to children's palliative care, communication is noticeably vital throughout the care pathway. Therefore, it is imperative that professionals and care providers be sensitive to the families' circumstances and their need to have open and honest communication, considering their culture and spiritual needs, and providing appropriate information at the right time (Essex et al., 2012). Additionally, providing sensitive and effective communication, while providing emotional support, allows children and families to make informed decisions about the child's care (Essex et al., 2012). However, there are some barriers to effective communication include the person's lack of confidence in starting difficult conversations, possibly due to their fear of worsening situations, or their inability to explore concerns or to answer difficult questions (Essex et al., 2012). To overcome these challenges, comprehensive training is essential. Furthermore, less experienced staff should have opportunities to observe and learn from skilled practitioners to develop effective communication techniques (Essex et al., 2012).

Some of the communication challenges include initiating conversations about death and end-of-life care can be particularly challenging, especially when speaking with children. Misconceptions, such as the belief that children cannot understand their condition or that telling the truth may harm them, often discourage open discussions (Essex et al., 2012). However, research in paediatric oncology highlights the importance of direct and honest communication with children (Essex et al., 2012). Hence, the NICE (2016) end-of-life guide outlines a few practical guidelines for care professionals to consider when engaging and communicating with children in palliative care. For example, treat the child with respect and engage with them by talking to them rather than about them. This can happen by addressing their concerns by listening tentatively and using simple language, recognising the child's body and play language (Essex et al., 2012). Essential aspects to always keep in mind, as continuously revealed, are the child's age and developmental stage, their level of awareness of their condition, and their understanding of death (Essex et al., 2012). In summary, open and honest communication is as crucial for children as it is for adults, but it requires additional sensitivity to their developmental level and family structure. Healthcare professionals must develop specialized communication skills to effectively engage with children and provide them with appropriate support (Essex et al., 2012).

Care planning and support:

Advance Care Planning (ACP) is an essential strategy in paediatric palliative care and in the care of children and young people with life-limiting conditions, ensuring that critical issues such as symptom management, resuscitation, and organ donation are addressed proactively (Essex et al., 2012). Beyond medical treatment, ACP should also include discussions about the child's education, ambitions, and religious, spiritual, and cultural beliefs, and family's preference regarding place of care and death should be incorporated, along with considerations for organ donation (NICE, 2016). Moreover, effective ACP also facilitates coordination between healthcare professionals and caregivers, allowing for the implementation of a parallel planning approach—where end-of-life planning occurs alongside ongoing treatment and care (Together for Short Lives, 2015).

According to Aidoo and Rajapakse (2018), the NICE guidelines for children end-of-life care highlight care planning as a key consideration when supporting children and their families. The considerations are as follows:

1. *"All infants, children and young people with a life-limiting condition should have a named specialist who leads on and coordinates their care. Transition should be in accordance with the NICE guidelines.*
2. *Advance care plans (ACPs) should be developed and regularly reviewed with the child or young person and their family. Discussions should be centred on anticipated clinical scenarios with appropriate management options and*

supporting continuity of care. ACPs can be developed antenatally and reviewed after birth. ACPs should be shared with the multidisciplinary team and the family.

3. *Organ and tissue donation should be discussed with the child or young person and their family and appropriate referrals organised as needed.*
4. *Psychological, social, and practical support (such as additional funding, education about medicine management and equipment) should be available to children and young people and their families.*
5. *Children, young people, and their families should be asked if they wish to discuss their religious, spiritual or cultural beliefs, and these should be considered when making decisions." (Aidoo & Rajapakse, 2018, pages 296 and 297)*

The NICE guidelines (2016) emphasize that ACP should be a detailed, individualized plan that clearly defines the needs and preferences of the child and their family. These NICE guidelines (2016) provide a broad framework for ACP, emphasizing its dynamic nature. ACPs should be regularly updated to reflect changes in the child's condition, evolving family preferences, and any new treatment options. The primary goal of ACP is to ensure that children, young people, and their families are actively involved in care decisions, considering their personal values, beliefs, and cultural perspectives. However, discussing ACP can be challenging. Families may struggle with the emotional difficulty of planning for end-of-life care, and differing opinions between family members and healthcare providers can create additional complexities. Furthermore, as NICE (2016) acknowledges, discussing treatment withdrawal or end-of-life decisions requires sensitivity to the child and family's emotional, religious, and cultural needs. Providing appropriate support during these discussions is essential to ensure that care decisions align with the child and family's wishes.

Service delivery:

The necessity for diverse services to be connected and multidisciplinary teams to provide the best care for children and young people and their families was highlighted in the NICE (2016). Effective communication, care coordination, and networking are all important principles in care. Furthermore, because children and young people have a wide range of needs throughout the course of their illness, they will require different services to meet those needs, and for them to receive the best care possible, services should communicate and collaborate to provide the best tailored care.

Importance of spirituality and religion:

As outlined in the NICE guidelines (2016), spirituality and religion are vital aspects of the care for children and young people with life-limiting conditions and who are near the end of their lives. Therefore, as part of paediatric palliative care, religious and spiritual factors must be taken into consideration in all aspects, such as communication, advance care planning, pain, and symptom management, discussing the place of death, and delivering service, such as chaplain services as part of the team. In other words, throughout care planning, it is imperative to integrate the beliefs and values of families, as well as children and young people with life-limiting illnesses, into all discussions regarding a child or young person's care (NICE, 2016). Having said that, people are likely to differ in their preferences, and while some may believe their values and beliefs are important and need to be acknowledged, others may find it difficult to openly discuss their beliefs and values (NICE, 2016). Also, it is important to recognise that children and young people may hold different views than those of their parents or carers (NICE, 2016). The primary documents mentioned above outline the following foundational principles that underpin paediatric palliative care. These principles emphasize a child- and family-centred approach, effective communication and collaborative decision-making, comprehensive support for both children and their families, and the critical role of advance care planning in ensuring tailored and proactive care.

Child and family centred care approach:

Taking care of children with life-limiting illnesses requires keeping their families in mind. It is therefore essential to respect the needs of families, such as language, as well as their individuality by respecting their values and beliefs. Also, it is important to recognise that families and friends of a dying person may require support to deal with the distress they experience after losing a loved one (Public Health England, 2016).

In the NSF (Essex et al., 2004), family centred care is universal to all children's services. Furthermore cultural, linguistic, religious, and spiritual concerns are identified as key elements of family-centred care. As a universal standard, it applies to all children and families regardless of their circumstances, indicating the importance of incorporating culture and religion into the care of children (Essex et al., 2004). Taking disabled children as an example, which includes those with life-limiting conditions, family centred care is crucial, as are access to services and quality of care (Essex et al., 2004). For families, respecting cultural and linguistic background is crucial since some use it as a coping mechanism. The NSF has therefore stressed that all organizations need training in cultural awareness, family-centred assessment, and how to communicate effectively and sensitively (Essex et al., 2004). To cope with stress, some families rely on cultural and linguistic background for strength (Essex et al., 2004). On the other hand, Public Health England (2016) viewed end-of-life care as a community matter, especially for individuals of diverse backgrounds. Therefore, it was suggested that when it comes to end-of-life care, having a community-centred approach is needed since death and dying are part of life and do not usually happen in isolation, and some people reaching the end of their life rather be surrounded by people in their communities (Public Health England, 2016).

Comprehensive support for children and their families:

As it was mentioned in almost all the strategies, spirituality is one of the care elements when it comes to children with life-limiting conditions, and it is part of the definition of palliative care. However, the concept of spirituality, along with religion, and culture were not

recognised as sociocultural or psychological coping mechanisms for children approaching the end of life. Nonetheless, Essex et al. (2012) recognised that spirituality, faith, religion, and cultural values are central to some people's lives, as they allow them to find meaning and purpose in life, and at times allows them to understand matters of life and death (Essex et al., 2012). Hence, an end-of-life guide created by Together for Short Lives (Essex et al., 2012) shines light on spirituality and its importance for children at end of life and their families, through providing key information about leading world religious and faith groups yet acknowledging that there are other faiths and cultures not mentioned. Guidance for health care professionals entailed looking at the broader picture of spirituality and faith as a social system for many religious groups. Viewing each situation as a unique one that may require different responses, with a degree of creativity and flexibility (Bennett et al., 2012). Keeping in mind that people are different and find comfort in various religious, spiritual, or cultural practices and rituals. Some may emphasize religious commitments that put them at ease; whereas others may not follow a specific faith but have essential religious and cultural values or traditions. Other people find solace by grasping their religious or spiritual practices, as it gives them hope, particularly concerning death (Bennett et al., 2012). Yet, Public Health England (2016) pointed out that access to end-of-life care by Black and Asian minority ethnic (BAME) groups is noticeably lower when compared to the white British population. Also, according to Public Health England (2016) the evident inequality in accessing end-of-life care is possibly due to inadequate communication with BAME groups that is caused by professionals' lack of sensitivity and understandings of different faiths (Public Health England, 2016).

Consequently, public Health England has published a resource for care providers and professionals to guide them in carrying a holistic approach to care for individuals at the end-of-life that considers the individuals' spiritual needs and ensures that the services are delivered appropriately and suitable to community settings (Public Health England, 2016). This resource highlighted that within each faith group, variations may exist which require professionals and care providers to be aware of. In other words, individuals may have practices based on cultural values that differ from other individuals following the same religion (Public Health England, 2016). Thus, it is vital to avoid making assumptions about an individual faith practice (Public Health England, 2016). The recommendations mainly encompass identifying the individuals' religious and spiritual needs that may impact their end-of-life care. Encouraging care providers to ask and listen to the individuals' needs and establish faith sensitive ways to communicate; for example, by establishing appropriate phrases to use such as death and dying. Moreover, throughout the development of the care plan, guidance highlights the need for practitioners to recognise the role of the family in the decision-making process. Additionally, ensure that language barriers are addressed, and families receive information about care and support services in the language of choice.

2.3: Barriers to Paediatric Palliative Care and End-of-life Care

As discussed, caring for a child with a life-threatening condition can be overwhelming. In Muslim families, some factors relating to their faith and culture may make it difficult for them to make decisions regarding their child with a life-threatening condition. There are barriers to paediatric palliative care that pose challenges to children and families preventing them from seeking or receiving care. Barriers to palliative care are divided into two; one is related to healthcare practitioners' viewpoint, and the other is associated with parental perception of paediatric palliative care. Salmani et al. (2018) have identified three categories of barriers to paediatric palliative care: parent-related barriers, barriers associated with health care providers, and barriers within healthcare systems. Particularly, physicians and other care providers encounter challenges in delivering appropriate care because of the patients' perceptions of health care related to their beliefs, values, religions, and language (Wiener et al., 2013).

Other factors that may hinder the effective provision of palliative care may include culture, language, religion and spirituality, and lack of communication. Faith for instance, and its teachings may impact a family's decision about their child’s illness and their new circumstances; and sometimes can allow them to better cope (Arutyunyan et al., 2016). In the context of this research study, barriers evident in this part of the literature are mainly the ones experienced by families and healthcare providers that are hindering adequate care delivery in a culturally diverse health care setting like language (in terms of communication generally, and with children), cultural differences, and religious beliefs and values (particularly within the Islamic faith).

Barriers to palliative care and end-of-life care created by diversity:

The concept of diversity has evolved and is significantly impacted by migration and globalisation (Williamson & Harrison, 2010). With increased migration worldwide, some changes occur and are reflected in the countries’ public sectors, including healthcare, where it is becoming more culturally and ethnically diverse (Renzaho et al., 2013). Moreover, this increase in cultural diversity puts migrants and marginalised groups, including racial and ethnic minorities, immigrants, and communities of low socioeconomic status, at a higher risk of encountering inadequate access to health and social care when compared to White people (Fisher-Borne et al., 2015). Despite improvements in health care quality for underprivileged groups, some marginalized groups do not receive adequate end-of-life care, according to Krakauer et al. (2002). In Europe, for example, Soerensen et al. (2016) discussed how ethnic minority groups receive a lower quality of care because of cultural barriers, language barriers, and bias of health care providers. Similarly, Clancy et al. (2020) mentioned that inadequate access to health and social care are some of the issues faced by migrant families that are likely caused by communication barriers, financial insufficiency, lack or limited knowledge and understanding of the healthcare system and their rights to care, among other obstacles.

In children’s healthcare for example, culture can have a major impact and can pose as a barrier to accessing paediatric care, doctor-patient communication, continuity of care, and preventive screening (Flores et al., 2000). According to Kirby et al. (2018), going through palliative care, in general, is especially challenging for patients and families from culturally and linguistically diverse backgrounds, as they may require extra support because of additional complications they may experience due to language barriers, cultural values, and possibly feeling isolated from the wider community. Abunafeesa and Elsayem (2017) conducted a study on multilingual adult patients from various ethnicities, confirming that the beliefs, culture, and religion of families are factors posing as barriers to end-of-life care. Particularly, patients may experience communication gaps with physicians, challenges related to the healthcare system, or doctor behaviours (Abunafeesa & Elsayem, 2017). In a scoping review by Fang, Sixsmith, Sinclair, & Horst (2016), it was indicated that minority groups have a harder time communicating their concerns and preferences pertaining to end-of-life to their health care providers (Fang et al., 2016). Moreover, gender has been identified as an impacting factor on end-of-life care among minority groups, where discrimination at the end of life is perceived differently between men and women (Fang et al., 2016). On the other hand, Verberne et al. (2018) have suggested that healthcare providers face obstacles that are possibly related to the extent of their readiness in terms of knowledge, education, experience, or staff support. More on the barriers experienced by healthcare providers in a multicultural setting will be discussed next.

Barriers faced by healthcare providers:

As mentioned earlier, and as evident in the literature, as diversity increases, health care providers continue to face obstacles when caring for individuals of diverse ethnic backgrounds, hampering the provision of effective palliative care (Kongnetiman et al., 2008). In a scoping review, Fang et al. (2016), have identified some barriers to end-of-life care in a culturally and spiritually diverse setting of care faced by patients and families which are associated with the attitude, knowledge, and understandings of health care providers. Mainly, these are cultural differences between healthcare providers, patients, and families; lack of knowledge and awareness of cultures and spirituality; excluding families from the process of decision making; care providers' perception of racial and religious discrimination; lack of culturally specific end-of-life information that would enable decision-making for culturally and spiritually diverse communities (Fang et al., 2016).

Lack of awareness or respect of cultural traditions and beliefs are other factors that may impact the patient-practitioner relationship in terms of communication and possibly influence the effective delivery of health care (Renzaho et al., 2013). Expanding on what Renzaho et al. (2013) mentioned, Kirby and colleagues have revealed that the doctor-patient-caregiver relationship is one of the areas in palliative care impacted by the diversity of culture and language and susceptible to interpersonal difficulties around palliative care, treatment options, and decisions to cease potentially life-prolonging treatments (Kirby et al.,2018). Popejoy et al. (2017) suggest that families and doctors are faced with significant challenges when a child is diagnosed with a life-threatening or life-limiting illness. In some cases, they may have to deal with dilemmas or differences of opinion regarding the appropriate treatment or intervention (Wright et al., 2009). For instance, conflict may arise when clinicians believe that withdrawing treatment is of the child's best interest, while the parents feel otherwise. Thus, individualised care for each family could be interrupted due to difficulties in overcoming such barriers. In a systematic analysis by Almutairi (2015), various communication challenges experienced by non-Muslim nurses caring for patients in Saudi Arabia were identified. The lack of knowledge of the Saudi Arabian culture hindered effective communication between patients and nurses (Almutairi, 2015). Also, not knowing how end-of-life is perceived by some cultures and religions may create obstacles in delivering the best quality of palliative care (Al-Shahri & Al-Khenaizan, 2005).

Communication and language barriers

In paediatric care settings, communicating with families regarding a child nearing the end of life is a complex task that becomes even more difficult when cultural barriers exist, particularly those created by language, making open and effective communication exceptionally difficult (Koenig & Davies, 2003). For that reason, good communication is the key to attaining a mutual understanding of the patient's situation, and essential because it is a way to help build relationships, resolve conflicts, deliver bad news, foster a common understanding of challenges, hopes, and goals, and improve collaboration in decision-making and in determining care plans that are consistent with these hopes and goals (Klick & Hauer, 2010). Moreover, good communication between patients and clinicians could positively impact the patients' experience by enhancing their service satisfaction, in addition to assisting patients in effectively following medical recommendations that would lead to an overall better health outcome (Almutairi, 2015).

Hence, generating crucial discussions and helping in maintaining better communication between patients, families, and the other medical team members is one of the roles represented by the paediatric palliative care team from the early stages of the diagnosis (Jones et al., 2011).

In a mixed-method research study, Hisao et al. (2007) explored the perspectives of parents and children with cancer and other life-threatening illnesses regarding communication in paediatric palliative care and found that the relationship between the physician, patient, and families as one of the areas impacted by communication. Namely, trust and honesty are vital, and so their lack would negatively impact the doctor-patient-family relationship, as well as leading to emotional distress and building resentment towards the physician (Hsiao et al., 2007). In children's palliative care, particularly end-of-life care for infants, children, and adolescents, openness and honesty have been identified as key components of communication, since they give parents a sense of control at a time where they feel they have no choice or control (Widger & Wilkins, 2004). Through open and honest conversation, as Jack et al. (2018) explained, families can discuss and share their understandings of the child's condition and potential treatments with children and health care professionals. Additionally, via good communication conflicts arising during the illness trajectory are reduced, and families are empowered to create a care plan in the child's best interest (Meert et al., 2008).

Overall, for health care practitioners, being honest about a child's disease and prognosis is essential for the delivery of good medical care (Jalmsell et al., 2013); as for parents, open communication and honest information are important for the provision of adequate care for their children (Kars et al., 2011). These aspects of communication become even more vital in situations where parents are facing the death of a child, which is considered the ultimate loss a family can endure (Ferrell et al., 2016). More challenges arise when families or health care providers caring for children at the end-of-life need to start a conversation about death and dying (Bennett et al., 2012). Ahmad and Siddiqi (2015) argue that it is imperative for patients and families to be fully involved, which means translators with specific palliative care knowledge are preferred to interpret the language and terminology used in palliative care. The next section will discuss some aspects when communicating with children living with life-threatening conditions, especially conveying information about death, and dying.

Communication with Children:

As discussed, healthcare professionals' communication with families is fundamental in the care of children with life-threatening conditions. On that account, children's wishes, and preferences cannot be overlooked when communicating with their physicians. Therefore, while involving the parents and guardians in various aspects of the child's care, clinicians and care providers must constantly keep in mind the rights for children to have their views and wishes that must be acknowledged and respected based on their developmental level and ability (McConnell et al., 2016). To ensure clarity and prevent significant misinterpretations, individuals involved in the child's care, including healthcare providers, parents, and caregivers, must consider the overall development of children and young people (Stein et al., 2019). This signifies that children's needs are related to their life course development; even for children living with illnesses, the perceptions of their illness, their understanding of death and dying, and the extent of their ability to control the situation are all determined by their developmental stage, which impacts their cognitive abilities (Muckaden et al., 2011).

It is suggested that discussing a diagnosis with children helps them understand their condition, which can empower them and enhance their compliance with difficult procedures and treatments (Stein et al., 2019). Alternatively, when children are not included in discussions about their incurable conditions, or information about unsuccessful treatments withheld, it could lead to confusion, frustration, distress, and anger (Aldridge et al., 2017). O'Halloran and Altmaier (1996) reviewed studies that looked at awareness of death among terminally ill children, children with chronic conditions, and healthy children. The authors argued that despite the age of the unhealthy children, their adjustment to their circumstances was far better when open discussions about their disease occur compared to children lacking the opportunity to discuss their conditions. Furthermore, children under the age of six adhered and adjusted better to treatments when told of their conditions at earlier stages. In contrast, the review has indicated that children shielded from the truth about their illness showed increased confusion, isolation, and mistrust of others (O'Halloran & Altmaier, 1996).

Consequently, parents and others often face difficult decisions when a child's condition worsens, including whether and how to discuss death with them (Jalmsell et al., 2015). The difficulty of talking to children and starting conversations about death lies in some misconceptions people may have about conveying messages to children, including the perception that children cannot understand or that telling the truth could harm them (Bennett et al., 2012). In a Dutch study conducted by van der Geest et al. (2015) on parents to examine their reasoning for discussing death with a child diagnosed with incurable cancer, most of the parents were against discussing impending death with their terminally ill child. Reasons for parents' inability to discuss death with their children included lack of confidence to start such conversations, fear of talking about death, and parents' inability to comprehend and cope with their child's imminent death (van der Geest et al., 2015). The desire to protect children is one of the most common reasons parents mention for not breaking bad news for their children (van der Geest et al., 2015). Another reason perceived by parents for their reluctance to talk about death to their child with a terminal illness is the child's young age (van der Geest et al., 2015). At times subtle hints and indirect questions from the child are avoided, other parents possibly do not tell the truth about their condition (Aldridge et al., 2017). Nevertheless, as Jalmsell and colleagues have mentioned from previous studies, bereaved parents who communicated with their child about death have not regretted their decision (2015). In a Swedish study conducted on parents who lost a child due to malignant disease from 1992 to 1997, most parents reported no regrets for talking to their terminally ill child about death. Conversely, parents who did not speak about death with their child had regretted their decisions (Kreicbergs et al., 2004).

2.4: Culture and Religion

Introduction

Life and death are phenomena interpreted differently amongst people. For some, cultural or religious rituals give meaning to these phenomena, and enhance their understanding of the passage from life to death (Koenig and Davies, 2003). Culture and religion, as apparent in the literature, are essential for various people because for many, their lives are based on cultural and spiritual practices and traditions; therefore, providing quality care is associated with healthcare providers' ability to be culturally sensitive and competent (Wiener et al., 2013). From what was mentioned previously, it is evident that ethnicity plays a role in how some people deal with end-of-life care. Given that people are different, so are their ways of dealing with all aspects of care and decision-making at end-of-life, which are to some degree altered by their cultural backgrounds (Krakauer et al., 2002).

To understand the impact of culture for families with children undergoing palliative care at end-of-life, the following part of the literature will explore the significance of culture in the context of healthcare, starting with the meaning of culture and its realms that can possibly shape palliative care and the experiences of families. Additional to the impact of culture, cultural sensitivity and other similar terms would be discussed more, along with the implications of being culturally sensitive for healthcare workers providing care for children in palliative and end-of-life care. Lastly, the effect of religion would be looked at, particularly Islam and the meaning of health, suffering, and what deemed important as religious coping mechanisms for Muslim families.

Culture and health care:

Culture is not solely about race or ethnicity, as many people believe (Gray, 2018). A culture can be broadly defined as a set of learned and shared patterns of thought and behaviour, such as language, values, deeds, religion, manners (Capell, Veenstra, & Dean, 2007), ethnicity, gender, sexual orientation, and socioeconomic status (American Academy of Paediatrics, 2004). In a literature review, Williamson, and Harrison (2010) identified two perspectives on culture in relation to midwifery and nursing. According to one perspective, culture is cognitive, which means that people from similar cultural backgrounds are presumed to share the same values, traditions, and beliefs (Williamson & Harrison, 2010). Based on Williamson and Harrison (2010), a second perspective of cultural definition includes factors such as education, socioeconomic, and social factors that influence an individual's health status rather than individual behaviours and beliefs. In spite of this, there can still be differences in cultural practices and religious beliefs even within the same group (Khalid, Saad, Abd Ghani, & Kadher, 2019), and a person may disagree with a culture even if they were born into it (Mazanec & Tyler, 2003). Also, people can identify with more than one cultural group, and their choices in health care, sometimes, can be affected by how they identify themselves (Gray, 2018; Mazanec & Tyler, 2003). As immigrants integrate into new societies, they can also be affected by some aspects of the culture of their new environments (Sarhill et al., 2001). Some individuals, however, as Sarhill et al write (2001) adhere to their religious and cultural traditions at the time of death, rather than to the new customs they have acquired (Sarhill et al., 2001).

The cultural lens is a way of looking at people and interpreting situations. It becomes even more evident during end-of-life care decision making when people from different cultures are involved (London & Sessa, 1999). In health care, for example, Arabiat, Al Jabery, Abdelkader, and Mahadeen (2013) argue that social norms and cultural beliefs influence how individuals perceive and cope with illness experiences. A person's culture can have significant influence on their perception of their diagnosis, their understanding of end-of-life care, treatment, and ultimately their ability to make healthcare decisions (Mohiuddin et al., 2020; Searight & Gafford, 2005). Furthermore, children's healthcare is directly affected by the cultural practices of their families in terms of health, illness, and wellbeing (Yildiz et al., 2018). Cultural practices can also impact children's conceptions of health as well as their socio-emotional development, attitudes toward health problems, and perception of illnesses, as well as their reactions to therapy (Yildiz et al., 2018).

Families of children receiving palliative care may have different perceptions of palliative care based on their cultural and religious backgrounds (Koenig & Davies, 2003), as some interventions performed as the child nears death are shaped by the family's beliefs and values (Salmani et al., 2018). More specifically, culture in children's palliative care can determine families' perceptions about treatments and outline their responsibility to make decisions (Haines et al., 2018). Haines and colleagues argue that Latinos, for example, are keen to pursue all possible options to save a child, which contributes to their reluctance to choose palliative care for their child with cancer (2018). The same is true for adults' end-of-life care, where culture has an impact on treatment choices. According to a study by Krakauer et al. (2002), African Americans are more likely to accept aggressive life-sustaining treatments, as compared to European Americans who are more likely to decline them.

De Graaff et al. (2012) suggest that immigrants may face culturally specific challenges due to differences in values and concepts such as patient-doctor relationships. Other controversial topics, such as autopsy and organ donation among paediatric cancer patients (Khalid et al., 2019), may have cultural roots (Haines et al., 2018). Cultural differences also lead to tension associated with differences in values, viewpoints, and experiences (Rosenberg et al., 2019). According to Rosenberg et al. (2019), paediatric clinicians and researchers report that bias, explicit or implicit, and preconceived notions about ethnic groups, patients, or families, complicate the process of navigating cultural differences. Health care providers must therefore have cultural competence and understand a patient's beliefs, spirituality, and cultural values in order to provide effective, individualized care (Abdullah et al., 2020); this implies that clinicians must be aware of and respect a patient's traditional beliefs, practices, and culture (Mazanec & Tyler, 2003). For example, when caring for families of children with cancer of diverse backgrounds, health care providers have to understand the impacts of culture on families and the coping mechanisms they use (Gray et al., 2014). In the following sections of the literature, cultural competence will be discussed as well as other terms like cultural sensitivity and cultural humility.

Cultural competence and Cultural humility:

Cultural competence is a vital part of delivering healthcare services in which healthcare providers continually strive to be prepared to work effectively within the cultural framework of the patient, as an individual or family member, or at a community level (Campinha-Bacote, 2002). Cultural competence, then, is the capability to comprehend and respect people from different cultures, focusing on aspects such as language, religion, spirituality, and ethnicity (Danso, 2018). Therefore, cultural competence extends beyond culture and religion to include sensitivity to other factors affecting patients, such as gender, sexual orientation, and socioeconomic status (Isaacson, 2014). Interestingly, Stubbe (2020) linked culture competence with patient-centred care, since taking into account the patient's needs while considering their culture, lifestyle, experiences, and viewpoints intersects with both patient-centred care and cultural competence (Stubbe, 2020).

According to Danso (2018), critics have pointed out that cultural competence includes three components: awareness, knowledge, and skills. Al-Shahri & Al-Khenaizan (2005) define cultural awareness as being aware of one's own cultural values, beliefs, and attitudes and those of the families cared for regarding matters such as end-of-life care. In addition to promoting sensitive care, such awareness can also reduce families' anxiety and provide them with comfort and reassurance (Campbell, 2006). By contrast, knowledge is the ability to be familiar with diverse groups and the needs they have, as well as develop attitudes that foster a good practitioner-client relationship (Danso, 2018). As noted in a concept analysis by Foronda (2008), knowledge of patients' cultural values, beliefs, and practices is crucial in achieving cultural sensitivity and ensuring quality care. “Skills” is the capability to combine knowledge and awareness to provide culturally appropriate services, resulting in effective communication and intercultural interactions (Danso, 2018). Thus, the concept of cultural competence is generally understood to include the knowledge, expertise, attitudes, and behaviours of healthcare professionals in order to effectively interact with patients from ethnically and culturally diverse backgrounds (Soerensen et al., 2016).

There have been different debates about the appropriate use of cultural competence. Koenig and Davies (2003) argue that clinicians do not have the capacity to memorize every individual's belief system or cultural practices, which makes it almost impossible for them to be fully competent. Culturally appropriate care or cultural sensitivity are more accepted concepts since they are based on certain skills, such as communication, and fundamentals, such as respecting diverse belief systems; they also allow individuals to reflect on their cultural values (Koenig & Davies, 2003). To provide culturally sensitive end-of-life care, openness and flexibility are essential to acknowledging, and respecting, individuality within a spectrum of cultural and spiritual beliefs and practices (Fang et al., 2016). Especially important is the need for nurses and health practitioners to avoid assumptions and stereotypes, and to become more sensitive, open, and caring (Foronda, 2008). In response, cultural humility has been introduced, which encompasses both cultural sensitivity and cultural competence (Foronda et al., 2016).

The concept of cultural humility is said to consist of two components: intrapersonal and interpersonal. The interpersonal dimension highlights practitioners' limited understanding of the cultures and worldviews of those they serve (Danso, 2018). Cultural humility, as explained by Isaccson (2014), involves taking responsibility when dealing with people from different backgrounds and making a conscious effort to honour their beliefs, customs, and values (Stubbe, 2020). It is therefore important to cultivate the skills of actively listening when dealing with people from different ethnicities, as well as being mindful of one's own perspectives, thoughts, and assumptions about the other's culture (Isaacson, 2014). On the other hand, the intrapersonal dimension refers more to the patient's perspective, asserting that it should be respected, and practitioners should approach it with an open mind (Danso, 2018). To be open or have an open mind, a person should be receptive to new ideas and approach them with an exploratory attitude and have the willingness to interact freely with people of different cultures, which is key to cultural humility (Foronda et al., 2016).

Cultural humility involves aspects like self-awareness and self-reflection (Isaacson, 2014). Constantly exploring analysing and revising one's views and beliefs, as well as being open and flexible to learn from others are key aspects of cultural humility (Stubbe, 2020). Although being aware of one's own beliefs is considered part of cultural humility, some authors have linked it to cultural competency. For example, in Mazanec and Tyler (2003) they state that cultural competency requires individuals to be aware of their own values, beliefs (religious and cultural), and attitudes. Likewise, Wiener et al. (2013) have endorsed the importance of reflecting on one's biases (implicit as well as explicit) to achieve cultural competence.

When compared to cultural competency, cultural humility has been identified as profound and more appropriate (Foronda et al., 2016). Nevertheless, Yancu and Farmer (2017) argue that cultural humility and cultural competence complement one another, rather than replacing each other. Being able to interact with a diverse population involves cultural humility and cultural competence because they both involve awareness, openness, and knowledge of other cultures as well as world views (Yancu, & Farmer, 2017). Cultural competence frameworks have the potential to help healthcare professionals provide better care to patients since it is more holistic, taking into account the patients' linguistic, social, and cultural needs rather than focusing exclusively on the patient's culture and religion (Kamat & Fischer, 2012; Camara & Rosengarten, 2021; Soerensen et al., 2016). Whereas cultural humility is a life-long commitment and process of self-assessment where an individual evaluates and critiques themselves continuously and addresses power imbalances (Campinha-Bacote, 2019). According to Foronda et al., (2016), cultural humility entails more than simply leaving the ego behind; instead, it requires having a humble attitude, believing in people's equality, and eliminating superiority.

Barriers to culturally sensitive care:

Culturally competent paediatric palliative care can be hindered by many factors (Kongnetiman et al., 2008); these include clinical factors, educational, institutional, attitude-related, ethical, financial, and regulatory barriers (Rushton & Catlin, 2002). As with paediatric palliative care, Mazanec and Tyler (2003) identify two broad categories of barriers to cultural competence: one relates to health providers, and the other relates to the health care system. It is possible for health care providers to face challenges when they do not fully understand the cultural practices and beliefs of their patients or when their beliefs differ from those of their patients (Mazanec & Tyler, 2003). In multicultural settings in most Western European countries the values of physicians and parents at the end of life may often differ, and they may hold opposing views on what is most appropriate for a critically and incurably ill child (Westra et al., 2009). Particularly, parents and clinicians may be at odds over decisions regarding withholding or withdrawing life-sustaining treatments, even though these decisions occur upon mutual consent (Westra et al., 2009); as a result, poor communication may result (Klessig, 1992).

The health care setting-related barriers, on the other hand, stem from the way it is constructed, since it is not designed to cater for the diversity of people, and most often follows a standard approach to care (Mazanec & Tyler, 2003). Intensive Care Units (ICU) are not prepared to accommodate some cultural rituals and needs of patients and their families (Mazanec & Tyler, 2003). For example, Pacific Islanders have cultural traditions that require the windows to be open when someone is dying to allow the soul to leave. Other cultural practices and rituals may not be possible in an ICU unit since other patients are present, limiting the number of visitors and interfering with communication and nurses' ability to interact with families to meet specific needs (Mazanec & Tyler, 2003).

The absence of cultural competence could lead to communication challenges (Almutairi, 2015), because interactions with patients and their families without understanding their background can have undesirable effects and lead to dissatisfaction with quality of care (Brooks, Manias, & Bloomer, 2019). Thus, it is imperative to provide cultural competency training to service providers in order for them to design culturally appropriate practices (Fisher-Borne, Cain, & Martin, 2015). Namely, students and clinicians should undergo cultural sensitivity trainings (Krakauer et al., 2002), which will help them form accurate opinions, attitudes, and assumptions when interacting with people from different cultural backgrounds (Connerley & Pedersen, 2005), which reduces misunderstandings (London & Sessa, 1999).

2.5: Faith in palliative care: Islamic Beliefs, Health, and End-of-Life Perspectives

Spirituality, faith, religion, and cultural values play a fundamental role in shaping how individuals find meaning and purpose in life, particularly during significant life events such as birth and death (Bennett et al., 2012). For many families, religious beliefs are deeply intertwined with their experiences of healthcare, influencing their perceptions of illness, suffering, and end-of-life care. Recognizing the significance of religion in these contexts requires healthcare professionals to have at least a basic understanding of their patients' faith traditions, as this knowledge is crucial for delivering culturally and religiously competent care. In the context of this study, the focus will be on the Islamic faith and its influence on perceptions of illness, suffering, and end-of-life decision-making. This section of the literature review will explore the Islamic concept of health and suffering, the ways in which religious beliefs shape end-of-life care decisions, and the coping strategies used by Muslim parents, and the Muslim community, when navigating the loss of a child.

Islamic Beliefs and Their Influence on Health and Illness

Islam is the name of the religion, and individuals who follow the Islamic faith are known as Muslims (Leong et al., 2016). The word "Islam" literally means submission, signifying a way of life centred on complete obedience to Allah's will (Lovering, 2012). A core tenet of Islamic belief is the attribution of all life events, whether joyful or painful, to God's will (Al-Shahri & Al-Khenaizan, 2005). Moreover, hardships, including illness, are seen as tests of faith (Silbermann & Hassan, 2011; Khan, 2002; Salmani et al., 2018). This perspective fosters reliance on divine will, often expressed through the phrase *insha'Allah* ("if God wills") (Hedayat, 2006). Overall, a fundamental aspect of Islamic belief is the concept of predestination, where life and death are viewed as being under Allah's control (Lovering, 2012). The Quran explicitly states that souls can only die by Allah's permission (3:145) (Saiyad, 2009). Consequently, Muslims are expected to accept divine decrees without resentment, as questioning or expressing anger toward God in response to suffering is considered inappropriate (Silbermann & Hassan, 2011). Although submission to God's will is paramount, Islam encourages individuals to seek medical treatment and make efforts to find solutions while ultimately believing that outcomes are determined by God (Hedayat, 2006).

Islam is not only a spiritual guide but also provides a framework for health and well-being. The religion emphasizes preventive care and outlines principles that influence Muslim perspectives on health and illness (Ayed et al., 2018). Islam provides a unique view of health and mortality, which shapes the coping mechanisms families use when faced with adversity, such as a life-threatening illness for a child. Islamic teachings are derived from two primary sources: the Quran and the Sunnah—the sayings, actions, and approvals of Prophet Muhammad; who is regarded as a role model, Muslims strive to emulate and follow in their daily lives (Lovering, 2012; Al-

Shahri & Al-Khenaizan, 2005; Ayed, & Ayed, 2018). Additionally, Muslim scholars, regarded as experts in legal and ethical matters, provide guidance on contemporary or controversial issues, including end-of-life care (Hedayat, 2006). Seeking their opinions is common, though individuals may not always adhere strictly to scholarly rulings due to personal or cultural beliefs (Hedayat, 2006). Another fundamental element in Islam is prayer (*salah*), which plays a crucial role in the daily lives of Muslims, serving as a source of spiritual strength and emotional resilience. It is performed five times a day by mature and mentally sound individuals from youth to old age (Hasanović et al., 2017). For those experiencing illness or suffering, prayer provides a direct connection to God, fostering inner peace and enhancing tolerance to pain (Badawi, 2011; Marzband et al., 2016). Consequently, religious rituals often become more significant for Muslim patients during times of sickness (Marzband et al., 2016).

The Sacred Value of Life in Islam

Islam hold life as sacred and considers health as a gift from God (Al-Shahri, 2016), that must be valued and preserved, irrespective of pain or suffering (Choong, 2015). Consequently, many Muslim families often believe that physicians are duty-bound to save lives in all circumstances (Attum et al., 2018). This belief often leads to objections against medical interventions that intentionally hasten death, as such actions are perceived as interfering with God's will. The Qur'an explicitly states that taking a person's life without justification is akin to killing all of humanity (Qur'an 5:32, 17:33), reinforcing the prohibition of suicide, euthanasia, and the withdrawal or withholding of life-sustaining treatments (Choong, 2015).

From an Islamic perspective, healing and the preservation of life fall under God's control, and He alone has the power to cure even the seemingly incurable (Al-Shahri, 2016). Hence, some Muslim patients and families may view palliative care with scepticism, associating it with despair, which contradicts Islamic teachings emphasizing reliance on God (Al-Shahri, 2016). Thereby, in medical contexts, both doctors and family caregivers are expected to prioritize life preservation and refrain from hastening death. However, despite medical professionals' efforts, healing is ultimately determined by God (Ayed, & Ayed, 2018; Attum et al., 2018). In other words, physicians are considered instruments through which God administers help, but the outcome of life and death rests in God's hands (Salmani et al., 2018).

Impact of Islamic religion on End-of-life decision

Decisions regarding end-of-life care, such as the withdrawal of life support, are deeply influenced by Islamic beliefs about death and the afterlife (Badawi, 2011). According to Salamani et al. (2018), religious beliefs, spiritual practices, and cultural backgrounds shape how parents of children with life-threatening conditions approach medical interventions, including the acceptance of do-not-resuscitate (DNR) orders and palliative care.

While new medical advancements can bring new sets of expectations and possibly revive hope, they can bring an array of issues that are not only clinical, but also moral, socio-cultural, legal, and economic (Al-Bar & Chamsi-Pasha, 2015). Islamic law provides guidance through fatwas (legal rulings), which outline conditions under which withdrawing or withholding treatment is permissible (Albar, 2007). Although hastening death is forbidden, Islamic jurisprudence follows the principle that necessity overrides prohibition (Khan, 2002). Just as in Western medicine, the ethical principle of nonmaleficence is central when discussing Islamic views of treatments and the role of clinicians. The principle of nonmaleficence, which is simply refraining from doing harm to others, is central to many Islamic traditions (Westra et al., 2009). This principle is manifested in the prophetic saying that harm must not be inflicted or reciprocated (Miller et al., 2014).

Consequently, if treatments are believed to cause harm more than benefit, then withholding them is considered the best decision, based on the Prophet saying “above all do no harm”; which is simply the ethical rule of non-maleficence (Albar, 2007). Hence, withdrawal of care is permitted under two key conditions: (1) when brain death is confirmed (Albar, 2007), and (2) when ongoing treatments provide no cure and only prolong suffering instead of alleviating it (Schultz et al., 2012). However, when illnesses are treatable, patients are encouraged to seek medical interventions, including resuscitation, until either recovery or inevitable death occurs (Saiyad, 2009). At the same time, it is advised that Muslims seek the necessary treatments to reduce any pain and suffering that they cannot endure (Schultz et al., 2012).

As far as autopsy is concerned, the Islamic perspective is that it is not permissible, unless it is deemed urgent (Adekoya, 2021). This is because Islam prohibits disfiguring the body after death, and Islam advocates respect for the body (Mohammed & Kharoshah, 2014). This ruling is derived from a Hadith, a reported saying of the prophet Mohammed, which states: "The breaking of the bone of a dead person is like breaking the bone of a living person.” (Mohammed & Kharoshah, 2014; p.81). Since it is believed that "necessity permits the forbidden" in Islam (Mohammed & Kharoshah, 2014; p.81), autopsies are permitted in legal cases where a crime has been committed or a death is suspected (Mohammed & Kharoshah, 2014). Autopsies have greater advantages under Islamic law if they serve justice, which is why they are permitted in certain legal cases (Mohammed & Kharoshah, 2014).

Religion and spirituality as coping mechanisms for parents with children at end of life:

Religion may guide some people in difficult circumstances, where they use it to cope with stressful life events and address questions related to life (Hexem et al., 2011). As noted by Pentaris and Tripathi (2022), spirituality and religion can help some individuals cope with terminal illness and make sense of death. As discussed in Pentaris and Tripathi (2022), healthcare providers with over 10 years of experience in palliative care and hospice care expressed their belief that the importance of religious beliefs and spirituality increases as patients approach the end of their lives; regardless of how they perceived their faith prior to being diagnosed (Pentaris & Tripathi, 2022). Families and parents of children in palliative care and at end-of-life may also seek comfort through their religious and spiritual beliefs (Pentaris & Tripathi, 2022). Furthermore, a study conducted by Miquel et al. (2024) examined the views of parents of children receiving palliative care about their faith and religious traditions and practices that they follow as they care for their children. In the study, participants had different religious beliefs, and some reported that their faith in God had been strengthened because of their child's diagnosis (Miquel et al., 2024) Interesting, their faith enabled them to embrace a poor diagnosis rather than fear it (Miquel et al., 2024). Additionally, Arutyunyan et al. (2016) found that families' faith and its teachings help them adjust to potential changes caused by the child's illness. The study by Miquel et al. (2024) also found that others placed their trust in God, believing that there must be a reason or purpose for the suffering placed on their child and them that is not necessarily known to them (Miquel et al., 2024).

There is, however, the possibility that religion may negatively affect parental bereavement. Accordingly, religion may be helpful to some people as a means of answering existential questions about death and for providing them with a social network that can provide support during times of bereavement (Lee et al., 2013). Others, on the other hand, may find it stressful since they may negatively interpret the circumstances in which they are experiencing bereavement, resulting in dysfunctional mood (Lee et al., 2013). Brown et al. (2007) argue that rather than religion serving as a source of hope and comfort, at such difficult times, some individuals may feel angry towards their gods, leading them to lose their faith. The expressions of despair and anger of some bereaved Muslims, however, may be misinterpreted by others as signs of spiritual deficits, which makes it difficult for them to openly admit to their emotional problems (Kristiansen & Sheikh, 2012). The following section provides an overview of some of the religious practices and rituals used by Muslims inflicted with pain and suffering, including families of children with terminal illness, to cope with their changing circumstances, as well as to seek comfort and healing.

Coping Mechanisms used by Muslims:

It is the expectation of Muslim parents, as it is of any other parent from any faith or culture, that their children will outlive them (Hedayat, 2006). Islamic traditions provide guidance on coping with stressful life events, offering recommendations for behaviours, ethics, and values that promote adaptive coping mechanisms (Sabry & Vohra, 2013). Prayers and supplications are therefore combined with medical interventions (or herbal remedies) to seek healing (Hedayat, 2006). Those in distress are believed to find comfort by reciting the Quran and making prophetic supplications (Ayed & Ayed, 2018; Al-Shahri, 2016). Besides reading Quranic verses, Khalid et al. (2019) report that Muslim families with terminally ill children often administer holy water to their children as it is believed to have healing properties. Additionally, since Islamic teachings place a high value on prayer, parents and family members use it to maintain a connection with God through which they can find comfort (Badawi, 2011). Through prayer, they become closer to God, seek His guidance, and ask Him to support them and reward them for their patience (Badawi, 2011). As for herbal remedies, traditionally, black cumin seeds (Nigella seeds) and honey are considered healing remedies in Islam (Al-Shahri, 2016). Furthermore, Zamzam water, which is taken from a well in the Holy Mosque in Makkah, is well known for its healing properties (Al-Shahri & Al-Khenaizan, 2005).

Death from an Islamic Perspective

The moment of death in Islam, as emphasized in the Quran, is when the soul departs from the body; however, there is no clear indication of when exactly the body becomes soulless (Miller et al., 2014). This ambiguity creates challenges in defining the exact moment of death. Khan (2002) proposes that death occurs when the brain ceases to function, but this definition has sparked debate, particularly because some argue that individuals who are brain-dead are not truly dead (Sarhill et al., 2001). Consequently, death in Islam is generally considered to be the cessation of all bodily functions (Miller et al., 2014). From a practical perspective, when death occurs, hospitals are encouraged to give families adequate time and space to mourn their loss (Hedayat, 2006). For Muslim families, death is not only a loss but also a time for specific rituals, which include washing the deceased, anointing, shrouding, and then proceeding with prayer and burial. These rituals are typically performed within 24 hours of death, unless a forensic autopsy is required by law (Hedayat, 2006). These practices are not simply cultural but are viewed as preparations for the afterlife, indicating that death is seen as a transitional stage leading to eternity (Mohiuddin et al., 2020).

End-of-life rituals for Muslims

Funeral rites and mourning practices are deeply embedded in religious traditions across various faiths, often including specific guidelines and procedures to follow during and after death (Brown et al., 2007). This is particularly evident in Islam, where funeral procedures, known as *Al-Janazah*, are considered sacred and must be conducted with the utmost care (Adekoya, 2021). Unlike some other religious traditions, Islamic funeral services do not include eulogies, ceremonies, viewings, or visitations (Adekoya, 2021). This section of the literature explores key aspects of Islamic funeral rites, burial customs, mourning practices, and the emotional responses to loss.

Immediate Post-Death Rituals and Burial Procedures:

There are some rituals to be followed immediately after death, which have been discussed by Lai and colleagues in a literature review (Lai et al., 2008). When death is confirmed in a hospital setting, the rituals include closing the deceased eyes and mouth, straightening their legs, and extending their arms alongside their bodies, and turning the deceased's head to their right shoulder (or facing the deceased towards the city of Mecca, whenever possible) (Sheikh, 1998; Lai et al., 2008). Once the body has been received by the family, and all logistical procedures have been completed, the rest of the rituals can be performed, starting by washing the body with pure water and using camphorated water (Lai et al., 2008).

Considering the importance of respecting the body and the privacy of the deceased, when washing them, the body is never exposed in its entirety (Ross, 2001). Also because of safety and hygiene concerns, such as the prevention of infectious diseases (Ross, 2001). After washing the body, then wrapping it with a simple, plain white cotton, unsewn fabric (Sheikh, 1998; Lai et al., 2008). Thereafter, the body is placed in a plain wooden coffin (Ross, 2001), followed by the completion of the remainder of the rituals, including a funeral prayer and burial. The funeral prayer, known as *Janazah prayer*, is then performed, in a mosque or a lawn yard where family, friends, and community members, including women can attend (Sheikh, 1998; Suleiman, 2003). Funeral prayers are followed by the funeral procession to the graveyard where the deceased is buried, and a final supplication is offered by all those attending the graveyard (Sheikh, 1998).

Cemetery restrictions:

Muslim scholars unanimously agree that Muslims are not permitted to be buried with non-Muslims (Hussain, 2022). Instead, they may bury their deceased in a designated separate area in their cities' cemeteries (Gatrad, 1994). This can present some challenges to Muslims. For example, as noted by Gatrad (1994), Muslims are likely to encounter some logistical constraints imposed by their region when practicing their Islamic burial practices in Britain. Also, there may be some legal restrictions, such as a waiting period between death and burial, or perhaps a specific timeframe for the use of grave plots, which may hinder the rapid burials required by Muslims (Balkan, 2015). Such restrictions may lead some to repatriate the deceased to their countries of origin, requiring embalming to complete the process, a practice discouraged by religious leaders (Gatrad, 1994). Hence, the British Islamic authorities advocate for local burials, since the process of transporting bodies involves bureaucratic delays that may exacerbate grief for the families (Gatrad, 1994). Accordingly, it is likely that families would refrain from repatriating if British regulations were more accommodating of such rituals.

Restrictions for Females Visiting Cemeteries:

The question of whether Muslim women are allowed to visit graves has been subject to debate due to differing interpretations within Islamic traditions and cultural contexts (Ahaddour et al., 2018). Many Muslim scholars prohibit women from visiting graveyards, while others permit it. Those who are with the opinion of women being forbidden to visit the graves of their loved ones, claim so due to women's emotional sensitivity, which may result in excessive expressions of sadness or grief behaviours such as wailing or lamentation (Ahaddour et al., 2018; Ross, 2011). As outlined in Gatrad (1994), Muslim women are prohibited from attending burials, including those of close female relatives or children, as women are emotionally vulnerable and may have difficulty maintaining composure during these occasions. Yet, some women still visit graves at other times, despite such actions being religiously discouraged or prohibited (Gatrad, 1994). In contrast, Suleiman (2023) argues that if women refrain from excessive expressions of grief during their visits to graves, they may accompany the funeral procession. Other scholars that permit women to visit graveyards believe that visiting graveyards allows people to contemplate death and life after death, which benefits women as well, not just men (Ahaddour et al., 2018).

Mourning and Grief in Islam:

Mourning is not prohibited in Islam, and it is acceptable to express grief and sorrow through tears, but certain expressions, such as wailing, are restricted (Ross, 2011). In some narrations of the prophet Mohamed, tears are permitted as a means of expressing grief. According to these narratives, Prophet Mohamed cried several times when he lost some loved ones, such as his son and when he visited his mother's grave (Mehraby, 2003). Relationships with the deceased can significantly impact how individuals cope with bereavement (Kristiansen & Sheikh, 2012). Losing a child, for instance, is widely considered to be one of the most adverse and distressing experiences for parents, and it is expected to cause a significant impact on them. A firm belief that the child will not be subject to judgment or punishment, and that the child's soul will ascend directly to paradise after death, even in the case of stillbirth, makes this process more bearable for Muslim parents (Kristiansen & Sheikh, 2012; Lai et al., 2008). Moreover, the constant reminder that they will be reunited with their child in paradise empowers them (Kristiansen & Sheikh, 2012).

Generally, Islamic traditions permit three days of public mourning during which individuals may refrain from participating in social or professional activities (Alhaddour et al., 2018). During this period, members of the community visit the bereaved to provide comfort, support, read Quran, and offer supplications for the deceased (Mehraby, 2003). Nevertheless, the grieving process does not conclude within such a short, limited timeframe, since each individual or family deals with grief differently (Mehraby, 2003). The way in which individuals react to the loss of a loved one is uniquely different from one individual to another (Kristiansen & Sheikh, 2012). It is common for grieving individuals to express a variety of reactions to loss, and Muslims are no different (Mehraby, 2003). Therefore, going through different emotions and reactions like denial, shock, disbelief, bargaining, guilt, or even depression should not be regarded as sinful, since they are common reactions to losing a loved one (Mehraby, 2003). Thereby, Mehraby (2003) highlighted the importance of allowing these individuals to freely express their grieving feelings, to avoid further psychological damage. Furthermore, they should seek support to channel their emotions in order to cope with these changing circumstances (Mehraby, 2003).

While grief can evoke strong emotions like anger and denial, these reactions tend to be less common among Muslims compared to those with a secular perspective (Kristiansen & Sheikh, 2012). This may be because Muslims often interpret the suffering and trials they experience as a test of faith and a sign of Allah's (God's) love, and in some instances atonement of one’s sins (Kristiansen & Sheikh, 2012; Hafez et al., 2021; Silbermann & Hassan, 2011). This belief is derived from one of the teachings of Prophet Mohammed stating that any form of pain, illness, or suffering, even something as minor as a thorn prick, serves as atonement for a Muslim's sins (Al-Shahri & Al-Khenaizan, 2005).

When confronted with the death of a loved one, Muslims turn to Allah, believing that his mercy will provide comfort and illumination (Kristiansen & Sheikh, 2012). Consequently, Muslim believers are constantly reminded to remain patient and to trust in Allah's providence Additionally, Muslims are comforted by the belief that this separation is temporary, and their anticipation to reunite with their loved ones in paradise (Kristiansen & Sheikh, 2012). Overall, the emotional burden of death, especially the death of children, can be overwhelming. However, the Islamic belief in the afterlife and the idea that everyone will eventually return to God can offer a sense of comfort to the grieving (Badawi, 2011). As the Quran (Chapter 2: Verse 156) states, “among the most praiseworthy people are those who, when afflicted with the death of a loved one or similar calamity, say: ‘To God we belong and to Him is our return’” (Badawi, 2011, p.137), this belief fosters acceptance and peace in the face of such profound loss. Although this may be true, it is not frowned upon to express sorrow or grief, nor is it considered a sign of disbelief; rather, it is viewed as an indication of a sensitive and spiritually alert heart (Kristiansen & Sheikh, 2012).

Supporting Bereaved Muslim Families

In time of loss, the extended family plays a crucial role in supporting the bereaved (Gatrad, 1994), and the Muslim communities are encouraged to extend condolences through various forms of support, such as emotional, physical, or financial support (Ahaddour et al., 2018). Mainly, families and friends offer their condolences by praying for the deceased's soul to be in a better place in the afterlife, and for the grieving individual to be granted patience at this difficult time and to be rewarded for it (Ahaddour et al., 2018). This supplication is an ongoing practice, as Muslims believe that those who remain patient and persistent in the face of adversity will be rewarded (Khan, 2002).

As part of traditional Islamic practices, Muslim communities are also encouraged to assist grieving families by providing them with material assistance, such as food, or by performing tasks that will relieve their burden (Ahaddour et al., 2018). It is believed that offering these types of condolences serves a dual purpose, along with offering solace to the grieving family, they are also rewarded for their actions (Ahaddour et al., 2018). While it is strongly encouraged for Muslims to offer assistance to grieving individuals, it is important for healthcare professionals to refrain from assuming this is the standard of practice for all Muslims, as this may be influenced by a variety of other factors, varying from individual to individual (Kristiansen & Sheikh, 2012).

Despite shared religious beliefs, Muslim communities are ethnically and culturally diverse, leading to variations in perspectives on health, illness, and medical care (Attum et al., 2018). Cultural influences can shape attitudes and behaviours, sometimes diverging from religious teachings (Badawi, 2011). Given this diversity, health care providers may find it challenging to be fully familiar with all Islamic practices (Fang et al., 2016). A universal approach to treating Muslim patients is often impractical, as cultural variations necessitate personalized care (Fang et al., 2016). In clinical settings, individualized and culturally sensitive care is essential when addressing the needs of Muslim patients and their families. Despite the recognized need for faith-sensitive care, healthcare providers often lack adequate training and resources to integrate religious considerations into palliative and end-of-life care (Camara & Rosengarten, 2021). While Muslim scholars provide guidance on complex ethical and medical issues, their rulings may not always be followed due to personal beliefs and cultural factors (Hedayat, 2006). This underscores the importance of tailoring healthcare approaches to each patient's unique religious and cultural background, ensuring that care aligns with their values and beliefs (Hedayat, 2006).

Conclusion:

The literature underscores the fundamental components of quality paediatric palliative care, including multidisciplinary holistic care, need-based assessment, family-centred approaches, and effective communication (Behrman & Field, 2003). Furthermore, existing literature reflected on how cultural competency in healthcare is essential for ensuring equitable, patient-centred care, particularly in diverse, multicultural societies. Culturally sensitive care has been shown to improve health outcomes, foster trust between healthcare providers and patients, and enhance communication (Behrman & Field, 2003). While these principles form the foundation of palliative and end-of-life (EOL) care, a critical gap remains in addressing the cultural and religious needs of Muslim families navigating complex healthcare decisions. Islamic faith, cultural values, and medical decision-making shape parental choices, yet policies often fail to accommodate them.

Additionally, the literature acknowledges the language and communication barriers faced by patients and their families in ethnically diverse healthcare settings. Challenges such as language barriers, implicit biases, and insufficient cultural training for healthcare professionals persist. These issues are particularly pronounced in paediatric palliative care, where providers must navigate complex emotional, ethical, and religious considerations. Although most studies approach these barriers from a general perspective, there remain a limited focus on the specific communication challenges encountered by Muslim families of children in palliative care. There is a notable gap in addressing how cultural factors influence language acquisition and integration, potentially affecting these families' ability to communicate effectively and make informed EOL decisions for their children.

Although many studies have explored the impact of culture and religion on adult palliative care, for Muslims, far fewer have focused on paediatric palliative care. Muslim families caring for children with life-limiting conditions often face difficult choices regarding medical interventions, pain management, and EOL care, all while striving to adhere to their faith-based values. Most studies have examined Islamic perspectives on health, pain, and suffering in adults, often emphasizing patience and spiritual rewards in the afterlife. Yet, for Muslim families with children undergoing palliative care or at end of life, the literature lacks research on how parents navigate the loss of a child while maintaining their culturally prescribed roles, including gender-based caregiving responsibilities. Similarly, evidence-based research on how healthcare professionals accommodate the religious and cultural needs of Muslim families in paediatric palliative care settings is limited.

Despite the growing recognition of cultural competency in healthcare, there is a notable gap in research addressing the unique challenges faced by healthcare professionals providing paediatric palliative care to Muslim families. This study aims to address these gaps by exploring how healthcare providers support Muslim families in fulfilling time-sensitive religious rituals and meeting their spiritual needs. It will also examine the need for additional training and institutional modifications to ensure culturally competent care. By focusing on practical applications rather than general knowledge of Islamic values and rituals, this research seeks to enhance best practices and improve the quality of paediatric palliative care for Muslim families. This study seeks to bridge these gaps by examining how Islamic teachings and cultural values influence EOL decision-making among Muslim parents of children with life-threatening illnesses. It will also explore the role of faith as a coping mechanism and assess the challenges healthcare providers face in delivering culturally sensitive care.

Chapter 3: Theoretical Framework

Theoretical Framework

This chapter presents the theoretical underpinnings of this research, which provide the framework for framing the research questions and interpreting the findings. It is essential to establish a strong theoretical framework before exploring perspectives of healthcare professionals on encountered barriers when caring for Muslim children and their families receiving palliative care, and possibly at the end of life. It is through the lens of this theoretical framework that concepts in this topic are analysed. It aims to provide a structured approach to understanding the many aspects of healthcare delivery within this context. The study primarily focused on cultural competence and family-centred care. Therefore, it draws upon key concepts from Symbolic Interactionism Theory, Structural Functionalism Theory, and Bronfenbrenner ecological systems theory. In integrating these frameworks, this study aims to provide insight into the challenges faced by healthcare professionals in their efforts to navigate the intersection between culture, religion, and medical practice in the care of Muslim children in palliative care and at the end of life. Through these frameworks, the intricate dynamics of human behaviour and social interactions can be analysed through multiple lenses from a health care provider's perspective regarding the impact of Islamic faith and culture on Muslim parent decision making from the perspective of paediatric palliative care and end-of-life care providers.

Symbolic Interactionism Theory:

Another theoretical framework adopted by this study is symbolic interactionalism, which allows an understanding of how Muslim families make decisions regarding children receiving palliative care within the context of their religion and culture. A symbolic interactionist interprets the world of experience in which an individual lives as one created by humans (Denzin, 1992). This implies that symbolic interactionists are interested in the unique interpretations of the individual's perspective, thus placing the emphasis on how individuals perceive and comprehend their world rather than the way social institutions construct and influence meaning (Carter & Fuller, 2015). It is through interactions that individuals interpret and create significance to their surroundings, which in turn helps them understand the world around them (Armendariz-Dyer, 2020).

Using symbolic interactionism theory, one can gain a greater understanding of people's lived experiences and the ways in which they convey their knowledge through social interactions (Armendariz-Dyer, 2020). Therefore, an important aspect of this theory focuses on interactions between individuals, arguing that the way symbols and language are used in these interactions influences how individuals communicate and behave (Carter & Fuller, 2015). It is through the interpretation of symbols used in these interactions and from social behaviour that meanings are constructed (Armendariz-Dyer, 2020). As well as social interactions, Denzin (1992) asserts that an individual's self-reflection on circumstances affects how meaning is assigned to symbols and things. Given that meanings are derived from interactions (de Souza et al., 2013) and experiences (Armendariz-Dyer, 2020), understanding the nature of people's interactions is crucial to understanding them (Armendariz-Dyer, 2020).

In terms of religion, this theory focuses on how people interpret their religious experiences, and the role religion plays in their lives (Barakan, 2012). Based on the symbolic interactionist perspective discussed above, the emphasis is on the meaning individuals attribute to their religious experiences (Barakan, 2012). It is also possible to examine the rituals and ceremonies associated with religion using symbolic interactionism theory (Barakan, 2012). Unless individuals interpret their own beliefs and practices as sacred, they cannot be considered sacred. It is the interpretation and meaning assigned to these beliefs and practices that give them significance and thereby give meaning to the lives of those who follow them (Barakan, 2012). In essence, this theory examines the use of symbols, words, and language in communication between individuals. The theory asserts that society is constructed through the continuous interpretation of symbols. A key aspect of this theory is that individuals interpret symbols based on their social interactions and engage with others accordingly.

In this study, Symbolic Interaction Theory is used as a framework to understand the religious symbols and rituals associated with illness and death used by Muslim families of children receiving palliative care and end-of-life care. The use of this theory is appropriate for understanding Muslim families' decisions, as their religious rituals and cultural traditions influence how they interact with health professionals regarding their child's care, make decisions, and take actions. Based on their interpretations of religious teachings and cultural practices, their actions are guided. Additionally, their actions are influenced by their perception of the consequences of these actions for their child with a life-threatening illness. Therefore, the health care provider should possess a thorough knowledge of the meaning behind the family's cultural and religious practices. Increasing awareness of these issues would enable children and their families to receive better care and support. In contrast, a lack of understanding can lead to conflict and confusion, resulting in dissatisfaction with the care provided.

Families may make decisions based on their perceptions of religious teachings, cultural practices, and what they believe is in the child's best interests. The relevance of this theory to the study lies in the fact that it offers insight into family-provider interactions and how families use cultural or religious symbols when making decisions or requesting services. By adopting a symbolic interactionist approach, this study aims to look at the way people interact with each other, how their identities are shaped by the meanings they attach to their actions, and how their cultural beliefs shape their behaviour. Ultimately, this study provides insight into how people form and maintain relationships.

Structural Functionalism Theory:

Structural Functionalism is one of the theoretical frameworks used in this study. According to Griffiths (2015), functionalists view society as a system in which its separate components must work together for the system to function properly. In this respect, the human body is used as an analogy, since the human body is dependent on its organs to function properly (Griffiths, 2015). As noted by Yang and Zhang (2023), Structural Functionalism Theory suggests that certain aspects of society, such as institutions, roles, and norms, exist to ensure society's long-term survival. The family system and religions are two examples of institutions in society, each with its own components that contribute to its survival either explicitly or implicitly (Yang & Zhang, 2023). Families are considered one of the most important units of society, since they play a key role in raising children, providing emotional support and guidance, and establishing social norms. Therefore, the health and wellbeing of family members play an important role in the survival and functioning of a family's institution (Yang & Zhang, 2023). Nevertheless, there are situations and change of circumstances that families can experience such as a child’s illness that can significantly impact the family and its wellbeing. Considering the family is a unit, if one member is affected by an adverse situation, like an illness, the entire family will suffer. As a result, the presence of a child suffering from a life-threatening or life-shortening illness would greatly affect the performance of the family. Thus, Structural Functionalism provides a theoretical framework for examining the importance of families in society and their role as contributing members. When studying families of children diagnosed with life-threatening illnesses, it is important to understand this theory, since the children's lives may be shortened, which would hinder the family's ability to function as an integral part of society.

Ecological Systems Theory:

The Bronfenbrenner Ecological Systems Theory (EST) is another theory used as a framework. In the context of this study, EST proposed by Bronfenbrenner is utilized in understanding the factors influencing Muslim parents in making decisions for their children in palliative care as perceived by healthcare professionals. The ecological systems model is one which conceptualizes an individual's development in terms of their surrounding environment and settings (Kazak, 1989). Bronfenbrenner argues that human development is profoundly influenced by the natural environment in which they live (Chandran et al., 2016). Hence, Urie Bronfenbrenner developed the Ecological Systems Theory to address the way in which the environment around children affects the child's development and interrelationships (Chandran et al., 2016) directly or indirectly (Crawford, 2020). This model suggests that a person's environment is made up of many interconnected systems, all of which interact to influence and shape how the individual grows and responds. Specifically, the model consists of nested systems that provide a framework for understanding social forces that influence human development (Crawford, 2020). Namely, there are five different subsystems that make up the ecological systems model: the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem, all essential for human growth (Bronfenbrenner, 1994).

In this model, the child is positioned at the centre of concentric circles representing the various sets of interconnected systems within the child's environment and each circle becomes increasingly distant from the child and bidirectionally influence the child’s development and wellbeing, directly or indirectly (Kazak, 2006;

Kazak et al., 2002). This implies that children are embedded in a variety of systems, from those that are close to them, such as the family, to those that are more distant, such as the cultural system (Chandran et al., 2016). The family is situated in the level directly surrounding the child, indicating that it is in the area where the child is directly involved and closely interacted with (Kazak et al., 2002**)**. The next level, which is also close to the child, is the point at which the family interacts with the healthcare team (Kazak et al., 2002**)**. Subsystems distant from the child include interactions between extended families, neighbourhoods, and communities.

It is widely used in fields such as education, social work, and family therapy to explain children's development based on the interrelationships between them, their families, and their surroundings. Using the ecological systems theory of Bronfenbrenner as a theoretical framework, one can examine the relationship between individuals and their environments (Algood et al., 2013) and determine how the various subsystems of the environment can influence someone's development (Crawford, 2020). Through the ecological systems model (Algood et al., 2013), a variety of issues can be assessed, including family relationships, mental health issues, healthcare social problems, inadequate income, conflict with law enforcement agencies, educational challenges, and unemployment (Algood et al., 2013).

Bronfenbrenner's Ecological Systems Theory is used in this study as the theoretical framework for this study. Through use of this model, it would be possible to examine the environment surrounding Muslim families with children with life-threatening conditions who are receiving palliative care or who are expected to be near the end of their lives, and the way the interrelations between the systems impact Muslim families and how the interrelationships between the systems affect Muslim families and their ability to make decisions consistent with their faith and culture and in the child's best interest. Figure 1 below illustrate the patient, which is the child in this study, and the systems around them that impact their care.

Incorporating Symbolic Interactionism, Ecological Systems Theory, and Structural Functionalism provides a valuable insight into the barriers that healthcare professionals encounter when caring for Muslim children in palliative and end-of-life care. They stress the importance of cultural understanding and cultural sensitivity, the ecological context surrounding the care of Muslim children, the importance of collaboration across systems, and the influence of structural factors on healthcare practices.

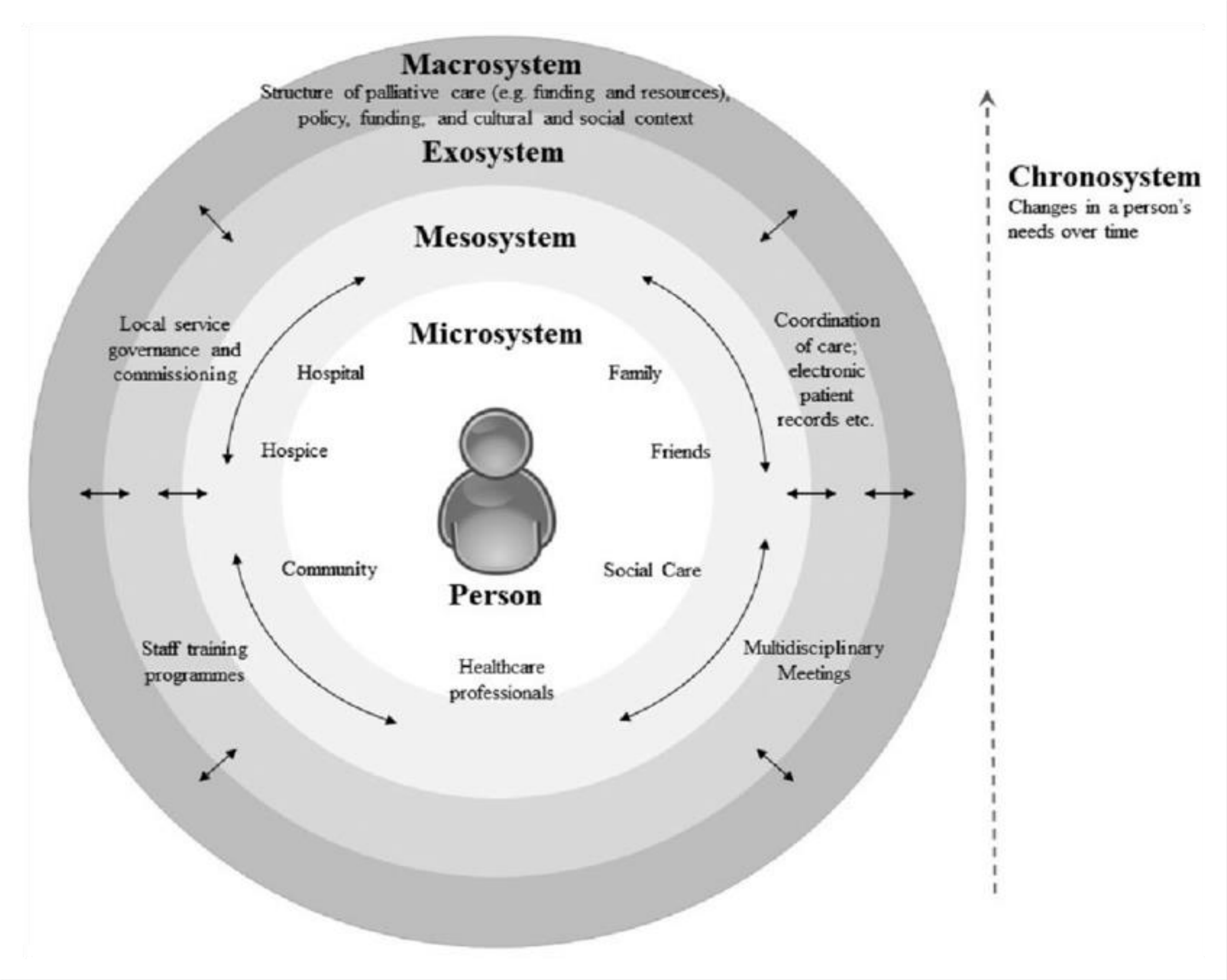

Figure 1: Ecological Systems Theory (for patients)

Chapter 4: Methodology

Introduction:

This chapter outlines the methodological basis and the considerations of the overall research design for this qualitative research study investigating the impact of Islamic teachings and culture on decision-making for Muslim families caring for children with life-threatening conditions, receiving palliative care or end-of-life care. Throughout this qualitative study, the primary objective is to examine and understand the factors that influence healthcare providers when caring for Muslim children and their families. In this context, the study is exploring the barriers they encountered that may have an impact on the care they provided. In adopting a qualitative research design, the study aims to gain insights into the lived experiences, perspectives, and behaviours of the participants, thereby providing rich and insightful information. Detailed information is provided about the research setting, sampling methodology, research participants (including inclusion and exclusion criteria), recruitment process, interview process, ethical approval of the study, data collection, and analysis. Moreover, ethical considerations regarding participant consent, confidentiality, and researcher reflexivity are thoroughly addressed to ensure the integrity and validity of the study.

Purpose of the study:

Using a qualitative approach, this study examines the influence of Islamic culture and religion on Muslim parents caring for children with serious illnesses and receiving palliative care at the end of their lives. The study also incorporated the perspectives of healthcare professionals and prequalified social work students regarding caring for Muslim children at the end of their lives. The study aims to contribute to providing care and support to ethnic minorities of Muslim faith. This will be done by implementing culturally and religiously appropriate programs for children with life-threatening illnesses and their families. The information can be transferred to other settings, including education and other support programs, where religion and culture may pose challenges to Muslim children and young people, to help design and implement culturally and religiously appropriate programs. Also, the study is intended to be instrumental in health and social care policy by focusing on cultural and religious policies relating to paediatric palliative care and end-of-life care.

Research Question:

How can the Islamic culture and religious teachings impact paediatric palliative care and end-of-life (EOL) decision-making for clinicians, and parents of children with life threatening illness?

Objectives of the study:

- To examine the extent to which faith and culture influence the decision-making process of Muslim parents whose children are diagnosed with life-threatening illnesses.
- To examine whether faith or culture can serve as coping mechanisms for parents and shape their views of their children's conditions.
- To explore the challenges that pre-qualified students and health care providers face in understanding the culture and traditions of their patients in regard to paediatric palliative care and end-of-life care in relation to their Islamic faith and culture.
- To identify and analyse the institutional factors that facilitate or hinder the inclusion of the Islamic faith and culture in paediatric palliative care and end-of-life care.

The Research Design

Research Paradigm:

Constructivist and interpretivist position

Methods of qualitative research are associated with interpretive approaches. The method involves asking questions and observing to gain a deeper understanding of the phenomenon being studied. Researchers use interpretive paradigms to examine the world from the perspective of participants. Through their experiences, researchers examine how people perceive or construct reality (Thanh & Thanh, 2015). Qualitative methods that take an interpretivist or constructivist theoretical perspective allow researchers to access the individuals' perception, as well as the meaning they give to their experiences (Saks & Allsop, 2013). In contrast, and taking survey data for example, may provide important information regarding the number and demographic traits of individuals with chronic illnesses (Saks & Allsop, 2013), yet it may provide insignificant data about people's experience living with a chronic illness (Saks & Allsop, 2013). Therefore, the use of unstructured and in-depth semi-structured interviews is a better choice to address the research objectives and achieve a valuable result (Saks & Allsop, 2013), and suitable when exploring sensitive issues (Elmir et al., 2011).

Rationale behind methodology

The overall design for this study is qualitative, which is deemed most appropriate for answering the research question and addressing the objectives. Qualitative research focuses on the meaning of participants' views and perceptions as opposed to quantitative approaches which may for example control results in controlled experiments (Strang, 2000). Therefore, studies using qualitative research methods are helpful for discovering how people make sense of the world around them (Spruyt, 2016). Similarly, Strang (2000) indicated that qualitative methods are better suited to examining people's attitudes, perceptions, thoughts, experiences, expectations, and motivations. The current study is interested in exploring how and why religion and culture are important aspects of end-of-life decision making; thus, qualitative research methods are best used for exploring people’s life experiences or common practices (Silverman, 2011).

Since this study focuses on children’s palliative care and end-of-life care, it is considered sensitive. The use of qualitative research is highly suitable for research on sensitive subjects such as palliative care since it allows the researcher to touch both the surface and the deeper emotions and feelings that are reflected in the responses of the participants (Wilkie, 1997). Though caution should be taken in undertaking sensitive research, for instance, the researcher may, delve into a participant's feelings when discussing sensitive issues and trigger feelings that may include pain, treatment-related feelings, and death (Wilkie, 1997). According to Elmir et al. (2011), sensitive topics may potentially cause physical, emotional, or psychological distress to participants or the researcher, provoking intense emotional reactions like humiliation, sadness, anger, fear, and anxiety. Research that is qualitative involves the emotional component of the phenomenon being explored, for example, palliative care research (Wilkie, 1997**).** Hence, participation in the study may result in some participants experiencing discomfort or emotional distress as a result of their increased indulgence in their current situation (Alexander, 2010). It is therefore important that the questions asked of participants are thoroughly considered and carefully chosen in order to be appropriate and to reduce the likelihood of triggering negative feelings on their part (Wilkie, 1997).

Research Strategy

Inclusion and Exclusion criteria:

One of the imperative aspects of developing high-quality research protocols is establishing criteria for inclusion and exclusion (Patino & Ferreira, 2018). It is the inclusion and exclusion criteria that determine who may be included in the study sample or not (Garg, 2016). Inclusion criteria define which characteristics are required of the targeted population for them to be included in the study, which facilitates answering the research question (Patino & Ferreira, 2018). Inclusion criteria may include demographics, geographical characteristics, and clinical characteristics (Patino & Ferreira, 2018). Contrary to inclusion criteria, which simply describe the characteristics individuals are required to possess to be eligible to participate in the study, exclusion criteria are those factors or characteristics that make individuals from the target population ineligible for the study (Garg, 2016). Exclusion criteria are characteristics that are potentially detrimental to the study's success or that may lead to a negative outcome (Patino & Ferreira, 2018).

The study's inclusion criteria:

In this study, the target population included Muslim parents, healthcare professionals, prequalified students, as well as leaders of the Muslim community and mosques. Muslim parents over the age of 18 who are caring for a terminally ill child whose life could be cut short by their illness were eligible. Also included in the study were mosque leaders, known as imams, and community leaders 18 years of age and older. These leaders work with Muslim communities in Wales. Also included in the study were prequalified students attending university in Wales. To be considered eligible for participation, students must be at least 18 years of age and enrolled in a social work or nursing degree program at a Welsh university. The inclusion criteria for healthcare professionals consisted of paediatric palliative care nurses, physicians, and general practitioners (GPs) from England and Wales.

Sampling Strategy and participants recruitment:

Study populations are groups of individuals, or even objects, whose characteristics, or behaviours a researcher wishes to examine (Berndt, 2020). As a result, the study's outcome would be based on data provided by or collected from the study's target population (Garg, 2016). Generally, it is difficult to gather information from everyone in a target population since it is usually very large (Stratton, 2021). Thus, the researcher must select a sample of eligible people in a population (Garg, 2016). Therefore, sampling techniques should be used to obtain samples deemed representative of the population to be examined (Berndt, 2020). Commonly, research sample selection strategies can be categorized into two general categories: probability sampling and non-probability sampling (Stratton, 2021). In quantitative research, there is a choice between probability or non-probability sampling methods (Berndt, 2020), whereas in qualitative research sampling methods are only non-probability, also known as non-random sampling methods (Gill, 2020). In qualitative studies, researchers select participants for the study who are able to be interviewed or observed for the purpose of the study in order to obtain their perspectives to gain a deeper understanding of the phenomenon in question (Gill, 2020). In quantitative studies it is highly desirable to obtain a random sample, since the aim is to reduce selection bias, whereas in qualitative studies, the aim is to study in depth phenomenon, and they are not typically concerned with generalisation, as long as the data saturation has been reached. Non-probability sampling techniques include purposive sampling, snowball sampling, quota sampling, and self-selection sampling (Berndt, 2020). The process of deciding on the appropriate sampling methods requires consideration of some aspects of the study, such as the research question, study design, elements of the population of interest, such as understanding of the population, their differences and similarities, and the size of the population (Berndt, 2020). As a result of these strategies, concepts and theories can be derived, or selected individuals and groups' experiences can be understood (Devers & Frankel, 2000).

Considering the research question and the sensitive nature of this research, purposeful sampling was deemed the most appropriate method of selecting participants from the target population. Purposive sampling involves participants chosen directly by the researcher. Another type of non-probability sampling used in this study was snowball strategy. Snowball recruitment, according to Gill (2020), where participants are referred to the researcher, which is different from convenience sampling, in which participants choose whether to participate after the study has been published (Stratton, 2021). The use of sampling strategies can be combined (Gill, 2020). This section will describe the sampling methods and recruitment strategies used for this study in more detail.

Sampling Strategies:

As mentioned previously, purposive sampling strategy was used in the present study, which is a type of non-probability sampling strategy also known as judgment sampling (Etikan, Musa, & Alkassim, 2016), which is different from random probability sampling (Devers & Frankel, 2000). In purposeful sampling, groups, individuals, or a set of behaviours are intentionally selected that provide insight into the topic being addressed (Devers & Frankel, 2000). By using purposive sampling techniques, the researcher seeks out individuals who can provide information, either through their experience or their knowledge (Etikan, Musa, & Alkassim, 2016). For this study, participants were Muslim families caring for children and young people with life-threatening conditions who were receiving palliative care at the end of their lives, pre-qualified social work students, and healthcare professionals providing palliative care to children and young people. The individuals represented specific populations, served specific purposes, and expressed their perspectives in light of their knowledge and experience.

Another non-probability sampling strategy is snowballing sampling (Berndt, 2020). Snowball sampling is characterized by an increase in the number of participants over time, similar to how snowballs accumulate snow as they roll down hills (Sedgwick, 2013). The effectiveness of this strategy depends on the first participant because they are the first step in locating other suitable participants (Berndt, 2020). This process could be used if it is difficult to recruit participants from a desired population due to access restrictions, “hard to reach” or hidden groups who may experience social exclusion, or disempowerment (Sedgwick, 2013). As in the present study, snowball sampling was incorporated to facilitate the recruitment of additional participants at a later stage as a result of a lack of participants following purposive sampling. Community leaders, health care professionals, and pre-qualified students were asked to share details about the study with other potential participants.

Process of recruiting participants:

Recruitment:

The study included health care professionals and Muslim parents from England and Wales. It also included pre-qualified social work students from a university in South Wales, and leaders from mosques and Muslim communities across South Wales. To facilitate recruitment, community organizations, mosques, hospices for children, and paediatric associations were consulted and agreed to act as gatekeepers. At the beginning of the study, the researcher emailed information packages detailing the objectives of the study, the risks and benefits to participants, and the nature of their involvement in the study to the relevant gatekeepers. Upon reviewing the information, gatekeepers agreed in principle until ethical approval and NHS research governance was obtained. Upon obtaining these, the researcher provided it to the gatekeepers. In turn, the gatekeepers shared the information with eligible participants, and those who were interested contacted the researcher directly.

Parents:

In this study, gatekeepers served as the link between the researcher and potential participants. To recruit Muslim parents, the researcher contacted children's hospices from England and Wales, youth cancer organizations, Together for Short Lives, which provides services to children and young people with life-limiting and life-threatening conditions throughout the UK, and from an organisation that caters for youth and other individuals from various ethnic minorities, which operates in South Wales. The researcher provided information about the study to potential gatekeepers, explaining the nature of the study and the involvement of the parents. In the following weeks, the gatekeeper evaluated and re-evaluated the study objectives and distributed the information to all eligible participants using the hospice or organization. The Teenage Cancer Trust was approached to act as a gatekeeper. The organization requested a form be completed, as well as additional details be provided. Following completion of all questions, the organization declined the request due to a lack of resources and internal procedures.

Children and young people:

Throughout the study, a qualitative approach was used. It should be acknowledged and reflected upon that from the outset of the study’s conception and initial aims, the targeted populations included Muslim parents, both mothers and fathers, caring for a child with a life-threatening condition and at the end of life, children living with a life-threatening condition, and approaching the end of their lives, as well as health care providers caring for children in palliative care. Study participants, both parents and children, are more likely to be vulnerable due to their personal circumstances, living with a terminal illness, and caring for a child with a life-threatening illness.

Initially, the study was designed to include children and young people aged 13 to 18 from England and Wales, with the objective of investigating their perceptions of Islamic teachings and culture and their ability to cope. The goal was to conduct narrative interviews with 20 children and young people between the ages of 13 and 18, lasting 30 minutes to one hour. I wished to explore children's and young people's world through conversation, discussing spirituality as a coping mechanism, and how their faith and Islamic culture influenced their lives. The interview also sought to explore children and young people's non-medical decision-making abilities, hopes, fears, and autonomy despite their conditions.

Gatekeepers assisted recruitment by acting as the first point of contact. Parker (2006) outlined multiple ways of gaining access to participants, including hospice records, hospital records, or referrals from GPs or other health care providers. Therefore, for this study, a variety of gatekeepers were contacted, including hospices for children, organizations for children with life-threatening and life-limiting conditions, and specialized children's hospitals. The gatekeepers were initially welcoming and agreed to take part in principle. As indicated by Parker (2006), gatekeepers have a legitimate responsibility to evaluate researchers' credibility and ensure research is ethically valid. During the course of the research study, some gatekeepers and individuals who initially agreed to participate in the study changed their roles and no longer held those positions. This caused the study to be transferred to other individuals in charge, who decided to re-evaluate the study's objectives at a later date, resulting in some delays in data collection. As Parkes (2006) argues, gatekeepers may place strict measures in place to prevent terminally ill and bereaved individuals from taking part in research, forcing researchers to alter their sampling methods. Hence, the researcher modified the methods of this study in order to meet the requirements of gatekeepers.

Regardless of the change in leadership, gatekeepers were committed to supporting the study and willing to recruit parents and children. In spite of efforts to simplify the information specifically for children and young people, and to ensure that the concept and the questions to be asked do not create additional burdens for participants, the initial intentions of the study were abruptly halted due to the outbreak of Corona virus which forced gatekeepers to halt recruitment. Children and young people with life-threatening and life-limiting conditions were exposed to additional challenges due to the COVID-19 pandemic (Scott et al., 2022). As a result of these challenges, other family members have been burdened with more care due to disruptions associated with service provision, including changes and cancellations of appointments, delays in home services, or loss of respite and in-home carers (Scott et al., 2022). In consequence, the recruitment process for this study had to be temporarily halted due to the perceived additional burden on children and young people and their families, while coping with existing pandemic-related distress. While the researcher continued to communicate with gatekeepers in order to identify more manageable methods of accessing children and young people, the decision that was deemed in the best interest of children, young people, and families was only to recruit parents, excluding children and young people from participating.

Ethical considerations:

In research relating to palliative and end-of-life care, research ethics boards (REBs) tend to be overly protective of participants because they are presumed to be vulnerable (Tomlinson et al., 2007). The ethical approval of this study was therefore a crucial and lengthy process that was required before it could be conducted. Two different pathways were followed to obtain the ethical approval; the first was through Swansea University's College of Human and Health Sciences Research Ethics Committee (CHHS), and the second was through the National Health Service Research and Governance process (NHS). A detailed discussion of both routes will be provided in this section. The steps taken to ensure ethical principles such as beneficence and nonmaleficence, informed consent, confidentiality, and privacy will also be described thoroughly.

Ethical concepts are largely derived from the principles of doing good (beneficence) and avoiding harm (nonmaleficence). As beneficence ensures the welfare of participants and society, nonmaleficence aims to avoid harming these participants and society (Avasthi et al., 2013). To comply with the principles of beneficence and non-maleficence, the study's benefits must be weighed against its risks (Houghton et al., 2010). Other ethical principles that are commonly applied when conducting health care research include autonomy (Goodwin, Mays, & Pope, 2020), confidentiality, informed consent, privacy, the ratio of risk to benefit, and the reporting of data and results (Hasan et al., 2021; Houghton et al., 2010; Orb et al., 2001). It is fundamental to adhere to these ethical principles at each stage of the research methodology to protect not only participants' rights, but their dignity as well (Hasan et al., 2021).

According to Tomlinson et al. (2007), ethical considerations and challenges to participation in paediatric palliative care research arise primarily from nonmaleficence and beneficence; that is, there is a risk of harm outweighing benefit. Participants may be subjected to a potential burden resulting from their participation in the study, and there is the possibility that children may not be aware that they will be dying, and parents may still be in denial about their child's inevitable death or may not be able to accept their child's inevitable death (Tomlinson et al., 2007). Studies incorporating ethical study designs, sampling techniques, data collection methods and tools, and data analysis techniques are likely to produce more accurate results (Hasan et al., 2021). Therefore, a framework informing the study's design should be incorporated, and the methods used to collect data should be tailored to the study's objectives (Seymour & Ingleton, 1999). Thus, this study was conducted in accordance with all the ethical principles mentioned above.

Informed consent:

Research studies require informed consent from participants. In qualitative research, consent is not always obtained once and straightforwardly, as it may need to be continuously negotiated as the study progresses (Goodwin et al., 2020). Based on this, Orb et al. (2001) state that informed consent is often viewed as an ongoing process rather than a one-time event. At various points throughout the research, participants may need to re-negotiate their consent to participate due to changes they have experienced or events that may require them to adjust their consent (Orb et al., 2001; Houghton et al., 2010). Access to information that clearly describes what the study may entail is part of autonomy (Goodwin, Mays, & Pope, 2020). Participant autonomy requires that sufficient information be provided about the study, including information about the potential risks and benefits of participation (Avasthi et al., 2013). As such, those invited to participate in research need to be informed about how the research will be conducted as well as what they will need to do (Wilkie, 1997), including the approximate length of time required, the procedures to be followed, and the potential risks involved (Scott, 2017). Moreover, those taking part in the study should be informed that participation in the study is voluntary (Goodwin et al., 2020), as they may refuse to participate (Avasthi et al., 2013) and withdraw from the study at any time without penalty (Orb et al., 2001). By receiving such information, participants can make an informed decision regarding their participation in the study (Scott, 2017). It is important to allow participants sufficient time to consider all the details before choosing to take part in the study (Avasthi et al., 2013).

For this study:

Parents, pre-qualifying students, and most leaders were continuously asked to consent to participation throughout the study. During the consent process, participants were first asked if they agreed to participate in an interview, after which consent was obtained prior to the interview, including consent for the interview to be audio-recorded and a written consent. During the recruitment process, gatekeepers shared information about the study with potential participants, including participant information sheets for health care professionals [see appendix A] and parents [Appendix C]; as well as consent form for parents [see appendix E] and for healthcare professionals [Appendix F]. Research participants were given sufficient time to consider the context of the study. While conducting the interview, the researcher demonstrated empathy and care for the participants and allowed them adequate time to respond. It was the researcher's intention to stop the interview if any of the above risks arose during the interview, console the participant, and provide participants with the option of either resuming the interview, or being debriefed and provided with all necessary contact information to decide whether to proceed with the study at a later date, or withdrawing from it.

Anonymity and Confidentiality

Confidentiality and privacy are fundamental ethical principles (Avasthi et al., 2013). Participants should be assured that their identity and any information they share will remain confidential prior to participating in the study (Wilkie, 1997). A way to maintain their privacy is to use pseudonyms and avoid characteristics that would reveal their identities (Houghton et al., 2010). Respondents' names should remain anonymous to conceal their identity and prevent it from appearing in the research tools or in the results (Sarantakos, 2013). Names should not be included in questionnaires or interview guides, and informed consent forms, if names are available, should be kept separate from the data so they cannot be linked (Sarantakos, 2013). In research-related data intended for publication, names should not be included, and any other information should make it impossible to identify a particular respondent (Sarantakos, 2013). Furthermore, individuals taking part in the study have a right to know who has access to their data, since knowing who has restricted access and who does not may encourage them to share sensitive information more freely (Wilkie, 1997).

During all stages of the research project, participants' confidentiality must be protected (Wilkie, 1997), not only during data collection but also in any publications related to the study (Orb et al., 2001). Upon completion of the research, the data should be retained for a specified period of time for a number of purposes, including evaluation, further research, additional monitoring, or legal reasons, such as when the authority requests an investigation (Avasthi et al., 2013). Nevertheless, the researcher must disclose any information that could harm or threaten participants or others, such as information regarding drug trafficking, abuse, and criminal activity, despite the fact that participants' information is confidential and private (Orb et al., 2001).

For the current study: The interviews with healthcare professionals and pre-qualified students were conducted online, through Zoom and Microsoft Teams. To ensure the privacy of participants, the interviews took place in a private room, where only the researcher was present. The participants' consent was obtained to record the interviews for transcription later. For the parents, initially, the interviews were intended to be face-to-face, in a location that convenient and easily accessible to the participant. Therefore, for the mother in this study, the interview was conducted face-to-face, at her house, as it is the most convenient location for her, considering her circumstances as a caregiver. To ensure privacy, the interview was in a separate room, where only the mother was present.

Transcribing and analysing the data were completed solely by the researcher. The collected data was anonymized, pseudonyms were used, and any other potentially identifying information, such as names of third parties, places of residence of children and young people, organizations, etc., was removed from the transcription. The analysed data was saved electronically in an encrypted format and stored on a secure university cloud drive. Personal information requested for research purposes was kept confidential. It should be noted that the identities of respondents were kept anonymous during the presentation of the report at conferences, and if the findings were published, the respondents' identities would remain anonymous as well. In accordance with mention the name of the GDPR regulation and Swansea University's guidelines, the data will be preserved and accessible for a minimum of 10 years after the research is completed. Records from studies with major health, clinical, social, environmental, or heritage importance, novel interventions, or studies that are ongoing or controversial should be retained for at least 20 years after completion of the study. It may be appropriate to keep such study data permanently within the university, a national collection, or as required by the funder’s data policy.

Risks and benefits of the current study:

Despite numerous arguments that research is an undue burden on families of dying children, some studies have demonstrated that bereaved parents who participated in research did not experience distress as a result of their participation (Tomlinson et al., 2007). Accordingly, some parents have participated in previous studies where they were either unaffected by their involvement or felt positive following their involvement (Tomlinson et al., 2007).

Risks

Participants were not expected to face any physical risks. Nevertheless, due to the sensitive nature of the topic, participants were at risk of emotional distress. Participants were permitted to withdraw from the study at any time during the study. According to Melville and Darren (2016), sensitive research can involve taboo, intrusive, or stigmatizing topics that can pose emotional challenges to participants and force them to confront personal issues that could be distressing (Melville & Darren, 2016). In addition, participants were free to withdraw from the study at any time without providing a reason or incurring any penalty. The interview times were determined based on the convenience of the participants.

For mosque-leader, health care professionals, and pre-qualifying students: Health care professionals, pre-qualifying students, and mosque leaders may find it uncomfortable or distressing to discuss end-of-life issues and the support they have provided to families of children with terminal illnesses. As a result of their emotionally demanding roles, they may experience some distress. Some may recall events or children who have died. They may also remember close relationships with their patients/clients due to empathy, or simply because they feel helpless at times.

Potential risks for parents: There are no doubts that the death of a child is one of the most challenging and devastating events that a family can experience (Goldman, 1998); it is even more difficult for parents and health care professionals (Price et al., 2005). The care of a child suffering from a life-threatening illness can be extremely stressful for parents. There is a great deal of stress that arises from being a caregiver, which is not only physical but also emotional due to the feeling of helplessness that comes with witnessing their child's pain and suffering, as well as facing the uncertainty and the possibility of losing their child. Interviews with parents may result in emotionally distressing and burdensome episodes related to the situation of their child and the impending death of the child. It is possible that the emotional distress is caused by a parent's fear of losing their child or of feeling helpless in the face of the difficulties that their child is experiencing.

Ameliorating risks to participants:

There was a plan in place to terminate the interview if a distressing issue occurred for any of the participants. Furthermore, participants would have been provided with support, including signposting to appropriate services and the option to withdraw from the study or arrange for an interview at a more convenient time. According to Orb et al. (2001), stopping an interview and offering support and referral to appropriate services in response to the participant's distress is an indication that the researcher acknowledges and respects the participant's rights. Alternatively, the decision to not terminate interviews or observation when participants are distressed may reflect that the researchers consider the benefits of the research to outweigh the distress experienced by the participant (Orb et al., 2001). Maybe also mention here about a debrief sheet and signpost to a copy in the appendices.

Benefits of the study:

It is important to note that participants were informed that their participation would not result in any direct or immediate tangible benefits. Wilkie (1997) emphasizes that patients and those participating in palliative care research should be aware that benefits may not be apparent immediately but may appear over time. A potential benefit of palliative care and end-of-life care research is to improve future patient outcomes and experiences (Tomlinson et al., 2007). It is, however, suggested by Sivell et al. (2015) that taking part in such interviews could have a positive impact on participants, as it allows them to talk about loved ones or to express their fears and hopes, which may have a therapeutic effect.

Overcoming ethical and methodological limitations

As acknowledged earlier, the study initially aimed to look at children's perspectives, and the literature has referred to the importance of including children in research regarding issues affecting them. However, the ethical board has the responsibility to protect participants from potential harms or risks placed on them that may be perceived as extra burden. This study has faced ethical challenges that has been mentioned in various literature. For example, the environment in which the study or interviews are taking place. In qualitative research, it is important to take into consideration the environment in which the research takes place, because it is expected to impact the relationship with participants. With children for example, the clinic and hospital settings are sometimes frightening, especially if children attend infrequently (Ireland & Holloway, 1996). In this study, the environment was considered multiple times and was modified accordingly to make it more convenient for participants.

Data Collection Method

Semi-Structured Interviews:

Healthcare professionals and prequalifying social students:

As mentioned, the study followed semi-structured interview techniques with healthcare professionals and pre-qualified social works students. Semi-structured interviews are commonly used in qualitative research (Doody, 2013). Semi-structured interviews are commonly used for flexibility, accessibility, and ease of understanding (Qu & Dumay, 2011). Aside from this, they are more convenient for obtaining information on significant aspects of behaviours and general experiences (Qu & Dumay, 2011). The modification of semi-structured interviews and the use of probes can enhance participant responses to questions (Qu & Dumay, 2011). In semi-structured interviews, the questions are set, but the researcher can adjust them to allow for clarifications from participants (Doody, 2013). It is also necessary to develop an interview guide in order to facilitate the collection of consistent information from all participants (Doody, 2013). Researchers can use semi-structured interviews to make adjustments and use probes to find different avenues they might not have thought of (Doody, 2013). The use of semi-structured interviews involves open-ended questions that are intended to enhance flexibility and allow the researcher to address unintentional issues that may arise (Doody, 2013). The use of semi-structured interviews involves open-ended questions that are intended to enhance flexibility and allow the researcher to address unintentional issues that may arise (Doody, 2013). Another aspect of semi-structural interviews that contributes to their flexibility is the researcher's ability to modify the wording and order of the questions according to the participant and the interview's direction (Doody, 2013). Additionally, it enables the researcher to ask additional questions (Doody, 2013).

Narrative Interviews:

Interviews with parents and children intended to follow an unstructured, narrative interviews approach. In the beginning, as mentioned before, children were expected to be potential participants. Therefore, taking into consideration their circumstances and development level, unstructured narrative interviews were the most appropriate data collection method. Even for parents, in this study, narrative interviews have been the suitable method because it would allow them to freely discuss their experience (Fox, 2009). Interviews using narrative techniques are used to gather stories of people's experiences (Anderson & Kirkpatrick, 2016). The use of a narrative approach in a study or practice complements the use of a patient-centred approach well (Anderson & Kirkpatrick, 2016). In this way, the narrative approach involves placing the participant at the centre of the study, and the results of the study are based on their experiences (Anderson & Kirkpatrick, 2016).

Narrative interviews follow a similar format to other types of qualitative research interviews (Anderson & Kirkpatrick, 2016). The questions are open-ended and designed to explore the why, what, and how that relate to the participant's experience (Anderson & Kirkpatrick, 2016). During narrative interviews, the interview schedule is not predetermined by the researcher in advance (Anderson & Kirkpatrick, 2016). Nevertheless, the interview is guided by the participant in terms of its content and pace (Anderson & Kirkpatrick, 2016). Participants decide whether to say anything (Anderson & Kirkpatrick, 2016). Therefore, a narrative interview differs from other qualitative interviews in that the participant is in control when it comes to what is most important to share, rather than the researcher taking the lead in terms of the study's direction (Anderson & Kirkpatrick, 2016). The narrative interviews are audio-recorded, followed by a verbatim transcription (Anderson & Kirkpatrick, 2016). In order to adequately capture and analyse narrative interviews, the researcher must constantly emphasize the participant's story throughout the data (Anderson & Kirkpatrick, 2016). This will allow the rich data to be clearly reflected and not lost in analysis (Anderson & Kirkpatrick, 2016).

Narrative interviews allow researchers to shed the light on people's experiences by gathering their stories (Anderson & Kirkpatrick, 2015). They are intended to explore meanings of individuals' personal experiences (Bingley, Thomas, Brown, Reeve, & Payne, 2013), from the perspective of the teller, in the context of their own life and experience (Gilbert, 2002). Unlike formal interviews, informal conversations do not impose strict rules and allow discussions to run naturally and easily (Ireland & Holloway, 1996). Due to the nature of narrative unstructured interviews, although participants may be willing to provide information, at times, they may require guidance about the amount of detail expected (Doody, 2013). Therefore, researchers can use probes, which are follow up questions used to encourage further elaboration or explanation by participants (Doody, 2013).

The interview with the parent participated in the study was flexible as it was guided by the mother's need and comfort to discuss her experience. The interview looked at the mother's attitude towards her child's illness and future prognosis. As mentioned, it was a narrative interview to allow the parent to talk freely about the impact cultural and religious values on her role and in understanding and coping with the child's illness and health deterioration. The discussion aimed to explore personal opinions about her child's care and if it's affected by religious beliefs or cultural values. In addition to their perspective on medical decisions at end-of-life and the way religion may influence their acceptance of it.

Interview process:

All interviews were carried out by the principal investigator in English, through Microsoft Teams or via telephone at times previously decided at participant convince. Interviews with healthcare professionals and social work students aimed to take between 30 minutes to 45 minutes. Interview questions guide was developed for both healthcare professionals' interviews [see appendix G] and pre-qualified students [See appendix H] based on the scope of the literature, and the scope of the research topic.

Particularly for interviews with social work students, it entailed two parts. First part was intended to explore the students' perceptions and understanding of cultural sensitivity when caring for individuals of ethnic minorities, especially Muslim children in palliative care and their families. The second part of the interview consisted of questions based on a case study, directed by the case of the child whose mother took part in the study. Since the mother's story included many powerful details about her child's condition, and how their community viewed it, it was used as a means of enticing students to think broadly and reflect on what they would do if this child was their patient. Conversely, interviews with parents and children were flexible as it was guided by the participants. Since the interviews with parents were intended to be narrative, unstructured interviews, questions were not predetermined. However, some questions were prepared, to direct the participants as needed. According to Anderson and Kirkpatrick (2016), a semi-structured interview technique can be incorporated into a narrative approach to health-related research. Using this approach, the researcher is able to create a topic guide that serves as a guide throughout the interview in order to ensure that the researcher does not lose track of what needs to be covered (Anderson & Kirkpatrick, 2016). All interviews were audio recorded for telephone interviews, and video/audio recorded for Microsoft Teams interviews, with participants' consent. However, in the case of any participant's objection to be audio-recorded or video recorded, the researcher will take alternative measures such as noting key words and manually record participants' responses. The researcher listened to what participants said, focusing on words, ideas and expressions to explore parents' experience, including their challenges, needs, and coping mechanisms.

Data Analysis Methods

Data Analysis

First, the data obtained through semi-structured virtual interviews with healthcare professionals was transcribed through Microsoft Teams. As for the telephone interviews with social work students, it was transcribed using a different digital software. This obtained data was then thematically analysed manually. The data was not digitally analysed through NVIVO because it was not extensive and can be processed manually. Thematic analysis is a widely used approach to data analysis in qualitative research (Bryman, 2012). This thematic analysis used the following steps:

Step 1: Reading and examining the transcribed data thoroughly to allow pattern identification.

Step 2: generating initial codes, then

Step 3: organize the initial codes into categories in order to generate themes (Onwuegbuzie et al., 2009).

As for the data collected through interviews with parents, which in this case was one interview, it followed a narrative analysis. In narrative analysis it is important to focus on the context of the narrative; the tone, imagery used by narrator, and the use of language (Anderson & Kirkpatrick, 2016). In other words, for this study, the emphasis was on how the parent experienced, perceived, and understood the place of Islam as it relates to their situation, their life-experience with the illness, their decision making and coping. Therefore, the researcher explored the entirety of a participant's story, paying attention to what the participant said and the way it was said. This was done by transcribing the data verbatim; reading and re-reading the transcript; and labelling relevant information and identifying patterns in the mother’s story that revolved or affected by her faith. It was all done manually.

To overcome the obstacles created by COVID, other ways were carried to ensure the research questions, it was decided to do extensive policy analysis on existing policies that are affecting children and young people with life-limiting conditions and at end of life. The following chapter consists of two parts: part A of the chapter discusses the findings of the interviews with healthcare professionals and prequalified social work students, and part B of the chapter will analyse the narrative interview with the Muslim mother in this study. Both will incorporate the theoretical frameworks of the study (Bronfenbrenner’s ecological systems theory, symbolic interactionism theory, and structural functionalism) throughout the chapter.

Chapter 5: Findings

Chapter 5A: Interview Insights: Healthcare Professionals & Social Work Students

Introduction:

Palliative and end-of-life care for children is characterized by profound complexities. These dimensions include medical, ethical, cultural, and spiritual aspects. Within this intricate pattern, the influence of religious beliefs, particularly Islam, on parental decision-making emerges as a significant yet understudied aspect. Considering the crucial role that parents play in the care of their children, it becomes imperative to understand how Islamic beliefs influence these decisions so that holistic and patient-centred care can be provided. This chapter provides the research findings addressing the following research question:

> ***How can the Islamic culture and religious teachings impact paediatric palliative care (PPC) and end-of-life (EOL) decision-making for clinicians, and parents of children with life threatening illness***?

In this study, qualitative research methodology was employed by conducting semi-structured interviews with healthcare professionals and pre-qualified social work university students involved in palliative care and end-of-life care for children. The study included 16 participants, in which 13 are paediatric healthcare professionals, mixed between consultants and clinical nurse specialists. The other three participants are prequalified social work students, two undergraduate students, and one postgraduate student. Through these interviews, the aim is to elicit perceptions and challenges encountered by participants, thereby providing insight into the multiple factors involved. In terms of social work students, this discussion looks at their perspectives of their preparation to work in a multicultural setting and caring for individuals from ethnic minorities, especially Muslim children in palliative care, and receiving end-of-life care. A comprehensive analysis of these findings aims to contribute to the growing literature on religion, culture, and healthcare decision-making, as well as provide useful insights for healthcare practitioners, policymakers, and educators.

A central component of the second part of this chapter (chapter 5 b) is analysis of findings from in-depth interviews with a Muslim mother caring for her daughter with Batten disease, a rare and degenerative neurological condition. The mother faces significant emotional and social complexities as she navigates her daughter’s extensive medical needs amidst considerable pressure and judgment from her community. Her decisions for her daughter’s care, though deeply personal and rooted in her understanding of faith, are sometimes perceived as a lack of trust in God or a rejection of hope for divine intervention and recovery. This experience underscores the tension that can arise when religious beliefs, medical realities, and community expectations intersect in challenging ways, particularly in end-of-life scenarios. As a result of highlighting the intersection between Islamic beliefs, parental decision-making, and healthcare provider barriers, this study aims to foster greater understanding, empathy, and inclusion in the provision of paediatric palliative and end-of-life care within diverse cultural settings.

In this part of the chapter (5a), key findings and thematic analysis are presented from the research investigation into the influence of Islam on parental decision-making regarding healthcare decisions for children who are in palliative care or receiving end-of-life care, as well as the difficulties healthcare professionals face in providing culturally sensitive care to their children and their families. An inductive coding technique was used for thematic analysis, guided by theoretical frameworks integrating concepts and drawing on the theoretical frameworks of symbolic interactionism, structural functionalism, and ecological systems theory to identify the complex decision-making processes among Muslim families caring for children with life-threatening illnesses who require palliative care or end-of-life care, as well as the challenges faced by healthcare professionals and social work students.

As a result of the analysis, nine major themes were identified, namely Diversity in the workforce; Building relationships; The Role of Training in Enhancing Cultural Competence in Healthcare; Communication Barriers; Language Barriers; The Role of Faith and Culture in Shaping Personal and Social Identity; Family Dynamics; Family-centred care; and Accommodating Rapid Burial Rituals (see table 1). These themes demonstrate how Islamic beliefs and culture influence healthcare decisions and barriers to care for families of children receiving palliative care or end-of-life care. The themes relate directly to the research objectives of this study, thereby providing insight into the complex dynamics influencing healthcare decision-making among Muslim families as well as practical suggestions for improving cultural competency in health care provision.

Healthcare providers and pre-qualified social work university students have provided a considerable amount of information from their perspective and based on their experiences. Based on the interviews, healthcare providers and social work students had varying levels of experience working with children and families from Muslim backgrounds. Throughout the chapter, themes and subthemes are described by using details drawn from the research interviews, linked to the theoretical framework using Bronfenbrenner's Ecological Systems Theory, relating to Structural Functionalism and Symbolic Interactionism theories. All are supported with relevant quotations from participants. The selected quotations seek to highlight certain aspects of the lived experience of families, and the perceptions of healthcare professionals, social work students, and community leaders, in order to shed light on aspects that reflect the influence of the Islamic faith and culture.

Theme	**Subtheme**
Theme 1: Diversity in the workforce	Acknowledging the lack of cultural diversity in workplace
	Needs to increase representation and relatability
	Recruitment challenges
Theme 2: Building relationships	Community engagement
	Reaching Out to Muslim and Multifaith Organizations
	Efforts to improve community engagement and outreach:
Theme 3: The Role of Training in Enhancing Cultural Competence in Healthcare	Gaps in existing training:
	The Need for Enhanced and Tailored Cultural education Training:
	Professional responsibilities to self-learning:
	Suggestions to improve cultural trainings and education:

Theme 4: Communication Barriers	Difference in opinion about treatment options:
	Navigating Disagreements in Determining a Child's Best Interest
Theme 5: Language Barriers	Accessible Interpretation services
	Limitations of translation services:
	Challenges in accessing translation services:
	Suggestions to overcome language barriers and translation challenges
Theme 6: The Role of Faith and Culture in Shaping Personal and Social Identity	
	Source of comfort and support
	Impacting decision-making process:
Theme 7: Family Dynamics	Challenging gender norms and bias
Theme 8: Family-centred care	Recognizing that each child and family is different:
	Role of healthcare professionals in family-centred care
	Assessing the cultural and religious needs of families
	Institutional Roles in Family-Cantered Care for Muslim Families
Theme 9: Accommodating Rapid Burial Rituals	Challenges and barriers in facilitating rapid burial
	Advocacy of healthcare professionals

Table 1: Themes and subthemes from interview with healthcare professionals

Theme 1: Diversity in the workforce

One of the recurring themes in this study is the lack of diversity in healthcare and social work settings, where the workforce is predominantly white British or of other white origin. Several participants across the study express concerns about the lack of diversity in healthcare settings, particularly in social work and paediatric palliative and end-of-life care, and the challenges this presents when caring for Muslim children and their families, and other patients from various ethnic and religious backgrounds. Under this theme, three subthemes are addressed, namely, acknowledging the lack of cultural diversity in the workplace, the need to increase representation and relatability of different cultures, and barriers to recruitment perceived by some participants as contributing to the lack of diversity in healthcare workforce and social work educational programs.

Acknowledging the lack of cultural diversity in workplace:

The following findings explore the impact of the workforce on practice and support of families of children in palliative care in England and Wales. The participants in the following interview extracts agree that the workplace environment lacking cultural diversity and dominated by individuals of white backgrounds. As a clinical nurse specialist in the study stated:

> *"…challenges, so, I think as a hospice, the workforce is generally white British, and that's because some people that apply for the job, are white British people. It's very difficult to recruit people of other faiths and cultures really."*
> ***(Participant 4: Clinical Nurse Specialist)***

The above participant talked about the workforce being predominantly of White British which poses a challenge to providing culturally sensitive care to Muslim families. From a microsystem level perspective, healthcare professionals are in direct contact with children and their families, therefore, having a workforce that consist of healthcare professionals that are culturally diverse, it would better the communication between families, as they share similar cultural, religious, or linguistic backgrounds. In terms of recruitment, the exosystem is where interaction outside of the hospice take place, that indirectly impact the hospice workforce. For example, healthcare policies and local communities. In terms of policies, possibly at the national level, not prioritizing diversity initiatives, or inclusivity trainings. As for communities, not promoting hospice and career vacancies among ethnic minorities or culturally diverse individuals.

It was also highlighted by another participant, a consultant paediatrician, how ethnic diversity and representation in healthcare settings may contribute to improved outcomes for individuals from culturally underrepresented backgrounds. The participant stated as follows:

> *"I don't know if this is the right thing to say, I hope it's not offensive, but if we have a really, sort of all white, heavily Christian, it doesn't really matter about the religion, but service provided by people made up of that demographic. It perhaps looks less acceptable, looks more alien. So, I think having people who will just get it without having to have it explained."* ***(Participant 2: Consultant Paediatrician)***

Participant 2 is also acknowledging that the workforce is heavily represented by White, Christian healthcare staff. The participant emphasising that the religion may not be of a great concern, however, being of a white demographic might create a barrier to culturally sensitive care. Looking at the perception of this participant from a microsystem, of Bronfenbrenner's ecological systems theory, it is where the direct interaction between Muslim families and healthcare professionals occurs. Therefore, a predominantly white, Christian healthcare professional, may encounter challenges in navigating the beliefs and values of the Muslim families of the child under their care, since they do not share similar ideologies.

The inability to navigate such fundamental principles may lead to a sense of alienation or discomfort for families. This feeling of discomfort maybe due to their cultural needs not being understood or valued. Sharing similar cultural backgrounds, allow families to interact comfortably with the healthcare professionals. As the participant indicated, they may have an implicit understanding or cultural empathy that would allow them to understand the needs of the family. This would foster a sense of trust and acceptance. On the contrary, the lack of diversity may lead families to need to justify their cultural needs, which can add emotional strain and may hinder communication.

As for the following participant, specific attention was drawn to the lack of diversity among staff who provide home care packages:

> *"... the care packages that they have put in at homes, you do tend to find it's pretty much white British or European staff going in providing these care packages. And so, I think that's a bit of a barrier."* ***(Participant 11: Clinical Nurse Specialist)***

Looking at the statement by participant 11 from a mesosystem level, the interaction is between the different microsystems surrounding the child. In this case, it would be the family and healthcare professionals. Therefore, as indicated, the care packages, which are directly delivered to parents by individuals who are White British, would impact these direct interactions with families. Within the mesosystem, the interactions between the microsystems and microsystem environments are impacted. For example, when care packages are delivered by white British healthcare professionals, or the work setting is predominantly white British or European, or a largely Welsh context that seems to disregard other cultures, then that may lead to a disconnect between families and healthcare professionals because of the cultural differences.

Whereas the following Wales' based social work student broadens the conversation by suggesting that social work services, which is mainly in Welsh context should take into account the broader range of the populations being served:

> *"A lot of our work is of Welsh context, I think sometimes, we need to look more at other contexts as well, not just Welsh. Because obviously, they have got a broad kind of, you know, a lot of cultures at the moment within the job I'm doing."* ***(Participant 15: Year 1 BSc Social Work Student)***

As indicated in the above statements, some of the participants stressed the importance of having a work environment that is diverse in terms of culture, ethnicity, and faith backgrounds. Participants stated that most of the healthcare workforce is composed of white British individuals. As a result, the workforce does not reflect the diversity of the communities served, which can negatively impact inclusivity, as well as outcomes and experiences for patients and families. It may result in services, such as paediatric palliative care and end-of-life care, appearing less acceptable to diverse communities, such as Muslim families in this case. Hence, the following participants discussed the importance of increasing cultural representations as a way of enhancing cultural diversity of healthcare and social work settings.

Needs to increase representation and relatability:

Increasing the diversity of the healthcare profession would contribute to a richer, educational experience for students, lead to more relevant research, and facilitate health policy change (Sullivan, 2004). Consequently, as explained by Sullivan (2004), diversity in the healthcare workforce would improve cultural competency at different levels, including system, organisational, and provider levels, among other aspects of healthcare services. In the following extracts, a student of social work stresses the importance of increasing social work diversity, particularly by increasing the number of people from Muslim faith backgrounds and those of other ethnicities. The participant indicated:

> *"I think getting more, getting more cultures in social work, more people from Muslim background, more people from, you know, Turkish background and polish background."* ***(Participant 15: Year 1 BSc Social Work Student)***

Discussing this statement from the microsystem level, where interactions would be directly with children or young people, and at the mesosystem where interactions between the social worker and Muslim families, cultural representation would positively impact these interactions and relationships. Within the workforce, social workers from various Muslim, cultural backgrounds, such as Turkish, or Polish, would bring their unique cultural knowledge, language skills, and lived experience that would contribute to improving communication, empathy, and trust with Muslim families, and the child, or young person from similar backgrounds they directly interact with. Most likely they would be more comfortable communicating and sharing personal or sensitive information. Therefore, increasing cultural representation would lead to stronger micro and mesosystems, since these interactions would ensure cultural values and practices are met and respected.

The same participant reinforces their belief that a more diverse social work workforce would lead to better support for families across the region, by saying:

> *"I do think that maybe, there is room for more cultures within social work, so that we can support more families within Wales, if this is happening in Wales. And that we need to be a bit more diverse in how we work in social work."*
> ***(Participant 15: Year 1 BSc Social Work Student)***

Similarly, according to a consultant paediatrician in the study:

> *"So, having a service that's made up of people who perhaps come from a particular faith or community, so, those people that are working there are going to be culturally sensitive, and potentially more culturally acceptable."*
> ***(Participant 2: Consultant Paediatrician)***

In the above quotes, both participants agree that the workforce must become more culturally diverse. Looking at the participants' responses in terms of ecological systems theory, this implies that the lack of cultural representation would impact the family's microsystem.

In the student's opinion, it is imperative to include professionals from Muslim backgrounds specifically, as well as those from various ethnic backgrounds, in order to provide better social work services to individuals from Muslim backgrounds and other ethnic backgrounds. The student believes that increased diversity in the workplace can result in more relevant and sensitive services, which can enhance the effectiveness of social work services for people of diverse backgrounds. The consultant confirms the importance of having a diverse workforce from different faiths and communities would result in increased cultural sensitivity when providing care to children and families of different cultural and faith backgrounds. In other words, bringing people from underrepresented faiths or communities into the field has the potential to enhance the work environment by making it more culturally sensitive and acceptable to patients and their families. In some instances, people from certain cultures who work within a community may be more culturally sensitive because they are part of that culture and have a greater understanding of its requirements. There were a few participants who identified some challenges in recruiting individuals from ethnic minorities into the social work and paediatric palliative care workforces and suggestions to overcome such challenges; these will be discussed in more detail below.

Recruitment challenges:

The following participants identified some factors that may contribute to the lack of cultural representation in paediatric palliative care settings and in social work educational programs. One of the healthcare professionals claimed that there is a shortage of candidates from diverse ethnic backgrounds, especially Asian healthcare professionals. In the words of this participant:

> *"We've had them (Asian staff or people from other nations) in the past, you know, but not at the moment. Obviously, they're not applying for our jobs."*
> ***(Participant 12: Clinical Nurse Specialist)***

According to the above participant, there is a shortage of staff of diverse nationalities, including Asians, which implies that the healthcare workforce needs to be diversified. Several implications may be derived from this participant's presumption, "they're not applying for our jobs", including a lack of effort in recruiting diverse candidates, barriers to the hiring process, or broader systemic issues. From an exosystem perspective, the assumption that they are not applying the jobs could be associated with lack of recruitment strategies reaching these communities. Since the exosystem involves policies and law, it is also possible that not applying for certain position is linked to the position requirement that are placed by policies and regulations, that are limiting people of diverse backgrounds to be part of this work environment. For example, visa requirement or work eligibility.

One social work student attributed the lack of interest in social work to the limited knowledge of how to obtain an education in the field. In the opinion of this participant:

> *"I think perhaps, those cultures [Muslim backgrounds] may be lacking in how they can go around have an education in social work."* ***(Participant 15: Year 1 BSc Social Work Student)***

The same participant continued and suggested that the field of social work offers numerous opportunities, which could be better promoted to diverse communities:

> *"Maybe we need to promote that [social work] a bit more. Obviously, you know, when people come over here and they want opportunities, there's opportunity to be in social work. And I know that social work is always open for plans, there's loads of jobs, you know, within social work, and maybe we should kind of be promoting that as well for more cultures to be involved."* ***(Participant 15: Year 1 BSc Social Work Student)***

According to the social work student, social work is a field that always provides opportunities and is open to all, it is simply a matter of promoting it more effectively, especially for people of ethnic minorities. As this student explained, people coming to the country (presumably immigrants, refugees, and asylum seekers of diverse backgrounds) seeking refuge could benefit from social work as they seek better opportunities in the field. Despite not directly stating it, the clinical specialist nurse implies that it may be necessary to understand why these groups are not applying for jobs in paediatric palliative care and what can be done to promote their involvement.

The subthemes explored within this theme emphasize the importance of inclusivity and representation of diverse cultures and religious backgrounds within the fields of social work and paediatric palliative care. The participants in the above statements discussed their different experiences in relation to the lack of cultural representation in paediatric palliative care and in social work with children and young people. Apart from the general work environment, specific aspects of children's palliative care are also addressed, such as care packages or the social work context. As an example, a participant stated that care packages are primarily delivered to families by white British or European staff, and a student referred to social work as being influenced heavily by Welsh culture. These comments indicate that there is a lack of consideration for cultural diversity within these work environments, which may impede the effective care of individuals of other cultural and religious backgrounds.

Recruiting a more multicultural workforce could potentially improve outcomes, since it would reflect the diverse needs of the population being served. Thus, participants have suggested recruitment strategies aimed at promoting social work programs to underrepresented groups, such as Muslims. By increasing diversity in social work and paediatric palliative care, practices can be made more inclusive and culturally competent, ultimately improving the quality of care and support provided to individuals and families of diverse cultures. The following theme will explore building relationships as a way of improving culturally sensitive care for Muslim families.

Theme 2: Building Relationships

Among the themes that emerged were the importance of building relationships with different external relevant services to provide better support for families and children from diverse backgrounds, especially Muslim children and their families. Building relationships with external service providers, such as community nurses and hospices, and local palliative care teams, was among the suggestions made by one of the healthcare providers in the study to help improve culturally sensitive care for Muslim families. As stated by the participant:

> *"we've built the relationships with external services, like the hospice or the palliative care local team, or the community nursing team. So, being able to provide that respite, or being able to provide that family support, having a reason to visit, allows us to build relationships."* ***(Participant 2: Consultant Paediatrician)***

In the previous quote, the participant highlighted the importance of building relationships with external services such as hospices, palliative care teams, and community nursing teams. The participant has discussed the importance of building relationships with external services that are not limited to improving culturally sensitive care for Muslim children and their families but are applicable to children from diverse cultural backgrounds. As a result of connecting with external services, families would be able to seek out various forms of support that they deem necessary.

Collaboration with specialized external services is essential for providing holistic care and support as it allows for a more comprehensive and multifaceted approach to individuals and families from diverse backgrounds. Providing support such as respite care and visiting families are some of the ways relationships can be built and potentially strengthened. Consequently, direct interaction and assistance are fundamental to fostering trust and collaboration. This study will examine three subthemes: community engagement, reaching out to Muslim and multifaith organizations, and efforts to improve community engagement and outreach to Muslim families.

Community engagement

In healthcare, community engagement involves collaboration between health care providers and the communities they serve. When families within Muslim communities have children requiring palliative care or end-of-life care, community involvement requires building trust, understanding the community's needs, and ensuring the services provided are culturally and religiously appropriate, in addition to being accessible. Furthermore, the services provided should be relevant and tailored to the specific challenges faced by the Muslim community. According to the WHO (2020):

> *"Community engagement is a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes." (WHO, 2020, vii)*

The concept of working with the community goes beyond providing healthcare services, such as palliative care and end-of-life care. The process involves listening to the concerns of the community and involving them in decisions, as well as empowering them to take an active approach to their own health. It is possible for healthcare providers to build trust, improve health outcomes, and create a more inclusive healthcare environment through community engagement.

This study identified a few important aspects of engaging communities, and consequently, building stronger relationships and achieving better results. Based on an interview with one of the healthcare professionals, who is a consultant paediatrician, one area that needs further development to ensure a culturally sensitive and appropriate care for Muslim children and their families starts with the way information is shared and provided. The participant stated:

> *"I think it's about putting the right information out there, about what's available and what's on offer. And in a way that isn't sort of from outside?! I guess, what might be perceived as outside. So, if it comes from within the community and it comes from trusted professional. So, I think it's people that are living within a community or trusted within a community. I think if the information is put across*

> *in a way that allows people to feel it's trustable, if that's a word. But it's something that is not imposed and not external, but it's internal for community and it's part of what's available. And also, not taking away from what's already there."* **(Participant 2: Consultant Paediatrician)**

As indicated by the paediatrician in the above passage, sharing information starts with the way information is disseminated. It is not only essential to deliver the right information, but also to ensure that it is delivered by the right person. In accordance with what the participant mentioned, if information comes from within the community, it is more likely to be accepted and trusted, rather than coming from external sources. In this regard, it illustrates the importance of local, trusted professionals for disseminating information. In the context of Muslim families, this can play part in breaking down barriers and allowing for effective ways of conveying information without imposing it on families. Overall, the above participant holds the view that any information that is believed to be imposed would have a negative impact, and families in such cases may perceive it as intrusive. Instead, as highlighted by the paediatrician, presenting information in a way that is deemed mindful and respectful of the community's norms and values would possibly have a better outcome.

In the opinion of the same healthcare professional, some Muslim families, however, do not necessarily require additional family support; this is because they already have strong community support. Hence, engaging with communities by building relationships must be approached differently. This participant continued and said:

> *"I think finding other ways of building those relationships; professionals that might perhaps have skills that are needed at end of life, that won't be there in the community, so, the more specialist palliative care. And finding ways for local communities that allow mutually beneficial relationships to build early on, in a child's life. I think that's one of the challenges. And making it culturally useful and culturally acceptable."* **(Participant 2: Consultant Paediatrician)**

According to what the participant mentioned above, to meet the needs of these families, paediatric palliative care services should collaborate with other professionals with a wide range of skills not commonly available in the community. Such collaboration could be beneficial for families caring for children with life-limiting conditions as well as those who need end-of-life care. Furthermore, establishing these relationships at the outset of a child's diagnosis or even earlier in their lives may enhance culturally acceptable services by enhancing mutual benefit.

Reaching Out to Muslim and Multifaith Organizations

Several participants suggested that multifaith and Muslim organizations should be approached to bridge the gap between healthcare professionals in paediatric palliative care and Muslim families with children requiring palliative or end-of-life care. As a result of reaching out to and connecting with these organizations, relationships with families can be built and trust can be strengthened. A healthcare professional stressed the importance of having a multifaith organization that can be reached whenever necessary. The participant indicated:

> *"There needs to be more access to that kind of multi faith expert knowledge. And who we can reach out to. And as our networks build, we, you know, we've got more and more people that we do have that at the end of the phone who we can ring."* **(Participant 11: Clinical Nurse Specialist)**

Furthermore, the participant expressed the need for a multifaith organization that can be contacted without hesitation, to create an environment where inquiries are welcomed and promptly addressed. As stated by the participant:

> *"I just think having really strong multifaith communities or multifaith organizations who you can reach out to and say, I've got this question, could you help me?"* **(Participant 11: Clinical Nurse Specialist)**

According to the clinical nurse in the above quotes, it is important to have multifaith organisations that are easily accessible where there are individuals knowledgeable and have expertise in different religious and cultural matters related to end-of-life care. The availability of these services ensures that healthcare professionals can provide culturally and spiritually appropriate support to patients, not only of the Muslim faith, but also from other faith traditions. In the opinion of this participant, expanding the network would allow healthcare providers access to more experts in the field of cultural and religious matters. It is therefore crucial to continue to strengthen relationships with multifaith communities in order to ensure that healthcare providers can quickly access relevant religious guidance when needed.

The following participant emphasized the importance of establishing relationships with Muslim communities to provide support, particularly for women, in specific areas, such as mental health support. This participant reported the following:

> *"I think just more involvement with Muslim community. I think, one thing we need is culturally sensitive counselling for parents because it's a different experience, especially for the women."* **(Participant 9: Clinical Nurse Specialist)**

As noted by following participant, some Muslims may already have established support from their local mosques. According to this participant, it is about developing ways to integrate this support network into hospital care, which can be a challenging task. As stated by the participant:

> *"…the practicing Muslims on the whole will have access to some support from their local mosque and their local imam. It's how we can involve those people in supporting, in the hospital. That's more difficult because very often that's kind of that's the mosque. And sometimes we can get input from them, but it's more difficult."* ***(Participant 8: Paediatric Palliative Care Consultant)***

In the above quotes, both participants emphasized the importance of engaging with Muslim communities and local mosques. According to participant 9, it is important to engage with Muslim mental health support, whereas participant 8 suggested that it is important to reach out to mosques and local imams that families are already interacting with for support.

As pointed out by participant 9, it is important to involve the Muslim community more in providing culturally sensitive counselling to parents, especially mothers. As participant 8 also noted, even though Muslim families tend to form a sense of community through their links to mosques and imams, there continues to be a disconnect between their network and healthcare providers, as in this case hospice care. Consequently, it is important to connect with these religious communities to provide the necessary support for Muslim children and their families, including psychological support based on their cultural values and religious beliefs, as well as general spiritual and religious support. The following part of this chapter explores further how chaplaincy services can provide Muslim families and children with the needed support that is aligned with their beliefs and values.

Using chaplaincy services:

Several participants in this study shared their experiences of collaborating with chaplaincy services to support Muslim children and their families. Some of these participants regarded these collaborations as valuable, regardless of whether the chaplain is Muslim or not. According to the following participant, chaplaincy services have been used with Muslim families in a variety of situations to facilitate difficult discussions or to resolve conflicts. As stated by this participant:

> *"We also have a really good chaplaincy service in the hospital that we can access, to try and support families if they're finding the discussions that we're having with them difficult or feeling that they want to avoid conflict as much as we can."* **(Participant 1: Children's palliative care Nurse Specialist)**

Another participant mentioned the benefits of existing chaplaincy services provided as part of a hospital collaboration. This chaplaincy service is described as an extremely valuable resource by the participant in the following excerpt:

> *"So, there's [a well-known hospital] and they've got a huge chaplaincy which is completely multi faith and that really, really good at resources."* ***(Participant 11: Clinical Nurse Specialist)***

It is clear from the following experience that the presence of a chaplain can provide comfort and support to families, regardless of whether the chaplain is Muslim.

> *"We did have a chaplain at the hospice. He was initially, I say initially [because] he's not with us anymore, but he was of Christian denomination. But actually, I also know, he worked really well with all faiths. And actually, I know he was really close to a lot of our Muslim families as well. He was just a chaplain, and actually, just spoke in general, knew about a lot of the other religions anyhow. So, he didn't have to be of Muslim or of Islamic faith. Sadly, we don't have a chaplain anymore."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

The following participant, however, held a slightly different viewpoint regarding the use of a non-Muslim chaplain to provide support for Muslim families.

> *"We've got a spiritual care team which is basically Christianity based, but they will, they will do their best to support all faiths, but on the whole, we tend to go through them to get access to whatever is needed, and it is difficult."* **(Participant 8: Paediatric Palliative Care Consultant)**

Several of the participants in this study had previous experience collaborating with chaplaincy services, as indicated by their responses above. As a result of these collaborations, Muslim families seeking end-of-life decisions and palliative care discussions for their children were effectively supported. It was noted, however, that even if non-Muslim spiritual teams can provide assistance to Muslim families, sometimes they may encounter difficulties, since they have to search for information about the Muslim faith, which can be a challenge at times.

Importance of accessing a Muslim chaplain:

Two participants made a specific reference to the importance of having a Muslim chaplain particularly. In their current setting, a clinical nurse specialist expressed a desire to have access to Muslim chaplains, suggesting such access to be limited or insufficient. In the opinion of this participant, access to a Muslim chaplain would be beneficial in the following ways:

> *"I wish that we had access to Chaplains, Muslim chaplains who are experienced in talking about those end-of-life issues. And you could advise."* ***(Participant 9: Clinical Nurse Specialist)***

Likewise, participant 8 indicated that having access to a Muslim chaplain would be helpful:

> *"And what would really help us, is good access to a Muslim chaplain."* ***(Participant 8: Paediatric Palliative Care Consultant)***

Participant 8 elaborated on where they encounter challenges when supporting Muslim families, which is the time when difficult decisions need to be made. The participant's perspective is as follows:

> *"But it's then the decision making that is more difficult, and I think for us personally here, our biggest challenge is almost struggling to get the support we need to help us support families because it's none of our team are of Islamic faith and we've got no real access to a Muslim chaplain easily."* ***(Participant 8: Paediatric Palliative Care Consultant)***

Additionally, the same participant stated that access to a Muslim chaplain had been a persistent problem and that a consistent effort had been made to address it. As stated by this participant:

> *"So, I think what I'm saying particularly is, this whole ongoing issue of access to consistent, Muslim chaplain, it's been something that's been raised a number of times and as far as I understand it, we've gone round and round in circles and it hasn't been resolved."* ***(Participant 8: Paediatric Palliative Care Consultant)***

The above extracts from participants 8 and 9 demonstrate the importance of having consistent access to Muslim chaplains experienced in discussing end-of-life issues. According to participant 8, this has been a longstanding issue that has been raised multiple times but has never been resolved effectively. Consequently, this lack of access can potentially impact the overall quality of paediatric palliative care, particularly for

Muslim families who may need religious counsel and support aligned with their faith. Overall, both participants highlight the necessity of having consistent and reliable access to Muslim chaplains experienced in end-of-life care to enhance decision-making, family support, and the quality of care in palliative care settings.

Efforts to improve community engagement and outreach:

There were few participants from one hospice who agreed that one of the initiatives they established to build bridges between them and Muslim families utilizing hospice care was having cultural liaison officers assist in building these bridges and breaking down cultural and religious barriers by clarifying some misconceptions. As an overview of this initiative, the following participant provided the following information:

> *"One of the things that we've employed at the hospices are two, they called cultural liaison officers, so the two ladies, they are Muslim faith and background, but they are trying to kind of pick out pockets of people that are within our demographic that could come to the Hospice that don't come."*
> ***(Participant 13: Nurse)***

A participant in the extract below also mentioned cultural liaison officers, as well as the possibility of collaborating with a spiritual care practitioner. According to this participant:

"Having said that, we have got these two cultural liaison officers, and we have just recruited a spiritual care practitioner, and she starts in a week's time, and she is a Muslim. And so, I think that might sort of help a little bit. I think with this sort of stuff, understanding and things." ***(Participant 4: Clinical Nurse Specialist)***

The participants further discussed the role of outreach workers and liaison officers in bridging the gap between healthcare providers and families from specific cultural or ethnic backgrounds. According to one participant, the role of the cultural liaison officers involves integrating families with hospices and hospices with the community to ensure that they are aware of hospice services for those who are not currently receiving them. As expressed by the participant:

> *"The cultural liaisons do a bit of both (liaise between families and the hospice, and the hospice and the community) to be honest. They were employed initially I*

> *think to reach out to the pockets of family. So, we were aware that there were families who had children with life limiting illnesses, but they weren't accessing us."* ***(Participant 13: Nurse)***

According to another nurse in the study, the role of these cultural liaison officers involves engaging the Muslim community and connecting with families using hospice care or in need of hospice care for their children. According to this participant:

> *"They [the cultural liaison officers] spend a lot of time going round with the families, sort of engaging the community."* ***(Participant 12: Nurse)***

During the discussion, the following participant specifically acknowledged that the role of these cultural liaison officers is to enhance the relationship between the hospice and Muslims in the community who require hospice care:

> *"I think that's what our spiritual liaisons do, we have two Muslim ladies that are working with local areas to try and improve that [hospice relationship with Muslim community]."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

Whereas participant 12 indicated that the cultural liaison officers work specifically with Asian communities, as they act as mediators between Asian families and healthcare professionals. Participant 12 stated the following:

> *"We have two outreach workers that work with the Asian communities. They're very good, sort of explaining why things might be happening or talking to families. You know, sort of mediate our point of view, if you like."* ***(Participant 12: Nurse)***

Cultural liaison officers were discussed as the hospice's initiative to build bridges with the Muslim community, particularly the Asian community, as it represents the largest demographic in the region. Through this effort, families will be able to communicate more effectively, build trust, and have better access to hospice care for their children. Additionally, ensure that healthcare professionals are aware of the cultural beliefs and values of Muslim families in order to facilitate effective culturally sensitive care. Overall, cultural liaison officers play a significant role in improving access to hospice care for Muslim and Asian communities. By facilitating communication, mediating cultural differences, and fostering stronger relationships between hospice staff and families, they are able to increase the level of inclusion and cultural competence of hospice care.

The subtheme of community engagement examined aspects that contribute to enhancing relationships between Muslim families and healthcare professionals providing palliative care to children. Additionally, participants discussed the importance of reaching out to Muslim and multifaith organizations in order to facilitate the development of relationships with Muslim families. A crucial component of providing support to families is establishing trust and building relationships, particularly in communities where there may be initial reluctance or stigma associated with discussing serious illnesses or seeking external assistance. Accordingly, some study participants believe that building relationships with communities involves sharing accurate, relevant information. Trusted community members were deemed valuable assets in communicating with and sharing information with families during palliative care processes.

Moreover, it was suggested that services should be developed collaboratively with community input rather than imposed from outside. As part of this theme, participants also mentioned the benefits of using existing chaplaincy services, and the need for Muslim chaplains to build these relationships with Muslim families. Lastly, some of them spoke about current efforts to bridge the gap between healthcare professionals and Muslim families in the community as a way to provide culturally sensitive palliative care. Overall, when it comes to building relationships with Muslim families, participants have discussed the importance of paying attention to cultural values and religious beliefs. By enhancing trust between healthcare professionals and families, this will result in improved relationships and improved healthcare outcomes. The next theme in this chapter discusses the role that training plays in enhancing cultural competence among social work students and paediatric palliative care professionals. In addition, the theme will examine the need for training specifically about the Muslim faith, as well as some aspects of end-of-life rituals, as opposed to general cultural competency training.

Within the theme of building relationships, and the subsequent subthemes, the exosystem may comprise policies, as well as community resources. The potential interactions would be between healthcare professionals and both multi-faith organisations and leaders from the Muslim communities to possibly develop policies and practices that are deemed culturally and religiously appropriate for Muslim children and their families. Also, through these interactions, the Muslim communities and multifaith organisations can address any barriers families may face in relation to the healthcare system. These efforts would potentially bridge the gap between healthcare professionals and palliative care services and the Muslim families in need of such services, ensuring culturally appropriate services that are both accessible and respectful of their needs.

Theme 3: The Role of Training in Enhancing Cultural Competence in Healthcare

In the interviews with healthcare professionals and social work students, cultural training and resources emerged as a key theme. Several participants discussed the need for targeted training and resources to enhance culturally competent care. In addition to discussing the importance of cultural competence and religion in general, participants expressed their views on current trainings and professional development events, and the need for more tailored training pertaining to Islamic values and rituals. As part of this theme, there are subthemes related to gaps in existing training, the need for enhanced and tailored cultural education training, professional responsibilities for self-learning, as well as suggestions for improving training so that Muslims and individuals from diverse cultural backgrounds will receive more culturally sensitive care.

Gaps in existing training:

In terms of existing training, some participants discussed their experience with existing training on culture and religion awareness and education. One participant shared an opinion regarding the services provided by hospices or Muslim chaplaincy services with which they collaborate. According to this participant:

> *"We have some training that we get through the hospital, through the chaplaincy team there. They've got a diverse chaplaincy team with a Muslim team there. They provide some training on religious beliefs and bereavement that we access."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

In the experience of participant 3, a Muslim team within the hospital's chaplaincy team conducted the training where it touched slightly on religious beliefs and bereavement.

Other participants, however, expressed some concerns regarding the existing training. It was noted by several participants that although the training provided may be well structured, it does not focus exclusively on one religion, but rather provides a general overview of a wide range of religious and cultural beliefs. In the opinion of one of them:

> *“We have done some training within the hospice on sort of general different religions and what families may believe.”* ***(Participant 4: Clinical Nurse Specialist)***

Additionally, another participant reported that despite the general nature of the training, it was a positive experience. According to the participant:

> *“We access the hospices as well, who are excellent, with the training that they give. On most of the days normally, generally, feature a session that touches on culture and faith, of all denominations.”* ***(Participant 1: Children's palliative care Nurse Specialist)***

As for the following two participants, they pointed out that to the specific equality and diversity training, which is also a general training, covering certain aspects of various religions. One nurse stated:

> *“Probably the trust’s [hospital board] equality and diversity training, but there's not a specific test. There is a bit of end-of-life care training that hospice care does provide, but I don't think it goes much in detail in specific religions.”* ***(Participant 7: Nurse)***

The other clinical nurse specialist noted such training on equality and diversity is part of other training and is not specific to cultures and religions. According to this participant:

> *“Here I've not had any training yet except for general, sort of equality, diversity and inclusion. So obviously we talk a bit about all religions in that. And is embedded into our symptom management end of life training around cultural practices around preparation of the body.”* ***(Participant 9: Clinical Nurse Specialist)***

The above participants express that the training may not go into detailed specifics about different religions, particularly in the context of end-of-life care. From the above extracts from the interviews, it is evident that some participants feel that trainings do not adequately cover specific religious beliefs and practices in the context of end-of-life care. Generally, trainings are offered on equality, diversity, and inclusion, incorporating various religions but not deepening into any particular faith.

As another participant pointed out in the following extracts, there are existing professional days, such as study days, yet faith and religious practices are not adequately discussed during these sessions. In the context of end-of-life care, this lack of training is considered to be a significant gap in the training provided to healthcare professionals. As the nurse mentioned:

> *"I can't think even in my training if we ever even broken out faith. I can't say that we did. And subsequently since that time, it's not really covered so much in the study day."* ***(Participant 6: Nurse)***
>
> *"But there's never actually any real mention about faith in those study days, it's bizarre."* ***(Participant 6: Nurse)***

During the same conversation, the participant also expressed her opinion regarding the approach taken in training about palliative care and end-of-life care. Her statements were as follows:

> *"I think sometimes what they do is very much more about the Christian faith. They don't tap into the others. And again, I think it might be a lack of confidence to be able to have those conversations when it's not familiar to you."* ***(Participant 6: Nurse)***
>
> *"So a lot of the study days I've been to are about palliative care and things like that, it's very much focused around the medical kind of how do you manage them, as in syringe driver, how do you have a respite plan, how do you have a symptom management plan, all of those kind of things, and, you know, how to identify, how to verify death, all those kind of things, how to go through to different funeral directors, all of that."* ***(Participant 6: Nurse)***

As explained by participant number 6, the trainings or professional development events, such as study days, provide general concepts concerning palliative care and end-of-life care for children. During the discussion, the participant expresses concern about the focus on Christian religion in healthcare practices, suggesting a need for more inclusive approaches to different religions. According to the quote, Christianity is viewed as being the predominant religion in healthcare settings, whereas other religions are often not considered or represented as well. She also expressed a strong opinion that the study days would be more focused on medical aspects of care for children in palliative care, along with general information regarding death and the logistics of managing symptoms, using medical equipment, and verifying death as part of the procedure.

The Need for Enhanced and Tailored Cultural education Training:

It was acknowledged by one of the participating nurses that during her experience with a Muslim family with a child facing death, mainly the challenges faced were associated with the lack of education about the Islamic faith and culture. In the words of this participant:

> *"But it was [barriers faced] all based on education, really, because certain staff members weren't aware of it." **(Participant 7: Nurse)***

Hence, participant 7 continued and highlighted the importance of training to address the needs of Muslim patient populations, and reinforced the value of education within healthcare teams:

> *"But training is what does the most. And people like us who we're employed in the job and we're already Muslim, you can help your ward out by educating them and talking to them about it to your colleagues. But our staff members [Muslim backgrounds] aren't going to be on every ward [all the time], are we?" **(Participant 7: Nurse)***

Accordingly, the following stated by one of the social work students in the study:

> *"a lot of training and knowledge on people's culture and background, I do think it's important when you're working in a kind of mixed culture" **(Participant 15: Year 1 BSc Social Work Student)***

One of the other social work students reaffirmed their experiences with trainings and called for a tailored approach. Considering how broad most training programs are, the student suggested they should focus more on cultural and religious differences. As stated by the student:

> *"I think that more training is needed. Definitely. I think that everything [in terms of training] is very broad. And I think that they could do more tailored sort of training... I've not worked in an agency where I've had a lot of training. But there's just seems to be a very blanket approach."" **(Participant 14: Year 2 BSc Social Work Student)***

It was noted by another student of social work that lack of training and support is encountered when working with children, notably young asylum seekers, which results in the need to learn more about the cultural needs of the young people they support. According to the participant:

> *"I do the placement I am in; I am working mainly with children. I am working with some young men who are unaccompanied asylum seekers. But really there's no support or training really around that. I've gone away and researched things." **(Participant 16: MSc Social Work Student)***

Both of the above social work students pointed out similar issues pertaining to the gap in professional training programs, where both students and professionals may not receive adequate preparation for dealing with complex, culturally sensitive issues, resulting in the need for independent research. Accordingly, the following subtheme is personal and professional responsibility described by some individuals as a way to learn more about the culture and religion of children and young people from diverse backgrounds, particularly those from Muslim backgrounds.

Professional responsibilities to self-learning:

The lack of individualized trainings prompted participant 14 to emphasize the importance of taking responsibility for raising their own cultural awareness and self-learning about different cultures of those they serve. The student specifically stated:

> *"I think the challenges [that can be potentially faced] are going to be that I haven't had a specific training and that I would have to take a high level of responsibility to raise my own awareness about culture. I think I would feel a sense of personal responsibility, professional responsibility to go and read information through journal articles, research, or any sort of literature. Kind of raise my awareness. I would feel privileged because I would feel that I'm getting to learn about another culture."* ***(Participant 14: Year 2 BSc Social Work Student)***

A similar commitment was taken by another healthcare professional to educate themselves and become familiar with the specific religious and cultural needs of a Muslim family with a child at the end of life. As stated by the participant:

> *"So, I was reading up on a lot of things…"* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

For the following participant, specific steps were taken to ensure that the religious needs of one of the Muslim families were met, such as identifying the direction a Muslim individual should perform prayer, known as the Qibla. As the participant stated:

> *"But I went and found out, read about it and came back and tried to find out which way of the ward, where the Qibla was. So, the mum would ask me, which way do I face to pray? And I'm like, one minute, I'll go and find out for you. Because each room was a bit different because of the layout of the ward. So obviously, I had to find out about that."* ***(Participant 7: Nurse)***

The students in the above-mentioned statements highlighted a critical point when it comes to training, which is the need for a different, more tailored approach to training, centred around the needs of the patients rather than having a broad approach to training. In other words, as implied by the statement, it is necessary to have a more focused and specialized training to meet the needs of social work practice effectively. Alternatively, as acknowledged by both participants, there would be a degree of responsibility placed on the participant to develop their own awareness and understanding of different cultures.

Also, according to few participants, professional and personal responsibilities include engaging with families to understand their perspective. It has been noted by two participants that honesty is essential when speaking to families and asking questions, which is a sensible way to educate oneself and gain knowledge, while offering personalized care at the same time. As stated by these participants:

> *"…. but also, being guided by the consultant and the family, and asking Dad. Being honest to dad at the beginning to say, I don't know a lot, and he guided me completely."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***
>
> *"I found that, actually, learning more about the religions through my own, listening to families, talking to them, understanding what their views are."* ***(Participant 11: Clinical Nurse Specialist)***

Together, these two quotes underline the importance of active learning and family involvement in culturally sensitive care. Both participants recognize that formal training on its own may not provide sufficient knowledge to handle the wide range of cultural and religious practices or challenges encountered in healthcare. Instead, these participants demonstrate that being open to guidance from families, and learning through their interactions, is an imperative way to learn more about the family's cultural and religious needs to provide them with culturally sensitive care.

An alternative means of obtaining the information and cultural understanding and education necessary to meet the patient's needs has been suggested participant 11 in the following statement:

> *"… but also, from reaching out to other organizations and at getting the support, and I feel that it's kind of educated me and made me understand where certain things come from. That some things come from a cultural perspective and a historic perspective, and some do come from the scriptures and the readings and, you know, the views of the faith."* ***(Participant 11: Clinical Nurse Specialist)***

In the following statement, participant 10 the acknowledged that even with some training being provided, cultural awareness and knowledge has been enhanced more by practical experiences over time.

> *"… I've had some little training. And I think, I've been nursing for 25 years nearly. I'm working on the wards; I've been involved with Muslim religions. I've been involved with other religions on the ward, and I have learned so much. So, I think, there be the more experienced nurse that has helped me as well."*
> ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

Although some of the participants acknowledge their limited knowledge of cultural or religious practices of families and the lack of comprehensive, tailored training, as indicated by their responses above, they demonstrate their commitment to learning and enhancing their knowledge in order to provide culturally sensitive, effective care. Besides reading relevant information, participants emphasize the importance of seeking advice from family members, consultants, and external organizations with expertise in religious and cultural matters. It is important to listen to children and their families, to ask questions, and to engage in an open dialogue with them regarding their faith and cultural values in order to gain a deeper understanding. As such, this reflects the continuous need for healthcare professionals to update their knowledge and skills, particularly in specialized fields such as palliative care where cultural and religious context are involved. Therefore, below in this chapter, some of the suggestions made by some of the participants to enhance cultural training and education in order to facilitate effective culturally sensitive care for Muslim families in particular, as well as people of diverse cultures generally will be discussed.

Willingness to learn:

The willingness to learn is one of the most critical qualities that healthcare professionals should possess. Because having the willingness and expressing the desire to learn about the culture and religions of others would ultimately lead to building relationships with children and their families because it provides a gateway to finding out what they need, which is crucial to establishing a sense of trust. As described by the participant:

> *"I think if you don't at least try, if you don't know enough about it, and you don't show that you want to learn more and be more supportive and understanding of the religion and the culture, your relationship is going to be very difficult.*

> *Because it's so important to the families that you understand where they're coming from and how their beliefs impact on what they're going through for the child.”* ***(Participant 1: Children's palliative care Nurse Specialist)***

The nurse believes that establishing trust and effective relationships requires a willingness to learn about the religion and culture of a family. A willingness to learn may facilitate the delivery of patient-centred care, which aligns with the cultural, spiritual, and emotional needs of patients and their families. As a result, understanding the impact of beliefs on a family's experience would be an important component of effectively supporting them. In contrast, a lack of desire to learn negatively impacts healthcare professionals, which can lead to ineffective performance.

Suggestions to improve cultural trainings and education:

The following participant made suggestions, such as educating the staff, as a way improving cultural sensitivity.

> *“So, more sort of education, especially for staff in hospitals, some education on the religious beliefs, and why they hold those beliefs [to improve culturally sensitive care]. I think the educational side of things would help improve end of life care and the information that's able to be provided for families.”*
> ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***
>
> *“Just educating people on the various barriers that you might face and the differences with Muslim beliefs compared to other religious beliefs. Especially probably around the burial so quickly after, after they've died. And why that's done.”* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

In the above statement, the participant referred to the importance educating healthcare staff on various religious beliefs, especially around end-of-life, to be able to better inform families. As for supporting Muslim families particularly, the participant highlighted the need for education on potential barriers faced by healthcare professionals, focusing on understanding religious beliefs and cultural practices related to burial rituals for Muslim families.

Participants made several suggestions regarding how to facilitate a more culturally sensitive care process for Muslim children and their families, which may also be useful for caring for children from other cultures or religions. One participant stressed the importance of undergoing informative trainings and having access to accessible resources. As described by the participants:

> *"I would like there to be somewhere I could go. And I could find the information I need. So, I would like there to be a hub, a Learning Hub. Somewhere that I could go[put/say] this family is from this culture, this religion. And I would like to be able to go there and say, what is there I can offer? What support? How would I approach this?"* **(Participant 16: MSc Social Work Student)**

One of the social work students, in the above statement, suggested that there should be some kind of centralized location where they can easily access and obtain information, that they referred to as a "Learning hub".

Two participants emphasised the need for specialized training and resources in Muslim End-of-life care. These participants underlined the importance of improving cultural competence through education and practical resources, particularly around end-of-life practices for Muslim patients. One participant draws attention to the specific religious needs, such as the practice of rapid burial in Islam, and the lack of education about these requirements in GP surgeries:

> *"I think there's not a lot of education about that [rapid burial] to GP surgeries so I think that would be really positive or just an information booklet or something on the religious beliefs and what you would expect after a child dies or when a child is dying from a Muslim point of view."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

The senior community paediatric palliative care nurse commented on the lack of education about certain cultural and religious practices. Particularly, this participant highlights the lack of knowledge among general practitioners (GPs) about one of the most significant Islamic end-of-life rituals that is rapid burial. It is suggested by this participant that one way to obtain such information is to provide better resources such as an information booklet that gives guidance on religious beliefs and expectations regarding end-of-life care for Muslims.

While the other participant, a nurse, echoes this need for structured training but expands on it by emphasizing the importance of experiential learning. They suggest that training should involve direct exposure to the entire process of death care, including what happens in mortuaries and funeral homes:

> *"I think you need to have a study day of exactly how we go to the chapel, and we know what the mortuary looks like, and we know what a funeral director does, how the coffin boxes look like. They do, do trainings where you can go and see how the whole process is. That is exactly what they*

> *need to do when it comes to a funeral, a Muslim death.”* ***(Participant 7: Nurse)***

> *“So, this is why, if you're going to do training, and if you're going to do a training on end-of-life care, maybe a chaplain, an imam, and someone else from every religious culture should have half an hour in that session telling them what you do, what are the do's and don'ts.”* ***(Participant 7: Nurse)***

The nurse participant expressed the need for specific training on the practices and rituals associated with Muslim death and funerals, but in a more practical way. For a deeper understanding of funerals and end-of-life care for Muslims, the participant recommends hands-on, experiential training, such as a visit to a chapel or mortuary. In this above nurse's opinion, it would be beneficial to provide training on the Islamic faith and culture, which would be facilitated by someone with more knowledge, such as a chaplain or an imam.

In general, participants reported that existing training is valuable in developing a general understanding of different faiths and cultures by focusing on general cultural competency principles. It is possible, however, that specific considerations related to underrepresented groups of culture, ethnicity, and religion may be overlooked. Participants noted that more tailored training opportunities are necessary to ensure that social work students and paediatric healthcare professionals are fully prepared to provide individualised care for Muslim families in a manner that respects their cultural and religious values. Accordingly, some participants discussed their professional responsibility to make sure they learn about the culture and faith of those to whom they are providing services. They have also made some suggestions, such as creating an accessible learning hub to enable healthcare professionals to obtain cultural or religious information they need for families or providing training on a few Islamic rituals, such as rapid burial. In the context of this discussion, certain factors that are essential to improving cultural training, and, as a consequence, improving Muslim family experiences have been highlighted.

Microsystems are characterized by direct interactions between those in the immediate environment surrounding the individual. Considering the direct interactions between healthcare professionals and parents, cultural training is imperative to enable healthcare professionals to provide culturally and religiously sensitive care. By understanding and respecting the family's cultural beliefs, values, practices, and rituals, clinicians can build trust and enhance patient care. This is particularly true in the case of end-of-life care for children.

The exosystem includes external systems that indirectly affect the child, such as the healthcare policies, institutional practices, or the parents' workplaces. It is therefore necessary to enhance existing cultural training at this level, where healthcare policies and institutional practices impact the structure of existing training. Additionally, at this level, changes are made to training in order to cater to the needs of a particular culture or religion. Several participants in this study believe that trainings are often broad and cover a range of religious beliefs but are not tailored to the specific needs of ethnic minorities, such as the end-of-life rituals required by Muslim families. The need to improve existing cultural training may arise as a result of changes to healthcare policies or organisational standards that impact the delivery of care. Accordingly, these suggested changes are likely to be shaped by health care guidelines impacting what paediatric palliative care providers receive in terms of formal education or specific training in religious practices and cultural norms that are relevant to diverse populations.

Theme 4: Communication Barriers

A key theme emerging from this study is the communication barriers arising from differing views about what is in the child's best interest between healthcare professionals and parents. When working with ethnic minorities, such as Muslim families, healthcare professionals and social work students may encounter certain issues that might cause breakdowns in communication. Among these issues are conflicts between them and the families regarding what is in the child's best interest. The following is an exploration of the perceptions and experiences of social workers and healthcare professionals related to navigating communication barriers associated with best interest decisions with Muslim families. Throughout this theme, the focus is decisions regarding treatment and intervention options and how Muslim families and healthcare professionals may differ on what constitutes the best interests of the child.

Additionally, the ways in which participants navigate disagreements about what is deemed to be in a child's best interest will be explored.

Difference in opinion about treatment options:

Muslim families and healthcare professionals sometimes come into conflict because of the family's desire to choose a treatment option contrary to the healthcare provider's recommendation. According to one of the clinical nurse specialists in the study:

> *"And we've also had things in the hospital where families wanted to pursue treatment. But hospital have felt that scans and things show quite a different picture to what the family hoping and see."* ***(Participant 4: Clinical Nurse Specialist)***

As stated by participant 4 above, treatment options are an area of conflict between medical opinions and the family's hope for a cure and recovery. Discrepancies between families and healthcare professionals can be caused by the interpretation of the prognosis based on things such as hospital scans that do not reflect the families' hopes or desires for continued treatment. It illustrates the challenges healthcare professionals face when families' expectations are not aligned with clinical realities. What the clinical nurse specialists highlighted in the above quote is regarding some of the communication barriers that can arise in palliative care and when a child is undergoing end-of-life care, as there could be a disconnect between the medical assessment and the family's hopes and expectations.

Occasionally, some Muslim families may believe that all medical treatments should be explored before limiting treatment. According to one of the participants:

> *"Muslim families, not all of them, but a lot, do want to try absolutely everything and they want to sort of persevere with treatment options, right as long as it's absolutely possible and don't want to put any limitations in a care plan which is fine."* ***(Participant 4: Clinical Nurse Specialist)***

The participant in the above quote indicated that many Muslim families tend to pursue all treatment options, as they do not wish to place limitations on the treatment plan. Despite the challenges that may arise for healthcare professionals as a result of this preference, they are still willing to accommodate what families wish for their children.

Similarly, another clinical nurse specialist in the study points out the conflict between Muslim parents' wishes for everything to be done for their children and health care professionals' judgments of what is best for the child. As the participant stated:

> *"But families are not willing to have that discussion [about futile treatment] because they feel that they want to try everything as and leave it in the hands of Allah. And that's something that comes up with other families as well, of course. But it does seem to be like as in my experience, more so with Muslims."*
> ***(Participant 9: Clinical Nurse Specialist)***

As shown in the above quote, Participant 9 refers to situations where continued treatment is considered futile, which indicates the point of view of healthcare professionals concerning the appropriateness and effectiveness of ongoing interventions. According to this participant, in such circumstances, the religious beliefs of Muslim families play a significant role in their decision to seek all possible medical treatment. Their religious beliefs dictate that they leave the outcome in Allah's hands. The suggestion that further treatment may be futile may cause conflict between family members and healthcare professionals, which could negatively impact communication between them.

Among the things that Muslim families may wish to pursue is insisting on full resuscitation regardless of the outcome and potential burden on the child, which may lead to conflicting perspectives between the family and healthcare professionals. According to one of the participants:

> *"I think it can be quite difficult. Of course, we've got some families that are adamant that their child is for full resuscitation and for full escalation to hospital, and you can see that the child is deteriorating and getting worse, and actually you know that putting them on a ventilator wouldn't be in their best interests, and it would be quite sad for the child and the family to have to go through it that way, and then knowing that you probably wouldn't get them off the ventilator." **(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Participant 3 emphasizes in the above passage that there is a conflict between what the family perceives to be in the child's best interests and the views held by the medical professionals regarding the child's full resuscitation. This participant reflects the medical opinion regarding the use of a ventilator as a child's condition deteriorates. This statement implies that the family may be motivated by hope for the best, but the medical opinion is concerned more about the child's quality of life and emotional burden the family may face.

One participant noted that there are other instances when families and healthcare professionals disagree on what is in the best interest of the child, such as the location of the child's final hours. As stated by the participant:

> *"I'm thinking generally where I struggle is around those children who treatment we know would be absolutely futile. And we as professionals generally think that the family probably could have a much better experience of their child's last days if they moved to a hospice or to home where they could have family and community around them."* **(Participant 9: Clinical Nurse Specialist)**

As another healthcare professional pointed out, what's in the best interest of the child is a peaceful death surrounded by loved ones, regardless of the location, without aggressive treatment interventions deemed not to be in the child's best interest. As explained by the health professional in the following passage:

> *"You know that actually passing away peacefully surrounded by family with them awake and aware that they're with their family rather than being heavily sedated on a ventilator or sort of in an unconscious state on a ventilator would probably not be, in my opinion, wouldn't be the best way to die, and families have really lovely deaths at home or in hospices or in hospital together without ventilators and things rather than going down that route."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

The best interests of the child, especially in palliative care and end-of-life care within Muslim families, can be a sensitive and complex issue as it often intersects with deeply held religious beliefs, cultural values, and emotional responses. Besides culture and religion, parents may have high expectations for the outcome of treatment. Although there may be significant medical difficulties, these beliefs are often influenced by religious and cultural values that prioritize saving lives and maintaining hope for recovery. In contrast, healthcare professionals may place a greater emphasis on achieving realistic results and minimizing potential suffering. Often, healthcare professionals make treatment decisions based on the child's quality of life, which may differ from the expectations of the family. Care providers may focus on maximizing quality of life and minimizing suffering, while families may place a greater emphasis on hope and potential recovery. As a result of these differing viewpoints, communication can become difficult and lead to misunderstandings. The following section will discuss what some of the participants revealed as their ways of navigating conflicts that are related to disagreements on what is in the child’s best interests.

Navigating Disagreements in Determining a Child's Best Interest

Communications during conflicts arising are guided by what is in the child's best interest. A student clearly revealed:

> *“My main objective here would be what would be in the best interest of the child.”* ***(Participant 15: Year 1 BSc Social Work Student)***

One of the participants in the study has described how they reach a decision that is in the child's best interest and appropriate for the family, taking into account their culture and religion. The participant stated:

> *“So, in those situations [where there are conflicts] I guess, multi professional meetings with lots of professionals and imams have been invited along as well. And then discussions with families and trying to explain the findings on scan often with the imam actually, that can be very helpful. Just depends on sort of the conflict as to how it is resolved, but yeah.”* ***(Participant 4: Clinical Nurse Specialist)***

Even though some Muslim families advocate the use of all possible treatment interventions that conflict with medical decisions regarding what is best for their children, thoughtful and compassionate communication is required in order to bridge this gap and respect both the medical evidence and the needs of the parents. The same above participant talked about the importance of open and honest communication by saying:

> *“But quite often, a lot of the care plans we write that the family would want to pursue all treatment options, would want active treatment, but also would appreciate open and honest conversations at the time and a lot of families seem to accept that. But you know, they just want professionals to be open and honest with them at the time.”* ***(Participant 4: Clinical Nurse Specialist)***

While disagreements can take many different directions, there is always the possibility that they may escalate to the point at which ethical procedures must be applied. Choosing an ethical path is often not in the child's best interest, as noted in the study by one of the healthcare providers. Moreover, it may be emotionally difficult and draining for the family and other caregivers. In spite of this, there are times when it is the only option available to facilitate reaching a decision. The following statement was made by one of the participants:

> *"And especially if then, they [families] are adamant that they still want everything done, and it has to go down an ethical route and go to ethics panel, I think it could be quite distressing, and you feel quite difficult because it's quite emotional for us sometimes, I think it's frustrating because you know that that's not what's best for the child." **(Participant 3: Senior Community Paediatric Palliative Care Nurse)***
>
> *"I think going down an ethical route, and then potentially a courtroom can make it really traumatic for the family." **(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

It is evident from the above participant's commentary that families often insist on pursuing all treatment options, even if it is not in the best interest of the child to do so. Choosing to follow an ethical path or potentially go to court can be distressing, not only for the family, but also for the members of the healthcare team. It is important to recognize that ethical dilemmas faced by healthcare professionals can be extremely difficult and distressing for everyone involved. There is no doubt that such ethical dilemmas that healthcare professionals face can be very distressing and difficult to deal with. The experience is distressing for the families since it can be highly traumatic and may further complicate the situation, and it is challenging for healthcare professionals as their medical judgment is determined by their desire to enhance the child's quality of life, rather than prolonging it.

In the same participant's opinion, despite the difficulty and burden of following an ethical path, families may feel more comfortable doing so because they have tried all possible means and fought for what they want, taking all possible measures to attain it. This participant continued by stating:

> *"But also, if that's right for them [going down ethical route], and it feels like they've then made all of the correct choices for the child, and they've really fought for them. And they feel that that was what they needed to do, then maybe that brings them more closure to know that they didn't ever give up. And it was us that gave up." **(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

This participant draws attention to the delicate balance between assisting a family in pursuing all possible treatment options and the healthcare professionals' responsibility to act in the child's best interest. According to the participant, allowing families to make decisions aligned with their beliefs may help them achieve closure, even if ultimately the medical team is required to make difficult decisions that the family may view as "giving up".

Theme 5: Translation Services to Overcome Language Barriers

Among the major themes identified in this study is the use of translation services to overcome language barriers. This section discusses language barriers in relation to the interpretation services that healthcare professionals and social work students are able to access to help them overcome these barriers. Additionally, the limitations of these interpretation services are discussed.

Healthcare professionals may face challenges in providing care and support to Muslim families and other families of diverse ethnicity and religion due to language barriers, which can impede meaningful interactions, understanding, and the delivery of necessary information and support to these families. One of the healthcare professionals in this study clearly indicated that language was a barrier when caring for a Muslim family with a child who is at end of life. The participant stated:

> *"Language barrier was a massive thing."* ***(Participant 7: Nurse)***
>
> *"Again, their care was a bit difficult because of the fact that there were cultural barriers, there was language barriers."* ***(Participant 7: Nurse)***

A student in the study has also raised the issue of language as a potential barrier when working with people from different cultures. The student stated:

> *"So, I'm very open to work with every culture, you know, obviously language can be a barrier for social workers."* ***(Participant 15: Year 1 BSc Social Work Student)***

The student demonstrated a willingness and openness to engage with individuals from diverse cultures. However, as noted, language barriers are expected to present an obstacle. The result is that language differences may impede understanding and interaction with patients and clients from diverse cultural backgrounds.

Another participant reiterated language as a barrier, leading to the need for interpreters, which can add another set of challenges. As stated by this participant:

> *"...then the added challenge is very often for our Muslim families, a lot of them, their first language isn't English and a lot of them we are using an interpreter as well. So, that adds an extra dimension which makes it even more difficult."* ***(Participant 8: Paediatric Palliative Care Consultant)***

As a result of encountered language barriers, healthcare professionals and social workers may use interpretation services to facilitate discussions and consultations with Muslim families whose child is receiving palliative care or is in the process of receiving end-of-life care. It is true that existing interpretation services can provide language support to a certain extent, but they can still present some challenges and limitations. Accordingly, the following part will explore the current interpretation services used by participants in this study and their limitations.

Accessible Interpretation services

Several participants discussed some of the practices they use to ensure that families are aware of medical processes and decisions. As an example, the following social work student indicated the use of an interpretation tool called language line as well as the use of family members as translators.

> *"But obviously, we have got tools that we can use to support families. You know, we've got language line and then there's obviously some families who can translate for us."* ***(Participant 15: Year 1 BSc Social Work Student)***

According to other participants, they use virtual interpretation services and interpreters to provide translation services via telephone. One said:

> *"…and necessarily we do have links with online and on phone interpreters so we can kind of do a 3-way call or we can have them physically in the in the Hospice"* ***(Participant 13: Nurse)***

Likewise, another nurse noted the use of telephone translation:

> *" …we've got, things like the translator, telephone translations."* ***(Participant 12: Nurse)***

Additionally, the following clinical nurse specialist indicated that physical interpreters are also used, as well as using telephone translation services.

> *"…but we do use interpreters by telephone and face to face, and that is something that I think has increased a lot in the last three or four years."* ***(Participant 4: Clinical Nurse Specialist)***

> *"We do use interpreters a lot, and we do have a telephone interpreting service that's good."* ***(Participant 4: Clinical Nurse Specialist)***

During the interviews, two participants shared their experiences with interpreters, emphasizing the need for interpreters to ensure that non-English-speaking families and individuals receive the support and care they require in a language they understand. This is what one of the participants, a student of social work, had to say:

> *"... I was working with the boys [asylum seekers], today actually, we had an interpreter to ensure their needs and wants and everything were met."*
> ***(Participant 16: MSC Social Work Student)***

As well, a clinical nurse specialist in paediatric palliative care in the study spoke positively about her involvement with an Arabic translator to ensure that the parent of a child at end-of-life receives information in her native language. Here is what the participant had to say:

> *"...but with the help of translators coming in and we had the PAC [paediatric advanced care] plan, the Advanced Care Plan written up in Arabic for Mom too." **(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

The above two participants reflect on their engagement with existing translation services which, in critical situations, facilitate better service delivery by overcoming language barriers and allowing healthcare providers to provide care to patients effectively. Other participants, however, have stated that translation services can sometimes cause some challenges, regardless of how good they may be. Therefore, the following is a discussion of the limitations of existing translation services as shared by these participants.

Limitations of translation services:

Some participants have expressed concern that the presence of an interpreter or an interpretation device can sometimes impede the provision of appropriate palliative care services. An issue raised by the clinical nurse specialist above relates to the varying levels of quality of interpreters. As the participant stated:

> *"You don't know for sure; some interpreters are better than others, aren't they?"*
> ***(Participant 4: Clinical Nurse Specialist)***

As a general comment, it may be related to the proficiency of the interpreters, or to their general knowledge and experience, which can vary in quality, so that some translators may be of better quality than others. In the end, these varying levels of qualities may affect the overall outcome of a family's experience. According to one of the social work students:

> *"So, what I'm saying, if it is palliative care, you want to make as sensitive as possible don't you? And the translation could, kind of be, a bit of a barrier."* ***(Participant 15: Year 1 BSc Social Work Student)***

The same student explained, despite the translation devices' benefits, they can often interfere with the development of a relationship with the child, leading to an impersonal care experience. It has been emphasized by the participant that the physical separation caused by technology can hinder the formation of a personal relationship between the caregiver and the patient or family.

> *"We use language line, which is over the phone. So, imagine holding the phone near a child who was having palliative care, and you translate, a mobile phone between you and the child. I just think it feels a bit impersonal. You want that time with the child. You want that connection. Don't you? You want that relationship with a child?"* ***(Participant 15: Year 1 BSc Social Work Student)***

Another participant noted that having a translator may make it difficult to convey empathy to the patient and build a personal relationship with them. As this clinical nurse specialist highlighted:

> *"Some interpreters are really good, but I don't think it helps with that natural flow of conversation, when everything's having to go via somebody else."* ***(Participant 4: Clinical Nurse Specialist)***

The above quote refers to one of the disadvantages of having an interpreter to facilitate communication between healthcare providers and patients or families who speak languages other than English. It is acknowledged by this clinical nurse that even though some interpreters are highly skilled, their presence, whether it be on the phone or face-to-face, can disrupt the natural flow of conversation. The viewpoints expressed here are like those expressed by participant 15 above, who viewed interpretation services as a barrier to developing relationships with children and their families. Mostly participant 4 highlighted both the benefits and challenges associated with the use of interpreters when providing care to families from diverse backgrounds.

As shown in the extract below, another participant expressed concern about the potential poor quality of video translation services. In the words of this participant:

> *"But ultimately, the biggest challenges we have are that the interpreter service we have is often a video service. It can be very inconsistent. We can end up with*

> *an interpreter's shift suddenly stops in the middle of the consultation and somebody else appears, quite significant problems with that interpreter. So that adds that extra dimension as well really."* ***(Participant 8: Paediatric Palliative Care Consultant)***

The limitations of the translation services used by this consultant, which are video services, lie in their overall quality, as significant issues may arise, resulting in interruptions or abrupt changes during consultations. It is possible, for example, that an interpreter's shift may end unexpectedly, and another interpreter may replace him or her, thereby disrupting communication continuity. This further complicates consultations, which may already be difficult in such circumstances.

Language proficiency

Healthcare professionals also face language proficiency challenges and issues associated with translation accuracy when using interpreters and translation services. One participant shared an experience with a Muslim family with a child at end of life, who happened to have died recently. The participant shared the following anecdote:

> *"So, we were finding when we were using and bringing them (the interpreters) to the home to interpret when we were discussing health relation, Dad felt they weren't using the correct termination for mom. So, dad always had to step in and tell mom a little bit more. So, we found that difficult at times."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***
>
> *"Dad felt they had interpretation to mom that wasn't sometimes correct."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

The participant explained further by saying:

> *"Dad kept saying, he's [the interpreter] not telling that in the health manner, and he's telling her in a different way. So, dad always has to sort of change wording sometimes."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

As described by participant 10 in the above statements, some Muslim families face challenges regarding the precision of communication provided by interpreters, even if they share the same faith as the family. The father's perception of the interpreter's lack of accuracy is highlighted in the above quote. This serves as an example of how family members perceive the quality of communication when they have a child in palliative care and end of life.

Another nurse in the study have pointed out that some of the medical language used in the hospice and the language pertaining to end-of-life care sometimes cannot be translated into other languages like Arabic. She said:

> *" What I understand is that I think a lot of our language doesn't translate into other languages, one of the girls [cultural liaison officer] was telling me the other day that in a lot of Arabic languages, there's no direct translation for like, end of life care or sentences like that, which obviously we deal with all the time.”* ***(Participant 12: Nurse)***

It is implied in the above quote that sometimes words can be lost in translation when their equivalents do not exist in other languages, such as Arabic in this case. In a similar manner, the previous participant mentioned the experience of one of the fathers where he felt the need to change some words since they had been translated incorrectly. As well, there may be a cultural difference in the way different languages and cultures express medical concepts and conditions. It is therefore imperative that interpreters understand the concepts they are interpreting and ensure that they deliver them as accurately and culturally appropriate as possible.

Challenges in accessing translation services:

In addition to the difficulties encountered when using existing translation services and issues related to interpreters' characteristics, participants in this study also expressed challenges accessing translation services. One of the students in this study reported having difficulty overcoming language barriers due to difficulty finding interpreters, despite knowing the steps to follow.

> *"I know how to find an interpreter to work in the young person's first language. So, they are heard in their own language, and they can be supported that way. But there's not a great amount of support if I'm honest.” (**Participant 16: MSC Social Work Student)***

As the above student pointed out, finding an interpreter is one of the most important steps to ensuring that young people are supported in their native language. Nevertheless, this student indicated that inadequate support systems and resources are a major challenge when it comes to supporting individuals of different ethnic backgrounds, including Muslim families.

Additionally, a health care professional expressed frustration about the lack of access to translators, despite their availability in the hospice. The nurse stated:

> *"You could have easily got translators in. Translators weren't brought in."*
> ***(Participant 7: Nurse)***

The nurse in the example above was speaking about an incident she had encountered while caring for a Muslim child from a family whose first language was not English. A lot of support was lacking from the hospice, and the consultants handling the case did not obtain a translator and relied on this nurse and her colleague because they were Muslim.

Furthermore, access barriers can sometimes be associated with some financial constraints imposed on healthcare providers, leading them to limit the use of language services that may be costly. One of the healthcare professionals in the study stated:

> *"So, we don't have funding for language because we're a charity. I mean we can use language line but at a great cost. So, what we tend to do is if we knew that another professional was visiting, we would try and join up with that visit and use their interpreter if we needed to communicate something really important."*
> ***(Participant 11: Clinical Nurse Specialist)***

According to participant 11, since the hospice is a charity, its services, such as language and translation services, depend on the funding. Consequently, a lack of funding greatly limits the language services they can access. As a result, they must seek alternative means to access translation, such as collaborating with other professionals to schedule appointments jointly in order to be able to use the same interpreter. In this circumstance, the use of language services such as language line is financially burdensome, resulting in difficulties for healthcare professionals in providing culturally appropriate care in the family's native language.

Suggestions to overcome language barriers and translation challenges:

Inconsistency of translation services, as described previously, was one of the limitations of the service, as well as the fact that the interpreter's shift could end during the consultation appointment, and a new interpreter would have to be assigned. Therefore, the same participant who raised this concern proposed the following as a possible solution that would make a significant difference and improve the effectiveness of care:

> *"...would be to be able to have an interpreter that we book on a named basis for the whole session that they can come face to face, that we can use the same interpreter for a series of discussions, which is often what we have."* ***(Participant 8: Paediatric Palliative Care Consultant)***

As previously indicated by one of the healthcare providers, a Muslim father pointed out that some information was mistranslated by the assigned interpreter. The participant stated that on the basis of this father's experience and the fact that sometimes being the translator could be an inconvenience, their services should be evaluated in order to be more effective and efficient. In this regard, the participant stated the following:

> *"So, we may need to look at the interpreters we are using, because I think when we use the interpreters for the Advanced Care plan, I think Muslim consultants and doctors and health professionals were involved to make sure the interpretation was correct."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

"...we were always thinking, well that could have been better for Dad, because Dad's grieving as well, but then he's got to work and be the interpreter for mum. So, we are looking at that now to see if that can be improved in our service." ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

The subthemes above relate to the major theme of linguistic barriers that emerged from the interviews with healthcare professionals and social work students. Based on these interviews, it was possible to gain a deeper understanding of the ways in which healthcare professionals and social work students attempt to mitigate communication barriers with Muslim families of children receiving palliative care or facing end-of-life care challenges. While there are accessible services where they can obtain interpreters in the requested language, these services have certain limitations that can place some burden on the family and the healthcare professionals.

When discussing translation challenges to overcome language barriers, participants discussed different issues. A number of these issues have been addressed, including services creating barriers between healthcare professionals and families, issues relating to the quality of services, such as video services and possible technical difficulties, and opinions about interpreter characteristics. Moreover, participants discussed institutional barriers that sometimes prevent them from being able to access translation services. Consequently, overcoming these barriers facilitates communication and enables Muslim families to address their cultural and religious needs, as well as provide culturally sensitive care that aligns with their values.

Theme 6: The Role of Faith and Culture in Shaping Personal and Social Identity

The role of faith and culture in shaping personal and social identity has been identified as one of the major themes in the study. It has been noted by several participants in this study that faith and culture play an important role in people's lives. The following participant highlighted the importance of culture and religion in influencing the end-of-life experiences of Muslim families of children receiving paediatric palliative care. According to this participant:

> *"So, I think it [culture and religion] plays a massive part in end-of-life care and support for that family and afterwards as well."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Subthemes to be discussed include faith and culture as a source of comfort and support, and their role in influencing decision-making.

Source of comfort and support

Faith and culture also play a central role in Muslim decision-making as it provides both moral guidance and emotional support during times of crisis. In this study, few healthcare providers indicated that in difficult times, some families may find comfort in their religious faith as well as in the knowledge that they have family support and extended family to turn to for assistance.

One participant broadly viewed religion as a potential source of comfort and support for some families:

> *"I think people's culture and their spirituality, or their religion can have a huge impact on where they're at and what they believe and for some people it's really comforting to know that they've got their religion, and they've got the support of family and extended family"* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Another participant expressed a similar viewpoint, perceiving religious beliefs as a source of strength for its followers:

> *"I think in a way that their faith may give them more strength because they have something to do, they've got somebody to pray to. But that again, it doesn't need to be specific to Islam, it could be anybody."* ***(Participant 11: Clinical Nurse Specialist)***

From their perspective, both healthcare professionals highlighted that Muslim families, as well as other faiths, may find comfort and support through their cultural values, religious beliefs and spiritual practices. It has been noted by participant 3 that the Islamic faith and culture may influence some people's circumstances, and the support received by extended families and the wider community. Participant 11 confirmed that Islamic faith can provide comfort and strength for some individuals, but this is also true for people of other faiths and cultures.

Family network support

The family unit is seen as a source of strength and compassion, where mutual care and support are vital duties for every member. According to one participant, extended family support is related to religious or cultural values of some Muslims. It is possible that such family networks and support are deeply rooted in Islamic cultural and religious values, which play an important role in shaping family and social relationships. In a study by Abdullah, Guo, and Harding (2020), Muslim patients at the end of life recognized their family members, extended relatives, and friends as sources of emotional support and motivation as well as companionship. Therefore, it is comforting to know that there is a family network that can provide support when needed to families with terminally ill children.

In the opinion of three participants, Muslim families have a strong family network and support. Muslim families are strong because of the large community, according to one participant:

> *"So, I think because there's such a large Muslim community and they are quite together in their beliefs and everything, I think it is quite strong. It's probably one of the more heightened religions because we see a lot more of it."*
> ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Similarly, participant 4 indicated that Muslim families have a substantial support system, which has led some families to choose their own community and support network over the support services provided by hospices. This participant indicated the following:

> *"Lots of the Muslim families, they've got massive family support networks around them… a fair number of Muslim families say, oh, no, we've got good family support, or we've got support through our own mosque, and we don't need support from the Hospice."* ***(Participant 4: Clinical Nurse Specialist)***

However, one paediatrician consultant believes that strong Muslim family networks are primarily driven by the family's culture rather than by their religious beliefs. In the opinion of this participant:

> *"I don't particularly see this as a religious thing, but it's certainly a cultural thing. But a lot of the families that we look after have a really strong family support."* ***(Participant 2: Consultant Paediatrician)***

According to the above extracts, Muslims typically have strong support networks which are crucial to coping with illness and receiving medical care. All three participants believe that Muslim families are united by their shared beliefs and values, which can come from their religion or culture.

Participant 2 and 3 observed that support for families with children in palliative care or at the end of their lives is not limited to extended family members, but also includes other Muslims in the community, who are not necessarily family members. A physical support can be provided by taking care of other children or assisting with various household chores such as cooking. Specifically, they stated:

> *"They [Muslim families] live with extended family. They have neighbours that aren't their relatives, and they have lots and lots of physical support for people to look after the other children, and to help cooking, including some practical stuff."* ***(Participant 2: Consultant Paediatrician)***

> *"…and especially I think after death, Muslim families come together so, so well and really support each other. The parents don't have to cook, they don't have to clean, they don't have to do anything, they can just focus on what they need to do and there'll be millions of family within that household prior to COVID and I think that is really lovely how they all come together and even people that don't know the child will be bringing food to the doorstep and that kind of thing."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

The above quotes describe the support as being more practical in nature, ranging from physical support to helping the terminally ill child's siblings with various chores, such as cleaning and cooking. Not only the extended family, but also community members, such as neighbours and friends, offer support to the family, even those who do not have a direct relationship with the family. Nevertheless, the involvement of extended family members or the broader community may sometimes be perceived as detrimental, placing a burden on the parents caring for a child receiving palliative care or in imminent danger of death.

Pressure and expectation from wider community and extended family:

Guilt and shame:

Families can experience adverse outcomes due to cultural demands and expectations placed on them by their extended families. Families may feel a sense of guilt due to familial ties between spouses. There was a brief mention of consanguineous parents in this study, which are commonly found in Muslim families. In the opinion of one of the participants, consanguineous parents may, to some extent, contribute to the development of a disabled child. Consequently, parents may feel guilty, believing that they are responsible for the development of their child's disability. As stated by the participant:

> *"But we definitely do have quite a large number of consanguineous parents and that obviously has a bit of an impact, and I think that could probably be quite hard for some of the families if they feel that they've obviously sort of caused their child to have a disability and a palliative care need because of their relation."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

The nurse in the above statement highlights the genetic risks associated with consanguineous parents, those related by blood, among Muslim families, emphasizing the possible genetic risks associated with such relationships. Particularly, issues concerning the likelihood of children having disabilities or long-term life-threatening conditions requiring palliative care. Because of that, parents may feel guilt and emotionally burdened.

Moreover, it has been mentioned by a participant that there are families who feel compelled to hide their terminally ill children due to the stigma imposed by the wider community for having a child whose life is shortened. According to this participant:

> *"We do have some families that there's a degree of shame or stigma about having a child who's got a shortened life expectancy or illness, who want to hide that from relatives. So, even though they might have that wider family support, they might not actually have the availability to be open and honest about their child's needs."* ***(Participant 2: Consultant Paediatrician)***

Parents who experience such feelings of shame, as participant 2 explained above, may be reluctant to openly discuss their needs with extended family members and the wider community.

Extended family and tension in decision-making

One of the healthcare professionals in the study highlights the tension between the wishes of the extended family, who may push for aggressive treatment options, and the recognition by the parents that such measures may not be in the best interest of the child. As highlighted by this individual:

> *"We have a lot where it's the extended family that have said, no, you can't give up on them, you need to do everything, and maybe the parents themselves, they can see that it's not what's best for the child."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Another participant shared a similar view, indicating that parents might feel compelled to align with the community's or extended family's expectations, even if it conflicts with their own beliefs or understanding of what might be best for their child. According to this participant:

> *"And I think there's also a cultural element to it, because I think sometimes parents maybe feel one thing, but I think they feel the pressure from the community to do something different, you know."* ***(Participant 4: Clinical Nurse Specialist)***

The same participant further explained the following:

> *"So, I think we do get parents that think, actually my child is going to die. I know that they've got a progressive condition. I know that they come towards the end of their life, but I think they can be reluctant to sort of change their direction of care, because they've got community behind them."* ***(Participant 4: Clinical Nurse Specialist)***

Other health care providers interviewed in the study reported that extended families can sometimes impede parents' acceptance of paediatric palliative care or end of life care. As the following excerpt illustrates, family dynamics within Muslim families can have a significant impact on parental choices; for example, extended family members, such as grandparents, can intervene in the decision-making process of parents:

> *"We've had it recently actually with a baby where the parents had opted for palliative care and end-of-life care and not to pursue cardiac surgery for their baby and it was the grandparents that were adamant that they were making the wrong decision, and they needed to have the cardiac surgery, and they needed to go down a "try-everything route". So, the parents then opted to choose not to tell the grandparents that that was what they'd chosen and it was quite strict then for when we were going into the home and visiting that we weren't to bring up the fact that it was the parents' choice not to accept the cardiac surgery and they'd said it was the medical decision that cardiac surgery wasn't an option."*
> ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

According to the above quote, there is a conflict between family expectations and parental autonomy in making end-of-life decisions. As explained by the participant, varying viewpoints within a family-particularly those of parents and grandparents-can complicate decisions regarding the treatment of critically ill children. While the parents' decision to pursue palliative care rather than aggressive treatment reflects their understanding of the child's needs, the grandparents' persistence in "trying everything" is indicative of the emotional struggle and hope associated with such a situation. Further consideration of family dynamics will be given in the following theme to better understand how they affect care and decision-making for families with children receiving palliative care or at the end of their lives.

Impacting decision-making process:

Furthermore, culture and religion can possibly shape the choices that families make about their child's care, including preferences for treatment, acceptance of palliative care, and decisions around end-of-life. In this study, it is demonstrated by some participants that faith and cultural values and practices of some Muslim families play a significant role in influencing their decisions regarding active treatments and end-of-life care. Families may feel the need to seek assistance from their mosque leaders (imams) or extended family members as major decisions are introduced.

In the opinion of the following two participants, when it comes to making difficult decisions for Muslim families, their religious beliefs and culture will have a significant impact, determining who will either make the decisions or guide parents in making critical decisions. As stated by the participants:

> *"Often, we'll have families that, if we've had difficult discussions with them, and maybe talk about different scenarios, then maybe escalation of treatment of care to the hospital that they maybe want to go away and speak to their imams or*

> *their elders within the community to get some advice."* ***(Participant 1: Children's palliative care Nurse Specialist)***

> *"I think experience wise, undoubtedly families' faith will influence decision making. It will influence who's involved in decision making, who has more of a responsibility in terms of the family hierarchy, and often it's the father and the father figures in the family who will have a greater influence."* ***(Participant 8: Paediatric Palliative Care Consultant)***

In the above extracts, participants 1 and 8 explained that some Muslim families tend to involve elders or religious leaders, such as imams, in healthcare decisions, reflecting the intricately intertwined relationship between religion, culture, and family structure in determining the way families approach end-of-life care.

Trust in Allah's (God's) will and predetermined plan:

A fundamental Islamic principle that was commonly mentioned in this study and perceived as impacting a family's decision-making process was believing in Allah's plan. Believing in Allah's-will is central to a Muslim's faith, signifying trust in divine wisdom and the understanding that everything happens according to God's plan. This belief encourages resilience and patience in the face of life's challenges. In situations where a family is faced with the situation of a terminally ill child, Islam provides some helpful guidance, such as taking refuge in Allah, praying, and trusting in his will to heal the child or reduce their suffering.

According to a participant in the study, some Muslim families strongly believe in pursuing all treatment interventions for their children, which makes them hesitant to have discussions regarding end-of-life care. The reason for this is that they adhere to the principle of fate, which holds that only Allah has the power to determine when a child will die. The participant stated:

> *"Families are not willing to have that discussion [about end-of-life] because they feel that they want to try everything and leave it in the hands of Allah."* ***(Participant 9: Clinical Nurse Specialist)***

Similarly, the following statements demonstrate that Muslim strongly believe that Allah is the only one capable of determining the time of death. As stated by participants 1 and 4:

> *"Again, often families will talk about, there will be a time that's written for them for when it's time for them to pass."* ***(Participant 1: Children's palliative care Nurse Specialist)***

> *"...a lot will say anything like, it'll be in Allah's time and it's up to God, and Allah will decide when the right time is for my child to go."* ***(Participant 4: Clinical Nurse Specialist)***

It is widely believed by all three participants that God is the only one who can predetermine the time of death. In this way, these extracts demonstrate how Islamic faith plays a central role in the way families navigate certain aspects and make difficult decisions when they have a child undergoing palliative care or end-of-life care.

During the study, one participant expressed that sometimes they encounter difficulties because of the strong belief held by some Muslims that Allah has the power to impose changes since he is the one who determines the time of death. The participant stated the following:

> *"We've recently had a difficult case where the family just didn't want to believe the child's illness and prognosis and therefore just, they believed their faith and God would make it all better and that was the only thing for them to believe and support."* ***(Participant 1: Children's palliative care Nurse Specialist)***

As described in the above incident, due to the strong belief that their fate has been decided by God, and the belief that God is capable of healing their child, some families maintain the hope that their child will recover fully. A belief in God's will over a realistic prognosis for the child may result in difficulties for healthcare professionals, including communication difficulties and conflicting views of what is best for the child.

Nevertheless, certain families may accept that there is no hope for their child's cure, as part of Allah's will. They may perceive this to be Allah's best plan for their child. One participant reported:

> "Sometimes we get families very much wanting active treatment. *And then a mom recently said, she feels Allah, saying it's time and which has been kind of almost believing things happen according to Allah's will, and actually enough is enough. I feel Allah saying it's time and we've also had other families who I've been unsure about end of life and things and family."* ***(Participant 13: Nurse)***

The following participants referred to different incidents and opinion, but also related it to the families' strong trust in God's will. One participant recalled an incident where the parents were comforted by their believe in God’s will for their child to pass:

> *“I wouldn't be able to know if it [family’s Islamic faith] made any impact on the care or not. But I think near the end, when it came to taking her [the child] airway out, it impacted the care afterwards in the sense that the parents were reassured [by their religious beliefs] this is what's meant to happen. It was her time [to die]. The staff in the ward, the family would turn around [to the staff], and say it's her time, it's her time to go.”* ***(Participant 7: Nurse)***

Another participant stated:

> *“And actually end-of-life care can be the slightly harder part for some families with the wider community to accept, so there can be pressure, sort of at the end to give up. But in other times it can be the opposite, actually because it's God's will as such, and nobody can change that will, and it's gonna happen when it's gonna happen. So, actually whatever we do, as long as we're doing it with good intention, then it's okay.”* ***(Participant 2: Consultant Paediatrician)***

As indicated by participant 2, during end-of-life situations, some families may feel pressured to continue active treatment, as desired by extended family members, or terminate treatment, as recommended by the medical team. However, for families who firmly believe in Allah's predetermined plan and will for their children, regardless of whether active treatment is continued or terminated, the children will die at Allah's designated time. In essence, the termination of the treatment did not cause the child's death, but rather Allah's predetermined time for the child to pass. Overall, every family interprets God's will differently. For example, some families openly accept their child's impending death as God's will, whereas others cling to hope for a cure as God's potential will.

Theme 7: Family Dynamics

Another theme that came out of the study was how family dynamics influence some of the decision-making abilities of Muslim families. Throughout the interviews, some participants explicitly differentiated between cultural and religious influences, suggesting that some roles and expectations are largely determined by cultural expectations rather than religious mandates. The main subtheme that will be discussed is challenging gender norms and bias. Within this subtheme, the role of gender will be explored in terms of caregiving responsibility, autonomy, and English language proficiency.

Challenging gender norms and bias

Gender roles in caregiving

There were several participants in the study who considered mothers to be the primary caregivers for their children, especially when it came to medical care. One participant stated the following:

> *"I don't deal with the dads as much and I think that's because again, it's culturally and I don't want to mix up sort of culture and religion cause it's different. The moms do the majority of the caring."* ***(Participant 9: Clinical Nurse Specialist)***

The statement by participant 9 illustrates how cultural norms position mothers as the primary caregivers, and how these expectations can shape interactions between healthcare professionals and family members. This view is further reinforced by participant 13, who remarks:

> *"...mum's perceived role to care for the child, and it's very much on the mum to do all of the care for the child or the medical needs."* ***(Participant 13: Nurse)***

By giving an example, participant 11 highlighted that fathers to some extent play a secondary role in the care of their children in palliative care. According to the participant:

> *"He [the father] wasn't the main carer for the child, the mum was."* ***(Participant 11: Clinical Nurse Specialist)***

From the experiences of the above three participants, it appears that certain gender roles and expectations exist within the dynamics of certain Muslim families, where mothers are more likely to serve as primary caregivers. All participants agree that fathers tend to play a less active role in caring for their children as compared to mothers.

Gender and autonomy

Some participants described how cultural norms, rather than religious guidelines, often limited Muslim women's autonomy, limiting their role to primary caregivers in the home, and having little input into different decisions regarding their palliative care child. One participant said:

> *"I don't know whether some of that's just sort of more culturally, obviously the females in the family, a lot of them are homemakers. They don't tend to have jobs and have independent lives outside of their home, and so they don't have perhaps the experience of talking and organizing things. So, I think I, I think again it's a cultural rather than a religious thing."* ***(Participant 11: Clinical Nurse Specialist)***

According to another participant, Muslim women may sometimes be forced to follow rituals or norms that make them seem marginalized or excluded, hindering their autonomy and limiting their involvement in the ritual of burying their children. As the participant strongly expressed:

> *"I mean, I've been on a night shift where somebody died and they've literally pushed the mom out of the room, and the men have come in and the mum has just been almost absolutely shunned out of the room and I think my colleagues were, you know, were very OH My goodness."* ***(Participant 13: Nurse)***

Participant 13 further commented on the problem of being excluded, pointing out that Muslim mothers are sometimes unable to access hospice support due to cultural expectations that they should be the sole caregivers of their children, rather than involving others in the care process, even if it is hospice care. The participant stated:

> *"... and actually, [moms] not allowed to accept help from a hospice, and so, sometimes we find that mums are quite keen to access support and have that break while they're here. We've had one where a dad wouldn't allow them [moms] to come here or the extended family is very much presumed no, you will cope, you will. It is your role. It's not the role for other people to do it, that don't know the child and we do get that with other with other families as well."* ***(Participant 13: Nurse)***

As indicated in the quote, there are cultural and perhaps social expectations that mothers should be the primary caregivers of their children, especially when it comes to handling their medical needs. Mothers are put under pressure by these expectations since they are made to believe that taking care of their children is their responsibility and not anyone else's. As a result of this perceived view of extended families, mothers may sometimes be discouraged from seeking or accepting external support, even when they desperately need it. Thus, mothers often feel reluctant to seek additional help or support, even when it is readily available and offered to them.

Gender and language proficiency

Two participants distinguished between the English proficiency of mothers and fathers. One participant indicated that the lack of English proficiency of the mother plays a role in her involvement in the decision-making process:

> *"...more often we're using the interpreter because mum's English is really more of a challenge than Dad. So, we've got that dynamic going on in terms of actually influencing decision making." (**Participant 8: Paediatric Palliative Care Consultant)***

While the other participant highlighted that sometimes fathers put restrictions on mothers to prevent them from learning English:

> *"But we have a lot where say dad is an English speaker. And the mums, I mean one mum said that she wasn't, kind of, almost allowed to learn English. So, they kind of not empowered to learn it." **(Participant 13: Nurse)***

Both participants demonstrate that fathers are perceived as having greater proficiency in English, whereas the limitations of mothers' linguistic abilities further marginalize their contributions in areas such as decision-making, reinforcing their reliance on their partners, and reducing their autonomy both within the family and in healthcare settings.

Several participants have expressed the opinion that gender norms and bias play an important role in family dynamics and who seems to have the authority to make decisions when a child is receiving palliative care or is nearing death. Gender plays a significant role in determining who is expected to assume the role of responsibility, which as can be seen from the responses of the participants, is the mother. The English language proficiency of mothers and fathers also differs, with fathers perceived to have better English skills than mothers. Also, gender appears to be a factor that affects autonomy, where mothers are perceived as less independent than fathers. These variations lead to the perception that fathers have a greater degree of authority over mothers when making decisions.

Theme 8: Family-centred care

Family-centred care is one of the major themes emerging from the study. Several aspects were identified by the study participants as being important in facilitating culturally sensitive care that meets the specific needs of each child and their family. Subthemes of this theme include recognizing that each child and family is different, the role of healthcare professionals in family-centred care, assessing the cultural and religious needs of families, and the institutional roles in family-centred care for Muslim families.

Recognizing that each child and family is different:

There is a strong emphasis among some participants on recognizing and respecting the unique characteristics and needs of every child and family. Among the participants, the following was stated as the general idea:

> *"…every child is different, and every picture is different."* ***(Participant 9: Clinical Nurse*** **Specialist)**

According to another participant, children's needs tend to change over time, requiring services to be adapted accordingly. This participant stated:

> *"…every child is different. I think every child needs change over time and it's about having an adaptable, and I guess multifaceted service."* ***(Participant 2: Consultant Paediatrician)***

Moreover, a third participant commented that each family's approach to their faith differs, even when they share similar religions or cultures. Thus, care should be tailored to the individual's needs and preferences.

> *"Obviously every family is different, and we try really hard to work with the family and their individual needs. So, within a belief, there's a lot of variation, isn't there? and everybody's individual in how they interpret that belief and how they let that belief out. So, we try very hard to be non-judgmental."* ***(Participant 4: Clinical Nurse Specialist)***

The participants above recognized that every child and family is unique, and that care should be tailored to their specific needs. They stressed the importance of recognizing, responding, and adapting to the constantly evolving needs of children and families, without judgement, whether in terms of medical care or cultural preferences.

Role of healthcare professionals in family-centred care

The participants in the study indicated that they have an active role to ensure that care is personalised to the needs of each child and family. There is a consensus between the following participants that it is essential to prioritise understanding what is important to each family, including their individual values, cultural practices, and wishes. One social work student highlighted their responsibility in being aware of the family's wishes for their child, by saying the following:

> *"My role would have to understand the wishes and feelings, obviously, and understand... what the parents want for this child."* ***(Participant 15: Year 1 BSc Social Work Student)***

Likewise, another social work student emphasised the importance of understanding the needs of the family:

> *"...and sort of like, understanding what's important to that family's needs."* ***(Participant 16: MSC Social Work Student)***

The third social work student stressed a person-centred approach to caring for children, which encompass the following:

> *"You need to find out what's important to the family. Like, what do they feel that they need from you. It would be very sort of person centred."* ***(Participant 14: Year 2 BSc Social Work Student)***

As for participant 9, talked about their responsibility in terms of incorporating the needs of the family during consultations and discussions with families. The participant highlighted the following:

> *"We do talk about those different practices, different cultures, what parents may want or what may be significant to a family that need to ask."* ***(Participant 9: Clinical Nurse Specialist)***

Participants in the above statements talked about a range of things regarding a family-focused approach to incorporating religion and culture into children's palliative care for Muslim children and their families. Rather than applying a one-size-fits-all solution, participants in the above statements demonstrate a family-centred approach that tailors cultural and religious support to the unique needs and circumstances of each family. The above clinical nurse specialist discusses current practices in assessing the cultural or religious needs of Muslim families, which includes asking families directly about what they consider important.

Avoid making assumptions:

Participants shed light on the importance of avoiding making assumptions about what the family may need. Hence, asking families about their preferences is an integral part of family-centred care. These participants said:

> *".... we try to make sure that we don't go in with assumptions that this is what this family will absolutely want."* ***(Participant 4: Clinical Nurse Specialist)***

> *"I think the more knowledge I have, the better, I've learned quite a lot. And one of the things I've learned is not to make assumptions either and not to try and always apply what I think. I expect people's religious observance to be not the same for everybody."* **(Participant 9: Clinical Nurse Specialist)**

> *"I think, as long as we communicate adequately, you know, and you're not making assumptions then that's fine."* **(Participant 12: Nurse)**

> *"One of the things is, it's so individual, so don't assume anything. As I say, that's kind of based on the culture thing, so it's not generalized."* **(Participant 13: Nurse)**

According to the above three participants, part of their role as healthcare professionals in providing family-centred care is to make sure they do not make assumptions about cultural values or religious beliefs of families.

Asking families:

Accordingly, some participants suggested that it is more effective to directly ask families about their needs and the problems they are facing, so that services can be tailored to their needs, including their cultural and religious requirements. It was noted by one participant that ethnic minority families are welcoming to discussions about their backgrounds and cultural or religious values. This participant said:

> *"And actually, most immigrant families, or minority families, are very happy to be asked, you know, they like sharing the knowledge."* **(Participant 12: Nurse)**

As another participant recommended, when in doubt, approach families and ask them questions, but make sure the questions are appropriate. The participant stated the following:

> *"So, and not being afraid to ask families as well, if it's appropriate, you know, if there's something that I'm not aware of or understand, to get some more understanding from them as well. And trying to get a parent voice as well, it's really useful, but sometimes it's not always appropriate."* **(Participant 1: Children's palliative care Nurse Specialist)**

According to a third participant, families are not routinely asked about their cultural and religious needs. As reported by the participant:

> *"I don't think we ask families enough what they want. And that goes across the board no matter what faith or background somebody has."* **(Participant 2: Consultant Paediatrician)**

As indicated above by the participants, rather than assuming what the family's cultural and religious needs are, it is preferable to directly approach families and ask them about such needs or to clarify any misunderstandings.

Active Listening:

As part of the effort to avoid making assumptions, some participants pointed out that it is essential to listen tentatively to families to identify their wishes and priorities, and to advocate for these needs as required. These participants stated the following:

> *"... and try and understand what they [parents] go into really. And obviously listening. And is to be an advocate for them really."* ***(Participant 15: Year 1 BSc Social Work Student)***
>
> *"But yeah, just kind of grasping really what's important and what's important culturally as well."* ***(Participant 14: Year 2 BSc Social Work Student)***

Another healthcare professional in the following statement shared a similar view in terms of the need to carefully listen to the needs of families. This participant highlighted the following:

> *"In any positive care situation, you'll always start with lots of active listening, and you'll be asking about their particular beliefs and asking about what's important for them for now, what's important for the future, what's important in terms of decision making and, and trying to understand it from their perspective."* ***(Participant 8: Paediatric Palliative Care Consultant)***

Each of the participants above stressed the importance of active listening when speaking with families about their cultural and religious needs. The participant 8 summarized how tailored care is accomplished, which includes all the above-mentioned factors, such as asking families about their needs and actively listening to their concerns. The viewpoint expressed by this participant indicates that a holistic approach, focusing on a family's needs, is important, as it would consider the family's current needs, future wishes, and cultural and religious priorities.

The Impact of Ignoring Religious Needs and Making assumptions

Several participants recalled different instances in which the care of Muslim children and their families was not necessarily fully customized according to their needs. One participant had an experience where religious needs were not taken into consideration by healthcare professionals, which resulted in some healthcare professionals overlooking those needs. Based on what this participant encountered, the following statement is made:

> *"I think that nobody at any point did anyone ever ask about their faith, what faith they had. Nobody asked that. I don't think anyone even thought of it as a point that they need to know about."* ***(Participant 6: Nurse)***

In the following statements, two participants reflected on incidents where previous assumptions were formed based on previous knowledge or understanding of certain religious practices followed by Muslims. According to their responses:

> *"There was a full day before she was able to be buried, and the family wanted her to stay at the Hospice, and that was something that we weren't expecting. So, we didn't really offer that to the family, but we realized afterwards that we made an assumption there. And that was a real realization for us because the family had been there for a while and had been for all the care planning."* ***(Participant 9: Clinical Nurse Specialist)***

> *"So, I gave them the option. So, I explained to them, what would you want to do? Hospice care is going to be this, and hospital is going to be this. And, you know, it's up to you. You can use a cold room if you want. Because obviously I wanted them to still have the options. Even if she was a Muslim, they might want to spend more time with their child. She's an infant at the end of the day, their first daughter. So, I did give them the option about a cold room and told them all about it."* ***(Participant 7: Nurse)***

These excerpts illustrate incidents that were encountered by different healthcare professionals in this study, where the religion of the family was not considered, as well as instances where assumptions were made. A lack of consideration for the family's religious needs implies that these needs have not been met, which may negatively affect the family's experience. The participant's reflection suggests that certain aspects of patient care, like understanding personal beliefs, may not be adequately addressed or communicated, highlighting a possible gap in comprehensive patient engagement.

Making assumptions can lead to missing out on offering certain options that families may wish to consider. As presented above, in one case, an assumption was made leading to a missed opportunity for care, while in the other case, the participant explicitly offered the option of a cold room, despite the family's Muslim faith. It is an example of challenging the assumption that all families of a particular faith will necessarily follow the same practices, such as immediate burial. In light of this, it is essential to refrain from making assumptions about the needs of a family based solely on its cultural or religious identity.

Assessing the cultural and religious needs of families

Participants in this study identified Advanced Care Plans (ACP) as an essential step in assessing the needs of children and families, including their religious and cultural needs and preferences. When participants were asked about the way in which the cultural and religious needs of Muslim families are assessed, a few participants stressed the importance of developing an advanced care plan to determine these needs, along with any other wishes, preferences, or hopes for children and their families. These participants responded as follows:

> *"And so, we get very involved in an advanced care plans as well, writing advanced care plans and talking to families and to children and young people about their sort of hopes and wishes around life, but also about end of life wishes."* ***(Participant 4: Clinical Nurse Specialist)***

> *"We do a thing called an advanced care plan. It's a national document that families can fill in. And it's got kind of likes and dislikes. So, what's important to the child? Do they particularly like a toy? If they [children] go into hospital, they don't like hospitals, so they might be tricky to get a cannula in."* ***(Participant 13: Nurse)***

As mentioned above, participants 4 and 13 presented an overview of advanced care plans and what they entail for children and young people as well as their families. According to the participants above, ACP provides a comprehensive description of what children, young people, and their families are seeking, not just in terms of physical care and medical procedures but also in terms of their personalities, interests, wishes, and hopes.

Additionally, the following three participants mentioned that the ACP also reflects the spiritual and cultural wishes of the family. According to one participant:

> *"We do advanced care planning, and we're routinely asking, if there are any spiritual or religious wishes or anything."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

The other two participants elaborated on the structure of the ACP. One indicating that it also takes into account the cultural and spiritual needs of the family:

> *"And that's part of our advanced care plan is there's a part on that of culture and spirituality. You know, there is a section on there that we would discuss with families of what are their wishes. What do they want for their child at the end of life so that we can get the most important people coming in to help us grant their wishes."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

An ACP was demonstrated to be effective for a Muslim family in this participant's experience. As stated by this participant:

> *"In this advanced care plan, it was all about what the family wanted. The best for this child at the end of life, so they wanted the child to be at home and they didn't want him to die in hospital. They didn't want to go to a Hospice. They wanted him home for all the Muslim community to support them, which that's what we did."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

As mentioned by the other participant, there is an end-of-life section of the ACP that looks at the needs of families when a child faces imminent death, which may also be tailored to Muslim rituals and practices. In particular, the participant stated:

> *"So, there's a page [in the care plan] about end of life, which is during death. So, things like organ donation and tissue donation and any spiritual care. So, actually, some people want the Quran playing all the time in the room or access to prayer mats or different things. So, you can put in as much detail as you like in that."* ***(Participant 13: Nurse)***

Throughout the above extracts, participant 5 highlighted the continuous assessment of families' religious and spiritual needs, as well as the use of an advanced care plan. As well, participant 10 pointed out that cultural and spiritual needs of families are addressed using an advanced care plan, which includes a section on spirituality and culture. While participant 13 focused specifically on the ways in which ACP can be tailored to meet the needs of Muslim families when a child is at the end of life and likely to die shortly.

Yet, despite the benefits of an advanced care plan, the following extracts from one of the participants talks about the possibility of parents being reluctant to start an advanced care plan.

> *"Some children may come home from hospital with them [advanced care plans], or if we've got a child with a life-limiting condition, who maybe the parents don't want to go through one."* ***(Participant 1: Children's palliative care Nurse Specialist)***

While participant 1 indicated that some families are hesitant to engage in an advanced care plan, she reiterated that healthcare professionals continue to listen to the needs of these families and suggest that they document their experiences and needs to support these families. She stated:

> *"but maybe if they [children] then start having regular admissions into the hospital, and sometimes there might be things from the hospital admissions that parents find frustrating or that they're not happy with, listening to them and supporting them through that, we can say, well, actually, what about if we started to write some things down that you find difficult, or just finding it hard for them to repeat the story of their child's illness every time they go into hospital."* ***(Participant 1: Children's palliative care Nurse Specialist)***

Some families are reluctant to initiate an advanced care plan, as participant 1 mentioned above. As a result, healthcare professionals may be required to adopt different approaches to meet the needs of these families, consider different ways to facilitate discussion about the children and their families' needs and wishes, as well as other information that will facilitate hospital admissions by saving families time when they are admitted.

Imams (mosque leaders) and chaplaincy involvement:

Two participants noted that as part of the assessment of the needs of the families, such as when creating an ACP, families are asked whether they would like an imam or a chaplaincy to be involved. One participant indicated that ACP allows for collaboration Muslim figures, such as Imams, when difficult end-of-life conversations arise. The participant stated:

> *"And also because of that [advance care planning], we're very aware of the need for involving people like the Imam when we're having difficult conversations."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***
>
> *"We have the imams involved, not just for the difficult decisions, but also just that support for almost like counselling and just that support for difficult times really."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

Similarly, the following participant emphasized that the care plan is an opportunity for families to freely express what they require, including whether chaplaincy is needed to assist in the care process. As mentioned by the participant:

> *"So, if that's [involving chaplaincy] what families want, we'll always try and respect that and we'll incorporate that into the care plan if we've got an opportunity to do so as well".* ***(Participant 1: Children's palliative care Nurse Specialist)***

The following participant noted that families have the option to choose their own imams, as they are not limited to the ones provided by hospitals, which are also perceived as supportive by families:

> *"We do sometimes get imams involved or ask if they've [families] gotten an imam, they want to speak to, or we can get the hospital imams to speak to them as well, which I think a lot of families find very supportive."* ***(Participant 4: Clinical Nurse Specialist)***

The above participants emphasize the importance of asking families if they wish to include Muslim religious figures, commonly known as imams, in the care process. As part of family-centred care, families are asked about their preferences and choice of imams, as they are not limited to those provided by the hospital. Imams can play a vital role in providing families with emotional and spiritual support and may even guide them through the process of making end-of-life decisions.

Overall, creating an advanced care plan, ensures that each child and their family can receive individualized care. An advanced care plan is developed in collaboration with families, allowing them to express their preferences and wishes for their child at any stage of their condition, as well as at the end of their lives. It is a comprehensive plan, addressing not only medical needs and their management, but also emotional, spiritual, religious and cultural concerns for children and their families. By establishing an advanced care plan, care providers can better navigate the complexities of end-of-life care.

Institutional Roles in Family-centred Care for Muslim Families

Some participants discussed some of the institutional measures in place to facilitate culturally competent and culturally appropriate care to meet the specific needs of Muslim families. Individualised support is provided to families by adapting to their needs, such as accommodating religious practices. As well as referring them to existing resources that could assist in accommodating their religious and cultural needs. The following participants noted that healthcare institutions have taken steps to create physical prayer spaces for Muslim families. According to one participant:

> *"And we've got a nice quiet area which used to be called the Chapel, but we've changed it into the sanctuary to try and make it a little bit more multifaith sounding. It's just been redone. And we've got nice little boxes in there that have got different sorts of artifacts and things that different religions might want to use and prayer mats and things like that."* ***(Participant 4: Clinical Nurse Specialist)***

Participants 12 emphasize the flexibility offered by the hospice in allowing families to pray at various locations, as convenient for them. As stated by the participant:

> *"we're quite open, we've got prayer mats. We've got like a multifaith Chapel. We're quite happy for people to just put them [prayer mats] down in the corner of the child's bedroom or things, you know. I mean, we've got all that sort of stuff. We cope with dietary requirements and everything, that's fine."* ***(Participant 12: Nurse)***

Moreover, a participant discussed accommodating the needs of Muslim families to adhere to Islamic food requirements, by pointing out:

> *"And our chef is good, and he always cooks halal meat and vegetarian options as well." (**Participant 4: Clinical Nurse Specialist)***

The same participant highlighted physical building alterations to accommodate post-death rituals required by Muslim families. As emphasised by this participant:

> *"we're having some building work done at the moment, which means the sanctuary isn't always open. So, sort of space for prayer and that kind of thing is a little bit more limited. But when the new sanctuary opens of course, it will be much better for ritual washing and for doing prayers." (**Participant 4: Clinical Nurse Specialist)***

Another participant described a collaboration with a local charity helping families with post-death rituals, specifically things required for burials. As indicated by this participant:

> *"And we use one of the charities which provide us the packs with the sheets and things for following on, from a child's death so that they can do the final sort of washing and wrapping."* ***(Participant 11: Clinical Nurse Specialist)***

As mentioned by the above participants, the hospice has made considerable efforts to create a multifaith, inclusive environment, offering prayer spaces, halal food, and support for religious rituals, even during times of construction. These actions reflect a deep commitment to accommodating the spiritual and cultural needs of families from diverse backgrounds, particularly within the context of paediatric palliative care.

Accessible resources:

Another participant discussed accessible resources that help them as healthcare professionals understand different religious beliefs, such as Islam and Islamic rituals at the end of life. According to this participant:

> *"We also have some guidelines and some workbooks for new staff that start, that talk a little bit about the different religions and different beliefs especially in terms of Muslim funerals as well."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

> *"We've got a lot of booklets on what to expect when your child's dying but there's nothing that's specific, Muslim specific, which would be quite useful."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

It has been pointed out by another participant that the charity's resources are not limited to healthcare professionals, as they are able to signpost Muslim parents and provide them with these solutions. As an example, suggest some valuable books for Muslim parents who have a child near the end of life, as these books may provide them with comfort at such a difficult time. As a result of the discussion, the participants made the following comments:

> *"Their [charity in the local hospital] different resources, they do several, that's quite a good one. I would give a parent who's potentially at the start of their journey. I find that book really good."* ***(Participant 11: Clinical Nurse Specialist)***

> *"And then there is another one [book], 'a gift for a bereaved parent', which again has lots of different quotes in there. And then there's a book for siblings as well, called we will meet in Janna. And so, I'll utilise all of those resources."* ***(Participant 11: Clinical Nurse Specialist)***

The following statement by the same participant indicates the positive outcome of these book recommendations:

> *“Some parents have gained real comfort from that [several resources] because it actually has quotes from the Quran in it, which sort of talk about their journey. And so, I had one mum whose son was very much likely to die in his kind of early childhood. And she was saying it says here, you know, if you're if your child dies before puberty, they're paving your way to Janna. And so, she found quite a lot of comfort from that.”* ***(Participant 11: Clinical Nurse Specialist)***

Participants 3 and 11 above have shed light on some of the useful resources provided for both Muslim families and healthcare professionals. Parents may find the resources helpful in the difficult process of caring for a dying child, which is in accordance with their Islamic beliefs. As mentioned by the participants, the current resources help families find comfort in their faith during the palliative care journey, but developing Muslim-specific booklets could further enhance the quality of care.

Under the theme of family-centred care, participants discussed the importance of providing care tailored to the specific needs of each Muslim child and their family. First, participants acknowledged that children are individuals, and therefore their needs vary depending on their circumstances as well as their cultural and religious beliefs. Accordingly, some participants highlighted their role as social workers or healthcare professionals in providing family-centred care, which means listening to the needs of each family and providing care according to their cultural and religious beliefs. Assumptions should be avoided at all costs, as they may negatively affect the quality of care provided to the family. An Advanced Care Plan (ACP) can assist in avoiding assumptions and providing a thorough assessment of the needs of children and their families. Children's ACPs describe what children, and their families may wish for throughout their journey of care, including their cultural and religious preferences. Additionally, the participants have pointed out that existing institutional efforts have been made to ensure Muslim families receive culturally appropriate care and are able to perform religious practices and abide by religious requirements. One of the Islamic religious rituals for rapid burials observed in the study will be discussed in detail in the following theme, as well as the challenges faced by healthcare professionals in attempting to accommodate it.

Theme 9: Accommodating Rapid Burial Rituals

One of the major themes emerging from the interviews is post death practices, which mainly include rapid burial. Most participants emphasise the importance of facilitating a rapid burial, which is a critical aspect of Muslim burial practices. The following are extracts from some of the interviews that are specifically related to the importance of rapid burials for Muslim families when their child passes away. There is a clear understanding among healthcare professionals in this study that there is a need to respect and accommodate the cultural and religious practices of Muslim families for rapid burials, even if sometimes things do not go according to the family's wishes. Specifically, they stated:

> *"I would say, obviously a rapid burial is a really big and important thing to a lot of the Muslim families and so we do our best to make sure that things go as smoothly as it possibly can after the child has died so that can happen as soon as possible."* ***(Participant 4: Clinical Nurse Specialist)***

> *"I think it's the kind of the rituals and that kind of thing, of the expectations. So, I think a lot of us know that families like the child to be buried as soon as possible." (**Participant 13: Nurse)***

> *"The only thing I can think of that they found it difficult was when the child passed away that Friday early morning, early hours of the morning, we were told by Dad that he needed to be buried within 24 hours and that did break my heart a little bit because we went out of the 24 hours."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

To demonstrate good practices, it is essential to understand the urgency of burial and the specific rituals associated with the end of life. It is clear from the statements of the following participants that such good practice involves comprehensive planning, which is crucial to meeting the needs of families seeking a rapid burial.

> *"We also try and make sure, where possible, we've sort of got as much planning done with things like end of life and desires to have a quick burial."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

> *"We like to try and facilitate things [in terms of Muslim funerals] as quickly as possible for the family because it's their belief and religion to have the child buried, ideally within 24 hours of them dying. We do try to facilitate that where we can and that can be quite hard if we can't do that for certain reasons."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Collaboration with other healthcare services and practices is an important aspect of good practice. A healthcare professional participating in this study stated:

> *"There's a local GP who's the director of the out of hours service. And he's trying to go around and meet people who are imminently dying. And then he can provide the cause of death certificate for them, once they have died."*
> ***(Participant 11: Clinical Nurse Specialist)***

Additionally, it is important to maintain transparency with family members as part of good practice. If any delay occurs due to other unforeseen circumstances, it is essential to maintain an open and honest communication with parents. Following are excerpts from the experiences of two healthcare professionals who participated in this study:

> *"And as I say, pleasingly, I had said, we will need to refer to the coroner. And they did remember that. And I said, so I'm really, I am worried that we won't get him buried today. I said, because we have to do that. That is not a choice."*
> ***(Participant 5: Consultant in Paediatric Palliative Medicine)***
>
> *"We were just outside the 24 hours, and we always explain to dad that obviously, you know, with Christmas time we had bank holidays that could happen that we… we 24 hours may not be appropriate. So, we always prepared the family that if he does pass away on the Sunday before bank holiday, we are going to have to wait a little bit longer and they took that on board,"*
> ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

Both participants in the above statements emphasize the importance of clear communication with families about the procedures to be followed. This includes the coroner's involvement, and other administrative or legal procedures that may result in burial delays. Therefore, below will be a further discussion of some barriers or challenges faced by some of the healthcare professionals in this study that can possibly hinder the process of rapid burials requested by Muslim families.

Challenges and barriers in facilitating rapid burial:

It is clear from what some participants have said previously, Muslim families need to be able to rapidly bury their children as part of their religious or cultural beliefs; however, some participants provided insight into certain factors that significantly contribute to the inability of rapid burials to take place.

Issuing death certificate:

Some Participants describe some of the challenges they encountered when trying to facilitate rapid burials. Regarding barriers to rapid burials, participants primarily discussed challenges outside their control, where other services are involved, such as coroners and general practitioners who are responsible for issuing medical cause of death (MCD) certificates, as well as local authorities, such as councils, who prepare burial grounds and register deaths. Following is a summary of the experiences of these participants:

> *"One of the other barriers would be, if there's any delay following death, around getting the medical cause of death certificate and then getting the registration, to be able to facilitate a rapid burial. But we're getting so much better at it, like we've got it down to a really, really smooth machine."* ***(Participant 11: Clinical Nurse Specialist)***

> *"But that [delay of burial] wasn't any anything to do with us. That was the registration of death and the Council. I think, it [the council] had to put equipment to do the burial site ready and it was a Friday, and they weren't able to do that within the same day. So, I was told by the registration offices that [of the local area] that they don't do same day burials."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

An issue associated with obtaining a MCD certificate has been raised by the following participant:

> *"But especially with the Muslim families, we try extra hard to make sure we have that every 28 days [a GP is required to see the child every 28 days to be able to write a cause of death certificate, in case a child passes away] so that we can then facilitate getting the death certificate quickly after they've passed away."* ***(Participant 3: Senior Community Paediatric Palliative Care Nurse)***

Overall, the above extracts illustrate procedural challenges faced by healthcare professionals when they are trying to facilitate timely burials, as required by some families as part of their religious Islamic rituals. Despite the efforts of healthcare professionals to support families in meeting these essential religious needs, some logistical issues may result in burials being delayed. Nevertheless, these healthcare professionals remain committed to improving such services in order to facilitate rapid burials.

Systemic Changes and Uncertainty

An individual participant detailed a significant change that would be introduced as a logistical step in obtaining the medical cause of death certificate. To this participant, this may add an additional layer of complexity to the process of obtaining a medical cause of death certificate, which could potentially delay the processing of rapid burial requests by Muslim families. Specifically, the following was said by this participant regarding the newly introduced procedure:

> *"Now, the other thing that it hasn't happened yet, but what worries me is, I don't know if you're aware, but the medical examiner process is going to come into play as well."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

Participant 5 expressed his concern regarding an upcoming additional step to post death process. Having to go this extra step with a Muslim family in the case where their child dies, would contribute to delaying burial, which is not usually acceptable by some Muslim families. From an exosystem, this logistical step is possibly mandated by policy or regulation in managing aspects of post death requirement.

In regard to the medical examiner, the consultant further indicated:

> *"So, the difference [in post death process] then with the medical examiner is… it's a little bit like, even for the cases that you don't need to refer to the coroner, you still need to know. I think as of September, you will then need to refer to the medical examiner."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

Considering the needs for Muslim population for rapid burial, the consultant mentioned the following:

> *"So, you then need to refer to them [medical examiners], even for the cases that you wouldn't normally need to refer to the coroner. I believe that they are, and particularly in areas where they have high Muslim populations, I think they are really trying to have them on call and have them as efficient as possible. And I'm hoping that it won't delay things too much, but it is yet another step in the process that has a potential to delay it. And I suppose that worries me, that worries me in a way for the families."* **(Participant 5: Consultant in Paediatric Palliative Medicine)**

Looking at the above three statements by participant 5 about the medical examiner from a microsystem viewpoint, where the interactions are between the healthcare professional and the family at the child's immediate environment. Having to go through this extra step is expected to cause delay in the burial process. For Muslim families, this might be a cause of distress, as it would interfere with their religious rituals. The consultant's concerns indicate an awareness of how these delays may compound families' grief, especially if these procedural requirements prevent them from following their cultural or religious practices in a timely manner. At the mesosystem, it is the interaction between the consultant and the medical examiner, since they are two microsystems in the child's mesosystem. With the potential for increased delay in releasing the death certificate to the family, this interaction creates additional stress for the consultant as they anticipate how this added step may impact their work with grieving families. From an exosystem, this added step occurred as a result of interactions that are not indirectly impacting families. This resulted from policy mandate, that is beyond the family or the consultant's control.

Advocacy of healthcare professionals

The interviews in this study revealed that some healthcare professionals are dedicated to ensuring children receive care in alignment with their families' religious beliefs and cultural values. Below are examples of participants who take an active role in advocating for a family's wishes and go to great lengths to ensure families adhere to their religious beliefs. During an empathic discussion, one participant described their commitment to providing continuous care and support to families and children, especially during sensitive and critical periods like end-of-life care. In specific terms:

> *"I was 100% going over and above to make sure that happened and I was on calls. I was doing night shifts with the family at home. I was [on calls], if he [the child] was ever [not well] on weekends. I'm only Monday to Friday 9 till five. If we've got end of life care, then I go on call, so my phone never went off on the weekends."* ***(Participant 10: Clinical Nurse Specialist Paediatric Palliative Care)***

Another participant also highlighted their personal sacrifice and dedication in order to fulfil the needs of the family for a rapid burial. Based on the participant's remarks:

> *"So, I felt like I had bent over backwards. I'd gone out in the middle of the night. I had not slept, but still got up at nine to try and do that. And actually, the very limited hours on a Sunday from the coroner and so on meant that we couldn't achieve that."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

The above extracts from two interviews illustrate the responsibility healthcare professionals feel to protect and support Muslim families during difficult times. The healthcare profession ensures that families caring for a child in their final days receive adequate support even after regular working hours. Furthermore, when a child dies, these healthcare professionals intervene with local authorities to ensure a rapid burial occurs to meet the family's wishes.

The following passage is taken also from the interview with participant 5 about conflicting views regarding rapid burials. This consultant was advocating for the well-being of the families, especially the mothers in such situations, to spend more time with their deceased child. According to this participant:

> *"One of the things that I said to, when I said to the mum [whose child died], I said, we won't be able to bury him that day. And she actually said to me…she said, and partly because we had warned her that we would need to refer to the coroner, she totally understood. She actually said to me, well, you know, that gives me another day with him. And I just thought, this is…I don't know, maybe I'm wrong to say this, but sometimes I do feel that the pressure from some of the family members and their desire to have a very quick burial doesn't always feel like the right thing for, sometimes the very immediate family, you know, sometimes the families, feels like they need a bit of time to grieve and spend time with their child after death. And in particular, I see that with the mums sometimes. And it feels a little bit like their child is instantly taken away from them in order to have their quick burial. And, and you can almost see that they never, categorically say that because they do want a quick burial, that's their beliefs and, and so on. But sometimes it just feels so stressful, so pressured that the poor immediate family, sometimes it feels from an outsider, it feels like they don't always have the time to grieve. And I, and I find that quite sad at times. But then I also, I'm fully aware, I am not religious and it's not for me to say that's wrong or what's, yeah. So, I certainly would never say that. And I would, but I'm just, I'm just speaking honestly with you."* ***(Participant 5: Consultant in Paediatric Palliative Medicine)***

From a microsystem, the direct interaction between the consultant (participant 5) and the family in their immediate environment, allowed him to notice the tension between the religious requirement for a quick burial and the emotional needs of the child's immediate family, especially mothers. The participant shares a concern that the pressure for a quick burial might deprive families of adequate time to grieve and spend time with their child after death. While the participant recognizes that it is not their place to challenge religious beliefs, they express an empathic observation that some mothers might benefit from more time with their child before the burial. This reflects a sensitive balancing act between respecting religious rituals and understanding the emotional toll these customs might take on grieving families.

From a symbolic interactionist perspective, the meaning of rapid burial is perceived differently by the consultant and the child's parents. Each one has created these meanings in accordance with through social interactions, and from their social contexts. Even though the mother is accepting of quick burial as a symbol of her faith, and a sign for respecting the deceased, internally, she is reinterpreting the meaning of delaying the burial as an opportunity to spend more time with her child. Overall, this consultant was expressing a genuine attempt to understand the complexity of the situation. At times where there is conflicting views and mixed emotions between the need to grieve and spend more time with the deceased child, and navigating the challenges posed by religious and cultural practices. There was a sense of sensitivity and humility as this consultant acknowledged his limitations in comprehending the family's religious perspective, while carefully avoiding making judgment.

Chapter 5B: Findings from the interview with the mother

Introduction

As mentioned before, this part findings' chapter explores an in depth the analysis of the narrative interview was conducted with a Muslim mother of 4 children from England. One of her children is an 11-year-old daughter, referred to as *Sumayra,* which was changed to protect her identity. Sumayra was diagnosed with a rare type of Batten's disease, which is a disease related to the child's nervous system. This interview was designed to provide insight into the mother's lived experience as a Muslim caregiver of a child in palliative care and facing imminent death. The mother reflected on her experience, giving a glimpse into her life as the sole carer for her daughter and caring for three other children. The aim of this analysis is to answer the research question:

> How can the Islamic culture and religious teachings impact paediatric palliative care and end-of-life (EOL) decision-making for clinicians, and parents of children with life threatening illness?

And mainly the following two objectives of the study:

- To examine the extent to which faith and culture influence the decision-making process of Muslim parents whose children are diagnosed with life-threatening illnesses.
- To examine whether faith or culture can serve as coping mechanisms for parents and shape their views of their children's conditions.

Throughout the interview discussed various aspects of her daughter's journey with Batten disease, beginning with the moment she realized something was wrong, then going through different avenues to find out more about the condition, and finally reaching the point where the condition was confirmed. Accordingly, the narrative analysis of the mother is divided into two parts, the first discussing the mother's story prior to the diagnosis of her child, followed by a discussion of her experiences and coping strategies following the diagnosis. In each part, verbatim segments of her interactions with those around her will be extracted from her story and analysed. Throughout the discussion, the theoretical frameworks which are the Bronfenbrenner's ecological systems theory, Symbolic Interactionism Theory, and Structural Functionalism. All theories will be applied accordingly to the extracts from the mother's interview.

Before diagnosis:

This part of the mother's emotional journey of caring for Sumayra will explore different stages and major points that the mother experienced until she was able to reach a final diagnosis for her daughter's condition. This is the initial part when she realized something was wrong. As mentioned by the mother:

> *"Sumayra was diagnosed in 2014. But in 2012, we knew that something is very wrong. It was kind of I knew that she had something wrong, but I counted it… is probably just the learning difficulties she's coming up with because she was fine. It is childhood dementia (caused by Batten disease), she was fine before the age of three and she started forgetting, then she started being a messy child. It was difficult to feed her… her own self. She started bumping into the things. Then hand eye coordination, she was losing, but she was never able…by the age of three, she was able to orally…she could tell you… she could count up to 20. But she was never able to put finger down and say this is…she could never say this is number two, this is number three. So, I used to go back before to the GP saying that there is something wrong, her brain is not processing as she should do by her age, but they used to attribute it to her having frequent ear infections*."

In the above extract from the interview, the mother describes when they first noticed something was unusual about their daughter. While the mother does not express her emotions and how she felt during the first stages of the journey, her tone suggests confusion, frustration, and helplessness. For example, saying such as: 'so, I used to go back before to the GP saying there is something wrong, her brain is not processing' indicates a strong sense of frustration, as the mother has repeatedly visited her daughter's general practitioner (GP) for persistent concerns that something is genuinely wrong with their child's development. Even so, the GP continues to attribute the child's symptoms to frequent ear infections: '*but they used to attribute it to her having frequent ear infections', suggesting* that the parent's observations and concerns were not being fully acknowledged or seriously addressed.

In terms of *ecological system theory*, the mother's direct involvement in Sumayra's care places her within the microsystem, which is the immediate environmental system around the child. Sumayra's microsystem includes her mother (the primary caregiver), healthcare professionals, family, and school. Based on the above extract, it appears that Sumayra's mother is her first point of contact, indicating that she is responsible for monitoring her and identifying major changes that require medical attention. The advocacy for Sumayra's health and the pursuit of a diagnosis are also components of the microsystem, both of which influence the speed with which a diagnosis is identified, as well as the appropriate level of care.

For the mesosystem, it consists of the interactions between different microsystems. The mesosystem in this case involves interactions between the mother (primary caregiver) and healthcare professionals seeking an understanding of Sumayra's condition. These interactions are crucial as they will provide the mother with an understanding of Sumayra's developmental and behavioural changes. As can be seen from the mother's narrative, there appears to be a misinterpretation of what she perceives as obvious developmental delays and behavioural problems. Sumayra's condition may have been detected earlier if the general practitioners had been more attentive to the mother's concerns, as this hurdle in communication may have prevented early intervention and support from being provided.

The mother continued to recall fundamental moments marking turning points in her journey as she is making sense of her child's diagnosis. She mentioned the following:

> *"And then we went… I started taking her [Sumayra] at a special needs school, thinking that they can tell me more how to… how to handle a child with learning disabilities, and dystonia and all these issues. And there I came across a mom there at a STEM play session, and she said that your daughter has got Batten which I didn't know the word, I had never heard it. So then one day when her son was coming out of the classroom, he was in nursery. He was…he was blind, and he was fully dependent. And he was four. Yeah, he was four. And she said, that's my son. And he has got Batten, your daughter has the same condition."*

As the mother described above, a pivotal point occurred when she had a discussion with another mother who had a son with Batten disease during a STEM (Science, Technology, Engineering, and Math) play session, who suggested that the narrator's daughter may also be suffering from Batten disease. In this case, *symbolic interactionism* offers a valuable lens to view the early stages of Sumayra's health and development that shaped the mother's awareness and understanding of her daughter's condition. Symbolic interactionism is concerned with the way that people create meaning through their interactions with others and by interpreting symbols. According to the above extract, Sumayra's mother became aware of Batten disease as a result of her interaction with the other parent. This was an eye-opening conversation that enabled

Sumayra's mother to reevaluate her daughter's developmental progress. A number of characteristics, such as the blindness of the other child and his dependency, could be interpreted as symbols that Sumayra's mother might use to track the progress of her daughter's condition in the future. Additionally, both parents shared a sense of empathy through this interaction. Therefore, recounting these initial interactions served as the basis for the mother to envision a variety of future possibilities for her daughter. She was able to put a meaning to the changes her daughter is experiencing by redefining certain symbols and behaviours.

Considering it from the perspective of the microsystem, the school environment provided Sumayra's mother with the opportunity of meeting and interacting with another parent who gave her a completely new perspective on what Sumayra is experiencing. Through this direct, impactful interaction during the STEM play, the mother learned about Batten disease and was able to develop a critical awareness and understanding of a possible explanation for her daughter's symptoms. According to the mesosystem, interactions between Sumayra's mother and the special needs school contribute to changes in Sumayra's situation. Sumayra's mother attempted to seek guidance and resources for her daughter's presumed learning difficulties by interacting with the school, which is one of Sumayra’s microsystems. As a result of these interactions, the mother had a new environment in which she was able to seek answers and adjust to her daughter's deteriorating health conditions. It is through the school that the mother is connected to a community of other parents, providing an opportunity for her to meet the parent who shed light on Batten disease.

As she continued to narrate, a comparison was made between her daughter and the other child with Batten disease. Based on the mother’s remark:

> *“But there was a big degree of difference between them because my daughter was walking and talking, she was very much a bubbly character. There's her child, was to the other extreme, so I couldn't relate it. I thought maybe not, maybe there is misunderstanding, all the… all the symptoms, they always overlap. But gradually, by the end of the year, and she was quarter to four, I thought that there is…she is definitely progressing towards that situation. And then in…they did some genetic tests, but it was done by geneticist here in England but came negative. But they want us to send it to Holland, it came back positive, but it was the rarest form of Batten, she was the second to be diagnosed with that type of Batten in UK. So, that's why it took that long.”*

The mother's narration revealed her initial disbelief and gradual acceptance that her daughter's illness had progressed to a more severe stage, similar to that of the other child. It is emotionally difficult for her to compare her daughter's condition to that of another child whose condition is significantly worse. Based on an *ecological systems theory perspective*, particularly in terms of the microsystem, the mother's initial observations about her daughter's development are representative of the microsystem level, as she is her caregiver and is directly in contact with Sumayra, enabling her to observe the changes and progression in her situation in great detail. Having a daughter who is 'bubbly' as opposed to the other child who is 'blind' and 'completely dependent' were clear differences preventing her from accepting the possibility that she might also have the same condition. As a result of her doubts regarding her child's diagnosis, she attributed it to possible misunderstanding, stating: '*maybe there is misunderstanding, all the… all the symptoms, they always overlap'.* It was these microsystem direct interactions between the mother and her daughter, Sumayra, which shaped the mother's evolving understanding of her daughter's condition.

During the discussion, the mother described the lengths they had to go through before finally receiving a diagnosis, which confirmed that her daughter had Batten disease, the rarest form, making her the second person in the UK to be diagnosed with it. She eventually accepted that her daughter also suffers from this condition. This can be explained through the mesosystem, which encompasses the interactions between the different microsystems around Sumayra, within which the multidisciplinary team is embedded. It is possible that the delay in diagnosis is due to the rarity of the disease, which requires complex interactions between a variety of healthcare professionals. Sumayra's diagnosis may have been influenced by external interactions through the exosystem. Different healthcare systems, such as those in the UK and Holland, interacted to facilitate the diagnosis process. Therefore, Sumayra's rare condition was ultimately determined and confirmed by genetic testing abroad, which may be directly related to the limitations of the UK health care system. These interactions eventually led to a more conclusive diagnosis, though the journey was prolonged and emotionally challenging. It was only over time (chronosystem) that the mother's initial denial evolved into something more concrete, requiring different medical examinations in the UK and genetic testing outside of the UK to receive a final diagnosis and confirmation that her daughter was affected by Batten disease.

The Ecological Systems Theory provides an insight into how the mother's understanding of Sumayra's rare disease is influenced by the interactions between multiple levels at the beginning of the journey. For example, it was the immediate environment (microsystem) that played the most significant role in enabling the recognition of abnormalities that required attention. Moving into the mesosystem, where interactions between different microsystems further shaped the diagnosis picture. Additionally, external interactions in the exosystem indirectly impacted Sumayra and contributed to her diagnosis. Following that, the chronosystem contributed to the understanding of Sumayra's diagnoses and her health over time. This diagnosis journey has been complex, continuously impacted by these interconnected systems as well as the emotional distress that accompanied each stage.

The diagnosis:

In this section of the findings, multiple elements related to the family environment and surroundings will be discussed from the perspective of the theoretical frameworks of ecological systems theory, symbolic interactionism, and structural functionalism. In particular, the impact of the diagnosis on the dynamics of the family, as well as the impact it has on the mother's role, as well as the other children in the family.

Diagnosis and family dynamics:

During the interview with the mother, she described the impact the diagnosis had on the family. The mother stated the following:

> *"In the beginning, when I moved to this city [from a different city in England] in 2012, Sumayra's dad, and I had three kids and are pregnant with the fourth child that time. Me and Sumayra's dad had separation at that time. Because of the issues relating to Sumayra, and he wasn't able to take this on board, by any means that something is going wrong. He used to say she is going towards a point where she will never be able to walk again. He wasn't able to accept it."*

This extract illustrates another pivotal point along the journey of caring for Sumayra, which was the separation of the parents. As the mother shows in her story, having a child with a life-threatening condition and multiple health complications can impose many changes on a family, which may require adjustments over time. However, as highlighted by the mother, *"he [the father] wasn't able to take this on board, by any means that something is going wrong"*. Due to the father's inability to accept Sumayra's health problems and his denial about her deteriorating state, there was significant strain within the family unit which eventually led to the separation of the couple. Considering this issue from an *ecological systems perspective*, it can be argued that this change in the family would significantly impact the microsystem, the immediate environment surrounding Sumayra, where she has direct contact with her mother, who is her caregiver, and her father, who may be part of her immediate support network.

The challenges Sumayra's family faces can also be understood by applying *structural functionalism* to examining how the family structure is affected by the change or disruption of certain roles. Changing family dynamics due to the separation of the parents, for instance, could affect the stability of the family. This means that the father's response to Sumayra's diagnosis and potential changes can contribute to a possible breakdown in the traditional roles of the parents in providing for and stabilizing their family. As an example, the father's role as a provider, which includes both financial and emotional support, may be adversely affected. This would result in the mother taking on additional care responsibilities, which would further disrupt the family's balance and stability.

To provide some context to the reasons for the father's reaction, the mother described their initial efforts to adjust to the new reality of raising a child with special needs. As the mother described it:

> *"And, on occasion, we used to say that life is not going, it doesn't look like we are going to have a normal life in a couple of years time. But that strain on our minds, me running back and forth to the GP. While we both were working. And us thinking that it… because we… we had never seen a child in a in a wheelchair. We've never seen an autistic child, never seen a child with learning disabilities. It was hardest part to accept that we are not… we can't do the social activities because we have a child appointment. Because she was having ear infections, every fortnight her vision was dropping. So, we have to go one hour journey, it used to be a lot of a hassle. So, going through all those, it was too much. And eventually, I said if… if you're not on the same page, we can't stay together, so we got separated in 2012."*

According to the mother in the above extract, they struggled to manage their daily lives, including their work and doctor's appointments, as they attempted to fulfil their role as parents. In her reflection, the mother describes the significance of the medical challenges her daughter has faced and the developmental challenges that they faced as a family, which will be discussed across the various layers of *ecological systems theory*. Parental difficulties in managing these responsibilities and additional tasks may disrupt

Sumayra's immediate environment (microsystem), which may result in negative consequences. Due to the complications in medical care and developmental challenges, the family's routine, and social life have been disrupted.

There is also a strain on the mesosystem, which is characterized by various interactions between different microsystems. In particular, the mother's story illustrates the difficulties they, as a couple, faced in maintaining relationships within their social networks. As a result of the unpredictable nature of care demands, they were required to make certain adjustments, resulting in a considerable disruption in their social life. At a macrosystem level, societal norms and expectations about what constitutes normal development for a child and what is considered normal for a family, affected the family and possibly shaped the father's outlook when adapting to a life that doesn't necessarily align with such societal ideals, which led him to decide to separate.

Through *symbolic interactionism*, this stage reflects how some symbolic meanings of raising a child with severe disability were impacted by the family's social interactions, or lack thereof. For example, saying: ‘we *had never seen a child in a in a wheelchair, we've never seen an autistic child, never seen a child with learning disabilities’ implies* that there is no baseline to know what it is like to have a disabled child. They did not have a reference point from which to reframe or reinterpret their experiences. Consequently, having a disabled child in a wheelchair was a confusing experience without prior exposure to others in similar situations. As a result, Sumayra's parents found themselves in a position of having to navigate these significant changes on their own and coming to terms with a new normal on their own.

Changes to the role of mother

The mother in this study highlighted how her child's illness reshaped her role and responsibility as a mother, leading to a negative impact on her health and well-being. In the following extract, she shared how her role as a mother was impacted, and explicitly depict her mental health, with her feeling depressed and guilty for misjudging the situation and failing to act in her daughter's best interests. She specified:

> *“It [role as a mother] changed completely because…but I still had to carry on all those duties. You know, because…but there was additional, it's Sumayra, because doctors didn't know, and I didn't know that she's going through dementia. So, I did go through the depression period. And the school identified*

> *it. They [the school] asked do you need…do you think you need help? And I said yes, I do need, I'm at a clinging point."*

Recalling the daily routine, before the diagnosis:

The following extracts illustrate a day in the life of the mother and the frustration she experienced for not understanding the motives and reasons behind her daughter's behaviour.

> "*Because I used to dress her [Sumayra] up first thing in the morning because she was bubbly and bright child. So, she was… she would have breakfast, but she would take time to eat the breakfast, and she would give you a blank stare halfway through. And you're sitting in saying, look, child, I've only got one hour to dress four of you, feed all of you, and for all five of us to get out to go to the school, two different directions. But she is giving you a blank stare. She's not opening her mouth. I didn't know that she has got… this is… this blank stare is not a child's blank stare, it is a seizure. It is a focus seizure."*

In describing the daily routine and stress she experienced throughout her care journey; she reflected on the emotional aspects of care. The immediate environment (microsystem) in which Sumayra lives, the mother, was under considerable stress due to having to care for multiple children, in a limited amount of time, along with dealing with Sumayra's perceived behavioural problems. According to *Symbolic Interactionism Theory*, Sumayra's mother interpreted and responded to Sumayra's temperaments based on their interactions and her own expectations of common child behaviour. Blank stares and eating habits, for example, are behavioural symbols that the mother misinterpreted based on her own perception or understanding of what constitutes some childhood behaviours. Not realizing these symptoms could be indicators of a more serious health problem. It was these misinterpretations that shaped Sumayra's mother's response, often resulting in frustration rather than sympathy. Since the mother is part of Sumayra's microsystem, she was later able to distinguish between the underlying meanings of Sumayra's unresponsiveness. As it was initially interpreted as a sign of Sumayra's behavioural difficulties, it later became apparent that she had a seizure related to her dementia.

As mentioned previously, the macrosystem encompasses elements of society such as norms and cultural values that will have an impact on the way families perceive certain aspects of the situation. Sumayra's behaviour was possibly shaped by the mother's perspective of these behaviours attained from her society, or influenced by cultural values, or by public awareness of the situation. It is possible that from a cultural perspective, the mother saw Sumayra's blank stares as a sign of disobedience. This is also in line with the Symbolic Interactionist viewpoint, which indicates that meanings are given through social interaction. As an example, the meaning of 'bright child' can be interpreted socially as someone who is capable of picking up on what needs to be done, with little or no supervision or instruction. Sumayra was perceived by her mother as a 'bubbly, bright child,' therefore it was expected that she would eat and dress in a timely manner, as she could see her siblings and mother getting ready to leave.

> *"I used to go mad. And then she would…I would dress her up after the breakfast, wash her, put her there and put the little two into the push chair and turn around to help Sumayra, because she had forgotten by that time how to walk properly. So, I had to hold her hands and she would hold, walk with a helping aid. And you turn around go to the lounge to get Sumayra. And she's sitting in a pool of her own poo. And she has no clue that this is poo. And she's rubbing her hand there. And she's… she gives me a confused look. I'm saying we got to be in the school by 840. And it's 835."*

She expressed her anger and frustration as she continued to explain their daily routine, touching on a deeper emotional layer of her experience. From an ecological systems theory perspective, this has an impact on the microsystem, since the main stressors experienced by the mother are directly related to Sumayra's behavioural challenges. Having to deal with such difficulties, the mother has exerted great efforts to support Sumayra, who has difficulty walking and controlling her bodily functions. While this effort can pose a great deal of emotional distress for the mother, it can also have a significant effect on the child, who is unaware of his or her surroundings.

The mesosystem represents the interactions between different microsystems, such as Sumayra's mother and the school, or healthcare professionals. The mother will be able to attain the necessary support Sumayra needs, whether it is medical or social support, if she communicates the changes in behaviour to the school, or healthcare professionals. Analysing their situation from a chronosystem perspective illustrates how the mother's role evolved over time in response to the illness. Taking care of Sumayra was becoming increasingly challenging for the mother, since she is a mother of multiple children, and has other caring obligations in addition to Sumayra's. From a symbolic interactionism perspective, it can be said that the mother's interpretation of her interactions with Sumayra and the meaning she attached to daily observations shaped her role as a caregiver. Despite not realizing that these symptoms may indicate a more serious health problem, Sumayra's inability to walk and loss of control over bodily functions were interpreted by her mother as indicators that she needed additional support.

In recalling Sumayra's early developmental and behavioural changes, the mother was able to revisit and reflect on various aspects of the process of discovering the diagnosis. As the story unfolded, her sense of guilt remained within her until she reached the present moment. Specifically, she stated:

> "*But now I look back. And it's heart-breaking, because if I had known that time that this is dementia, I could have controlled myself and said, oh, I'm sorry, Sumayra, I will wash you up, rather than saying, why have you done it? Why didn't you tell me? Why couldn't you hold on? You know where the toilet is, you're nappy trained. Rather than going mad, I could have turned back and given her a bit… a bit of sympathy. So that's…I don't know what's heart-breaking? Her being on palliative, or those years.*"

Throughout the above extract, one can sense a powerful combination of regret, grief, and empathy on the part of the mother, who is remembering the times before she knew Sumayra was suffering from childhood dementia. Using ecological systems theory, symbolic interactionism, and structural functionalism to examine this extract provides a multi-layered perspective on the mother's experiences and her interpretations of what her daughter was experiencing.

According to ecological systems theory, Sumayra is in direct contact with her mother as the caregiver at the microsystem level. Besides providing emotional support, this close relationship can also lead to conflict and misunderstandings. Hence, Sumayra's relationship with her mother in this system is characterised by a wide range of miscommunications, conflicts, and confusion that were felt deeply as the mother reflected on the incidents that occurred. It was confusing for the mother when Sumayra displayed unexpected behaviour, such as failing to use the toilet, despite having been trained to do so. Considering the degree of interaction between the mother and her daughter, and the social meanings attached to not adhering to certain expectations, these misbehaviours may have been interpreted as being lazy since it was assumed the child was aware of what was right and wrong. Therefore, based on symbolic interactionism, the mother's actions reflected the meaning she assigned to the symbols.

As a result of direct interactions with her daughter, she was able to identify certain abnormal behaviours, which led to the identification of an underlying cause, later identified as childhood dementia. Without the mother's close and direct contact with Sumayra at the microsystem level, this would not have been possible. Accordingly, the mother's interpretation of Sumayra's behaviour has changed. In particular, after learning about childhood dementia, the mother's understanding of Sumayra's behaviour was altered; she has clearly seen that loss of bodily function, unresponsiveness, slow eating, and needing assistance walking are all indicators of Sumayra's health deterioration. This change in interpretation resulted in the mother feeling emotional pain and regret as she realized she could have responded with empathy if she had understood the true nature of her daughter's struggle. Therefore, the mother's tone reflected her self-criticism, for not doing enough to know what the problem with Sumayra was. As a mesosystem is a place where interactions among different microsystems occur, being hard on herself could be the result of a lack of support Sumayra was receiving from other microsystems around her, such as the school, or the healthcare team. Nevertheless, as time progressed (chronosystem), the mother's perceptions of her daughter's condition evolved, allowing her to adjust to social demands. However, this feeling of guilt kept resurfacing, as she felt that if she had known what was wrong with her child sooner, she would have adapted more quickly and coped better, thus preventing her from being harsh.

A structural functionalist view would suggest that the pressure put on the mother by their daily routine contributed to shaking the stability of the family. It contributed to the mother's stress, anger, and frustration that she did not grasp why Sumayra was acting in such a way as she was trained to use the toilet and perceived to know not to do certain things. It has significantly affected the expected role of the mother, not just as a caregiver, but also as someone who should have sympathy and empathy for her children. Therefore, the mother expressed regret for not understanding the situation better and for not managing and meeting the expectations associated with caregiving. Due to these feelings, the caregiver's position within the family context is shaken. A family in such a situation needs strong caregiving abilities to be able to cope with such distress and changes in family dynamics that are caused by the illness of a child.

Management and coping

Role of school:

The mother has then talked about another essential part of her journey caring for her daughter’s Batten disease, which is the role of the Sumayra’s school in providing support.

> *“Luckily, Sumayra got a very nice School, which we used to go for STEM play, because they already had seen a child with that rare condition. So, they were able to put things in place for Sumayra right…at the right time. And that helped a lot because the nurse knew whom she should be going to see, what steps would happen next. Whereas I had no clue, and I had no clue of this side of the life. So, she… they used to invite me to come in and have a look at the classrooms and the equipment and the wheelchairs and the how the kids have the what are what is a standing frame and what are the walking aids. So, it was a completely different world. We have a lot of support. Sumayra’s team is very well. They are very, very supportive. And after this nursery that she went in, they laid very good foundations, they educated me very well. They registered me to epilepsy society for the brief interviews and lectures. And so, I learned different types of epilepsy and how to manage them and what can go wrong, and things like these.”*

Considering the above extract from an ecological systems theory perspective, and particularly the microsystem in which Sumayra is directly impacted, the school played a critical role in helping the mother navigate the challenges she faced while caring for Sumayra's complex needs. According to the mother, the school provided a supportive environment that included resources for the mother and various equipment for Sumayra, such as standing frames and walking aids. Sumayra's mother appreciated that it was a welcoming and educational environment, which made her feel more comfortable and confident in meeting her daughter's needs. As a result of this direct interaction with the school's environment and its supportive team, the mother gained knowledge and felt empowered, which reinforced a positive outcome for Sumayra.

As can be seen from the above extracts, Sumayra's journey with Batten disease has been greatly impacted by the collaboration between her mother and the school. This collaboration can be attributed to the mesosystem of the ecological systems theory. With the collaboration between the school and home, Sumayra's mother was given a higher level of support, which included more than just practical assistance. Furthermore, the mother was provided with information about her daughter's condition, including more information about epilepsy, which was an excellent gesture that assisted her in managing Sumayra's condition more effectively. Accordingly, Sumayra’s mother highlighted the positive effect of school-family collaboration, which reinforced her skills, and built her confidence to ensure continuity of care. Moreover, considering that the exosystem includes external environments not directly related to Sumayra, the epilepsy society falls under this category. While Sumayra is not directly involved with the epilepsy society, its educational resources equip Sumayra's mother with essential information about managing epilepsy, and consequently improve her ability to provide better care to Sumayra. As a result of this indirect support, Sumayra's care is improved as the mother can navigate more confidently the complexities of Sumayra's medical needs.

This extract provides a good illustration of what structural functionalism means with regard to the role of different societal systems in maintaining stability. In this case, the school and epilepsy society are examples of societal systems working together to provide a level of support for Sumayra's mother, which will contribute to the family's sense of stability. Structural functionalism argues that societal systems can still work together regardless of their role and function. Thus, Sumayra's mother's positive experience was the result of collaboration between two systems that serve different purposes but share the same ultimate objective, which is to provide the mother with the support and assistance she requires to care for her daughter effectively and efficiently.

Additionally, the mother highlighted an aspect of the school's environment that relates to other parents who are facing the same struggles as she is in caring for a child with special needs. She highlighted the following:

> *“And when you go out to the schools, then you see kids who are at the far extreme where your own child is, and then you can pick up a bit of strength from their moms. That ‘oh, if they can come to the school with a hair brushed, and a bit of makeup on, they're still bubbly, I can do that. Sure. It’s not that hard.’ It's a lot of learning when you go out and meet these people who tell you that we still…we have adapted to life, we have accepted it, we have adapted to it. Rather than where I used to go to [in another city in the UK]. It used to be very depressing, because everyone [Muslim families] who was in the hallway in the waiting room, they would sometimes approach me and they would say, God is… just God has given you a challenge. And I used to think why isn't separation an enough challenge?! My parents are not here for us. Isn't it enough?! That I'm not with my parents?! I don't have a family here. So why?!!”*

As such, the above extract demonstrates the mother’s direct interaction with the school's environment, which is part of Sumayra's microsystem. Even though the children in the school might be significantly more challenging than her daughter, their mothers appear to be adapting, which she found to be inspirational and energizing. This shared experience with other mothers who faced similar challenges helped Sumayra’s mother gain strength and maintain some connections that encouraged and motivated her to maintain her health. As she stated, *oh, if they can come to the school with a hair brushed, and a bit of makeup on, they're still bubbly, I can do that. Sure. It’s not that hard.’*

A comparison was made by the mother between her current experience with the school's community and her previous experience in the surrounding community. Although they were greatly different in the manner in which they engaged with her, those in the school were incredibly supportive of her, even without saying a word. Yet, those from her previous community, who shared the same religious belief as her, framed her experience as a religious test, referring to it as a test from God. As a result of this other environment, the mother became increasingly frustrated, as she has already been coping with enough challenges, and refused to accept their perceived judgment that whichever difficulty she is experiencing is intended to challenge her. She considered this to be unfair since she is already experiencing a sense of isolation and disconnection from her family.

From a Symbolic Interactionist perspective, the mother's narrative illustrates how her interaction with her immediate environment influences her experience and attitude. A sense of exhilaration was associated with the mother's experience within the school's environment, as she attached positive meanings to their interactions. When referring to other mothers at the school as 'bubbly,' this signifies a positive outlook reflected in their appearance. However, her interactions with people from her previous community revealed negative connotations. Through her communication with people and the meaning conveyed through her language, she formulated a negative perception of her social group, implying they had a negative impact on her and posed additional burdens.

End-of-life decision-making

As part of the interview, the mother discussed having difficult conversations about end-of-life care. Sumayra's mother often finds herself in situations where she must make difficult and emotionally charged end-of-life decisions for her daughter, while facing the reality that her daughter's survival is linked to intensive medical interventions. As illustrated in the following extract, the mother reflected on a discussion she had with Sumayra's healthcare professional during one of Sumayra's relapses. As she stated:

> *"Because Sumayra hit PICU in 2018, January, and when I got there at three o'clock in the morning, I said to the consultant, I said, I know it's end of the life, she doesn't have quality of life anyway. And we know that things will progress. And, but she has got very good team, she's got very comfortable life. But because of the diagnosis, we know, and the progression that we know, will eventually happen. And if you have to turn things off from my side, you have full authority. Because end of the day, it has been the medical intervention that has kept her going so far. Because she has got PACT. She has PACT, she has got anti-epileptic medicines, she has got to pull on the cap, round the clock medical care if she didn't have these things, medical interventions, you wouldn't have survived anyway. She was resuscitated twice that morning. So, she wouldn't be with us anyway. So, and they said that, yes."*

As the sole caregiver and closely monitoring Sumayra, the mother is making decisions according to what she perceives to be in her child's best interests. From a symbolic interactionist perspective, the mother's ongoing interactions with Sumayra enabled her to give meaning to that suffering. Thus, by interpreting her daughter's struggle, she was able to determine what was best for her. It is only through the interventions she was receiving that she was surviving. This suggests that the mother interprets these interventions as symbols of gratitude and hope. However, the mother was willing to give up her hope if it would end the suffering of her child.

Communication between Sumayra's consultant, PACT (Paediatric Advanced Care Team), and her mother is a key component of Sumayra's mesosystem. The mother's interactions with the consultant illustrate a deeper understanding of her daughter's condition, enabling her to take an active part in her care. Through this collaboration, Sumayra's team provided the necessary information, empowering the family to make informed decisions. Considering the mother's story, the collaborative efforts of the medical team to ensure Sumayra receives all the interventions she requires to ensure her wellbeing and quality of life are considered part of the exosystem. Although Sumayra does not directly engage with these services, they have an impact on her experience, as these interventions, as the mother indicated, are what allow her to survive.

Unlike the mother, the father was against the idea of withdrawing treatments. According to the mother:

> *"But when and an hour later, when dad travelled up there to hospital, he and… that time he burst into tears. And he said that…what has happened to her? why she's here? That was the first time it hit him hard that the reality… that this is the reality that he had been not acknowledging for all those years. So, he then proposed some questions that no, you can't turn off the machine."*

As indicated by the mother, the father was confronted by the reality of his daughter's circumstances and deteriorating health. Being uninvolved and disconnected from Sumayra's microsystem placed him in this position, where he was unaware of the changes in Sumayra's health. Therefore, he found that difficult to accept, and there was a disagreement between Sumayra's mother's decision and her father's decision. In each case, they came to a conclusion based on their emotional reactions to the way they perceive and see what is best for their child. The mother elaborated more on her reasoning versus Sumayra's father's reasoning. She indicated:

> *"Third day they do a brain scan, and I said, I don't want you to do a brain scan. Because she…her…her disease is neurodegenerative. So, they wouldn't have got any clue from the brain scan anyway. But dad, when came on the scene, he had this question, he had these questions that, what would I say to the Imam? that I turned on the machine, myself, so I had actually no hope in God. I have taken the life of my own child. And so, he had those hard questions."*

The mother in the above passage discussed the dilemmas associated with making critical end-of-life decisions for their daughter. As she discussed, there is a difference in opinion between the way she sees what is best for Sumayra and the way Sumayra's father views the situation. When viewed from a microsystem perspective, it can be argued that because the mother is the caregiver and has been directly involved in Sumayra's care, she is acutely aware of the changes in her condition. For example, saying things like '*her disease is neurodegenerative, so they wouldn't have got any clue from the brain scan anyway', is indicative* not just of her deep involvement, but of her awareness of what the results she is expecting of the scans. Given the neurodegenerative nature of the illness, the mother is certain that brain scans would be ineffective. This demonstrates her sense of protection and her awareness of the limitations of treatment. As opposed to the mother, the father is approaching the situation from a different perspective, thinking more broadly about ethical and faith-related issues. Specifically, he is concerned about how the leader of the Muslim community will view his choices and their moral implications, perceiving him as lacking faith or losing hope in God. As a result, Sumayra's mesosystem, where the interactions between family members and the community take place, would be affected.

In the context of symbolic interactionism theory, one can argue that the father's reluctance to turn off the machine may be attributed to the symbolic or religious significance that is associated with such action. It may be interpreted that turning the machine represents giving up hope in God or abandoning his responsibility as a parent to do everything in his power to save his daughter. Moreover, it is through cultural or religious interactions that people often make sense of certain concepts, such as life and what is considered moral. Therefore, it is likely that the father's perceptions of withdrawing life support are influenced by his cultural and religious beliefs, which contribute to his concern that he will be judged by the imam. This example illustrates how symbolic interactionism sees even personal decisions as deeply entwined with broader social symbols and interactions that shape the meanings people attribute to their actions.

Cultural representation among healthcare staff

Additionally, the mother described the support they received from the medical team to assist Sumayra's father in making decisions. Among the things that were highlighted by the mother as having a great impact was the fact that the consultants had Asian backgrounds, similar to Sumayra and her family. As described by the mother:

> *"But there was…were Asian consultants there, and the consultants, they gave him [Sumayra's father] for five sessions, over the period of time, the next few weeks, they had discuss things with him and to inform him that it is from here onward once you hit the PICU, then it's not really …you've got to consider how much intervention is enough. For the sake of the oath…Because your body has right on you. They explained it to him that we have taken an oath, and we become a doctor, that we will save the lives. So, we can't do something that can interrupt with the gods, God or the nature anyway. So, it was bit comforting to see that the amount of time they were spending with him to give him that kind of ability to make a decision. We never had to go through that. That opened up my eyes because I thought, yes, it is many parents. They do struggle."*

Within a mesosystem context, the interaction between the family, especially the father, and consultants with similar cultural backgrounds created a supportive environment where the family felt understood and respected. As shown in this incident, interactions between the family and the medical consultant within this mesosystem are influencing the father's decision-making abilities. Spending extensive time with the father to explain the implications of any decision made, as well as highlighting medical ethics that were aligned with the family's cultural values, contributed to his sense of comfort and ease. By doing so, the father was able to make more informed and emotionally supportive decisions. Essentially, this family's experiences were profoundly affected by the interaction and mutual understanding between microsystems, in this case family and healthcare professionals, enabling them to make more informed decisions. Moreover, it underscores the importance of culturally sensitive, holistic care in creating positive and supportive healthcare experiences.

Mother’s approach:

During the interview, the mother described how her approach to making decisions for her daughter has changed from pursuing all possible interventions to focusing on the quality of life of the child. As she stated:

> **“***...until I was Sumayra’s mom, I never had this understanding. I never used to think that enough is enough. I used to think science is there! a doctor's job is to make you better. And that’s it, there's no question… if he's not doing this, he's not doing his job.”*

From a symbolic interactionist perspective, the mother's view of illness and wellbeing shifted through her experience caring for her critically ill and disabled daughter. By closely interacting with her daughter and the healthcare team, she was able to reinterpret things like quality of life and medical interventions. The more she interacted with healthcare professionals, the more she gained an understanding of what it means to take on caregiving responsibilities. One of the turning points in her life was when she was first introduced to the concept of an Advanced Care Plan (ACP). She recalled the following:

> *“And when the…for the first time and Sumayra’s neurologist said to me, he was an Indian neurologist, almost of my age. We chatted about the things. So, it was interesting to chat to someone who is coming from the same cultural background. Although different religion. And he said you have to, on your next visit you have to come in sign ACP, which is acute care plan, on there you put in that how far you want them to intervene? Do you want them to do…provide oxygen? Do you want them to take your child on PICU? Off life support or not? Do you want resuscitation or not? I couldn't comprehend that she is...She will ever get to that ever get to that stage. Because she was still walking and talking. And he said that... as the neurologist, it's my job to tell you, my job to tell you when enough is enough. And I won't not intervene after that. And I said, I can’t*

> *accept that!! I'm not signing it! So, I was very stubborn there, and I said, I'm not signing it because your job is to save my child."*

From a mesosystem viewpoint, the interactions were happening between the mother and a neurologist sharing similar cultural background as her. Even though the mother was in denial and found it difficult to comprehend the possibility of her daughter's condition to worsen, these conversations with the neurologist who shares a similar cultural background as the mother, created an environment that may feel more relatable and supportive, fostering trust and open communication. Through this initial interaction, the mother was guided to consider treatment options, and life-sustaining treatments. Which led to another part of her interaction with the same neurologist, who tirelessly continued to attempt to prepare the mother for the inevitabilities of childhood dementia. As the mother narrated:

> *"Then he tried to explain me that, look, her nervous system is shutting down, she's got childhood dementia, she will go, she will regress every day. And they will come a point when she will have no brain cells working at all. So, what there left for me to say?!! so, I kind of understood that I still really did not want to understand. And I said, you're trying to tell me that you would make the decisions for my child life?! And he said, yes. And I said, no, you can't do that. It was a hard conversation."*

Following such frequent insightful interactions with the neurologist, she challenged her initial belief that a physician is obligated to save and cure her child. During the progression of the illness, such difficult conversations were necessary to allow her to see the bigger picture. The following extract is taken from the mother's journey of caring for Sumayra, where she had to reconsider and make a crucial decision regarding her end-of-life care. According to the mother, who spoke emotionally:

> *"But they [hospitals] do everything in their capacity that is available. But it was my decision to, after the two resuscitations to state that… that's…that's enough. It was when I saw her. Because I was the first relative to see her up on the bed straight after the resuscitation. I think it's cruel. It is Very, very cruel. For a healthy person, it saves the life. Who has a future. But for a child who is already…already compromised. On a lot of health aspects. It's very cruel."*

The mother's presence in the child's microsystem, and as the first point of contact after a major health fall, influenced her to reconsider what was best for her child. In the view of symbolic interactionists, the mother continually forced to reinterpret the meaning of her child's life as she provided for her complex medical needs. Throughout the previous extract, the mother mentioned that she believed it was normal to attempt to save the life of her child at all costs. However, the mother's perception of what is best for her child has changed over time, which can be explained by the chronosystem of ecological systems theory. Resuscitation may initially have symbolized hope or the preservation of life, but over time, and in interaction with healthcare professionals, the mother's views have changed. As a result of witnessing the effects of two resuscitations on Sumayra's body, the meaning of resuscitation changed dramatically, moving from one that is intended to save life to one that poses harm. It was described as 'cruel' by the mother, suggesting that her daughter was subjected to unnecessary suffering, which could have been avoided. This reinterpretation led the mother to stop further intervention, believing that continual resuscitations were only prolonging her child's suffering.

Additionally, the mother referred to the ways in which she has been making sense of her situation. Throughout the following excerpt, she discusses one of the most influential books she read, which greatly influenced her views on when and how to determine the right level of intervention for her daughter. According to her, she strongly believes:

> *"But… Atul Gawande is a Canadian or American neurosurgeon. He has got…he's written a book "being immortal", and it's very, very important book for all of us parents. And all the carers who have got patients of a paediatric who are going towards that stage. Because it talks of that, when people need to understand that enough is enough, rather than saying, alright, we've been on PICU once we can go out there again, probably we will get a better result. But no, you may come back with a vegetative state, you may come back with much worse situation. And the child may spend rest of the life in more pain, because all the medicines have their side effects."*

In the statement above, the mother expressed her strong opinion regarding the book Being Immortal. Having read the book, she was able to gain a completely different perspective on her child's condition. According to Sumayra's mother, this book contains a powerful message for all parents and caregivers of children suffering from terminal illnesses. It is an eye-opener to read the book, since it suggests critically evaluating a child's experience in PICU (Paediatric Intensive Care Unit), rather than holding on to the hope that something better will happen, be open to the possibility that 'you may come back with a much worse situation', and medications may not improve the situation. In fact, medications may worsen the condition rather than improving it. This book has contributed to the interpretation of having a child in a 'vegetative state', especially after returning from a paediatric intensive care unit. It is an opportunity to reevaluate the circumstances, and to say, 'enough is enough'. In the context of symbolic interactionism, reading can be used to explain the meanings that the mother is assigning to her child's situation. It was as if the mother was interacting with someone with expertise in their field, as the book was written by a neurosurgeon. The connection offered her comfort and reassurance, as she felt validated in her feelings and decisions.

The mother shared an emotionally challenging incident in which she had to make tough decisions. As a caregiver, she faced the challenge of finding a balance between providing relief from seizures and avoiding long-term side effects that would have worsened her child's condition. As expressed by the mother:

> *"It is like, at the time, Sumayra is going through hormonal seizure stage, because she is midway through her cycle, period cycle. So that means with the hormonal imbalance, she can have more seizures…. But we have a plan to treat them. So… But if I go for the… for the medicines that are there to help, like, progesterone and other medicines, hormones, and the side effect is they lower the bone density. So, with a child that is already very fragile, like Sumayra, I have to weigh pros and cons. Because she doesn't have much time left anyway, do I want her to live rest of the life with osteoporosis? That, I will never be able to handle because she's not mobile anyway. You know, so you have to weigh, it's better to give her chloralhydrate and help her to sleep during these times or give her medicine that can cause osteoporosis, or brittle bones? it's hard [decision]. But you got to say, what you want to achieve in the long term? And what you don't want to happen in the long term? And… but it's still tricky."*

From an ecological systems perspective, being part of Sumayra's microsystem, which means being in direct contact with her, allows the mother to devise a treatment plan that is appropriate for her daughter's prognosis and hormonal imbalance. Having been in such a close environment with Sumayra, observing how fragile and weak she became, forces her to make alternative judgements regarding what she prefers the long-term outcome for her daughter to be. Consequently, she has a profound responsibility to weigh the risks and benefits of her potential decision, the quality of life versus prolonging life.

At the mesosystem level, such difficult decisions would require extensive interaction between the mother and Sumayra's healthcare team. Consult with healthcare professionals to understand the risks and benefits of various treatment interventions for Sumayra's seizure. Asking difficult questions while remembering that her daughter may die at any moment, as the mother stated: 'She doesn't have much time left anyway.'

Additionally, it would be helpful to reach out to Sumayra's school, as they have also been a source of support for the family, as stated previously by her mother. Furthermore, in the exosystem, interactions between the medical team within the healthcare system are not directly involving the mother, yet the outcome of these relationships impact her decision. It means that the interactions between the multidisciplinary team that lead to the choice of medicines can occur without the mother's involvement, but the consequences of those interactions still affect her decision.

At the macrosystem level, the mother's preference for quality of life over longevity may reflect values or perceptions influenced by broader societal, cultural, or religious perspectives regarding the dignity of life and ethical care. Time, as part of the chronosystem, creates a sense of urgency, causing Sumayra's chronic, degenerative illness to dictate treatment options. Choosing Sumayra's quality of life would require her mother to make decisions that might alleviate her daughter's suffering but might also result in her death. As a result of applying the multilayered approach of the Ecological Systems Theory, the mother's attempt at making a fatal decision for her daughter has been explained. Being involved with the healthcare team and interacting with them within the various systems surrounding Sumayra would enable her to make informed decisions, aligned with her daughter's best interests.

The findings of this section of the study addressed various turning points that led Sumayra's mother to believe that the most suitable decisions for her daughter should be those based on quality of life, rather than aiming for a cure. The mother appreciated the support of the medical team in the family, but the decisions regarding whether to proceed with certain medications or interventions were primarily driven by the fragility of her daughter and the potential suffering she may suffer. Through observing her daughter's changes, along with continuous communication with the medical team, and reading about the changes, the mother created a new interpretation of pain and suffering. The next section will look at the implications of her decisions, including her explaining her reasoning for her children, and the way her family and community perceived her decisions.

Family opinion about her approach:

View of her children:

The mother provided insight into her relationship with her other children. She discussed her children's awareness of their sister's condition and the changes in her life in the following extract. Thus, she spoke about her approach to helping them cope with their sister's circumstances and the decisions she has been making for her. She stated the following:

> *"They [her other children] do understand why we need to, we have to say enough is enough for Sumayra. They do understand, the eldest is 12 and a half. So, I do chat with her, and so the… she does understand, because I wanted her to know why being a mom, I have to take this decision, rather than her holding on to her feelings, and then later in life, say, or someone else saying to her that mom had been really cruel. And so. she has taken it very well. Although she does see she doesn't want her to go. But I always say to her, look, being Muslims, our basic line belief is, we can go any minute. This life is not our life. That's why there are prayers five times a day, not just once a week. Because we can die before the next prayer. So, make her focus on that point. And I'd say I haven't made any decision here for Sumayra. It's God's decision. If in my… in my God's diary. I have to go first, I will go first, no one can save me."*

Throughout the above statement, the mother refers primarily to her eldest daughter. In terms of ecological systems theory, the siblings are part of Sumayra's immediate environment (microsystem). Having been in that immediate environment, they are aware of the changes that are occurring in Sumayra's health and wellbeing. As a result, the mother and her children, particularly her daughter, have a close relationship. This allows her to have an open and honest dialogue, which helps her understand the difficulties the mother is experiencing when navigating end-of-life decisions for Sumayra. By conveying her reasons openly, the mother aims to create an environment of trust, empathy, and emotional support. Moreover, she seeks to create a safe space in which her daughter is encouraged to express her feelings, thus preventing future disappointments and judgments.

The potential interactions in the mesosystem will be between the children (microsystem) and the extended family or community (another microsystem). The mother's narration indicates that she is concerned about potential interactions between these microsystems, the children, and the extended family and community. Specifically, she wishes to protect her daughter from possible future encounters that may adversely affect her mental health; through their perception of her mother's action that may significantly affect her feelings. From the perspective of a chronosystem, this refers to the impact of the mother's actions over time. To avoid potential future misunderstandings or resentment, it would be beneficial to openly discuss the mother's intended decisions for Sumayra, which opt for quality of life over prolonging suffering. Additionally, she believes that teaching her daughter about religious values and the importance of accepting God will prepare her for the future, as she believes religious values will assist her in overcoming future challenges.

In her statement, the mother claims that her eldest daughter understands the way she thinks and approaches major end-of-life decisions. While this is the case, it does not make it easier for her to accept the fact that her sister, Sumayra, would eventually pass away. Therefore, the mother uses their religious teachings to comfort her eldest daughter. By framing her decision in terms of God's plan, she is communicating her decision within the context of faith. This can be viewed from the perspective of symbolic interactions, because the mother is using religious symbols to create shared meaning around such difficult decisions. Using the positive meaning attached to prayers, the mother wants to convey an important message to her daughter that she believes will benefit her in the future and will assist her in coping with the uncertainty of life. In openly discussing her choice with her eldest child, she reinforces her role as a caring, responsible mother, acting out of necessity rather than cruelty. Through these interactions, a shared understanding is developed between the family members, thereby transforming a painful decision into a meaningful act rooted in their religious and family values.

Perceptions of family and Muslim community:

During the discussion, the mother described the effects of her intense decisions on her family and the Muslim community. Her choices were interpreted as a sign of despair and a lack of faith in God's will to improve her daughter's health. Consequently, she felt a deep sense of isolation and disappointment, as she had hoped for more empathy and solidarity from those around her. The perceptions of the family and community, as well as the burden that the mother endured while caring for Sumayra and her siblings, will be explored in further detail.

Family Reaction:

There was a deep sense of frustration expressed by the mother regarding how her family does not fully comprehend the extent of her daughter's suffering or the impact it has on the quality of her life. As stated by the mother:

> *"The family didn't agree in the first place, and they still don't have the concept of how poorly she is. I mean, how disabled she is. How compromised the quality of life is, with Sumayra. Although of course, she's sitting there. She's smiling. She's well looked after. But we, the ones who are caring for her, we understand the quality of life. And the people who see her in the day-to-day life, from outside, they can't understand that."*

According to the mother, her family around her is only basing their opinions on what can be seen on the surface. From the outside looking in, the family seems detached from Sumayra's reality since she appears comfortable and happy to them. Taking a microsystem perspective, the mother is extremely cognisant of her daughter's situation, as she is well aware of her limitations, discomfort, and the pain and suffering she is experiencing, which are not readily apparent to her extended family. As part of the mesosystem, there is an interaction between Sumayra's mother (one of the microsystems surrounding Sumayra) and her family. It could be argued that there is a disconnect between Sumayra's mother and her family based on their differing perceptions of the impact of Sumayra's condition on her wellbeing.

As she reflected on her family's understanding and perception of her decisions, the mother bitterly expressed her disappointment in their judgments. She appears uncomfortable with their opinions and is unable to comprehend why they do not see it from her perspective. In her view, it is frustrating that they are shocked at the decisions she has been making and constantly wondering what is causing her to lose hope. As the mother put it:

> *"They [family] always have this question, but why? Why are you losing hope? They do say that Allah is there. And you understand the meaning. Yes, Allah is there, but Allah does not want an unnecessary pain. Because it's pain would be from the external factor, not a natural pain. It will be the pain of the machines induced by the machines. But they do not because they have not been to that situation."*

As can be seen from the above statement, the mother was having difficulty accepting the reasons for her family's disapproval of her decision-making abilities. She finds it painful that they equate her decision to reconsider life-sustaining treatments with doubting her faith in Allah (God). In terms of a symbolic interactionist perspective, there is a clear contrast between the way Sumayra's mother makes sense of her situation and the way her family interprets it. Despite both believing strongly in God's power, their understanding of that power is reflected differently in their approach to the situation. Taking the mother's interpretation of faith as an example, she believes that Allah is a compassionate entity that would not wish unnecessary suffering upon anyone. Her family, however, believes that having faith in Allah entails enduring hardships while remaining hopeful.

Furthermore, in this example, a machine appears as one of the symbols, expressing a life support system. There are differences between the meaning attached to these symbols by the mother and her family members. For the mother, the machines are external sources that are contributing to the pain and suffering of her daughter, which can be prevented. Other members of the family, however, see these machines as a symbol of hope, which is keeping Sumayra alive. Since these symbols are interpreted differently depending on the individual's beliefs and views, conflicts arise, despite the family's shared love and concern for Sumayra. Also, tension appears to exist between the mother and her family, as they disagree with how she is managing her daughter's circumstances and perceive her as pessimistic. From a macrosystemic perspective, this situation is about societal values, norms, and beliefs that influence Sumayra's family's perception of illness and disability. Sumayra's mother may be under pressure from religious expectations and cultural values to maintain hope despite the reality of her daughter's suffering.

The mother’s siblings’ perspectives:

As the mother reflected, she considered how her close family, namely her sister and brother, viewed her. There was an intensely emotional and complex moment expressed by her, in which every member of the family seemed to be fighting with their own emotions and holding on to hope for Sumayra's recovery. While persistently questioning the faith of the mother. In the words of the mother:

> *“My sister was a....they were…they have struggled in the beginning. And my brother-in-law was like, whatever you think is better for her, we will go with it. But my sister, my brother, they were very emotional. My brother especially, he said, “why you have no faith in God? saying that she's not (Sumayra) for PICU anymore, is saying that you don't have believe in God. So, what do you pray in your prayers to pray for her recovery?” I said, I pray for her comfort. If there is comfort in recovery, God will give her Shifaa, if there is no comfort in recovery, God will decide for her whatever is better for her. And I'm leaving that option with God. But he didn't accept that. He said, you are not… God has told you to work toward it. I said I am working towards it…What else can I do (nervous*

> *laughter) ...but because he is not…. he was very emotional thinking that I have put an end to everything. I'm not."*

The mother's account indicates that her immediate family had different views, with one member of her family supporting her decision, while her siblings opposed it. Her siblings were very critical of her judgments, portraying them as not aligned with their Islamic faith and belief in God's power. Her siblings were also among those who consistently questioned her faith in God, even to the point of doubting that she even believed in God. From a symbolic interactionist perspective, the mother and her brother have drastically different interpretations of what faith in God means. According to the mother, she prays for the comfort of her daughter but leaves the decision of what that comfort will be in the hands of God. It is up to God to determine if her child's comfort lies in cure, or in death, as a means to end suffering. The meaning of this prayer reflects what the mother perceives as her ultimate faith in God, which is trusting God's decision, regardless of the outcome. However, as the mother made clear, this is not what the brother regards as trusting in God. The mother pointed out that for the brother, believing in God means seeking all possible means of curing Sumayra.

Furthermore, symbolic interactionism assumes that people negotiate meanings through social interaction. The dialogue between Sumayra's mother and her brother is an example of such negotiations, where both are trying to persuade one another of what faith means in relation to Sumayra's health. Essentially, the brother's argument is that he believes in the divine power of God to heal Sumayra through medical interventions that are perceived by Sumayra's mother as negative. Thus, the mother's negotiation is based on her daughter's quality of life, with her trust in God's wisdom to make the best decision for her. In this ongoing interaction, both siblings are attempting to demonstrate that their viewpoints are aligned with their belief in God and the responsibility of providing care for Sumayra.

The mother's Muslim community judgments on her end-of-life care choices for her daughter:

Sumayra's mother openly discussed aspects of her community that had a significant impact on her life experience. Her heartbreaking narrations revealed her burdensome experience as well as the judgments she experienced from the Muslim community. She began by describing the lack of support from the community, and what she believes the reasons are behind their actions. The following is what she says:

> *"No, we don't [find support from the community], it's difficult to say because in our community, we don't have the exposure to these kind of...these kind of conditions. We don't... we think that life is just about being healthy and being enjoying the day and having the party and get together and being together and then open-door policy. And whereas for many families is not the option, they struggle from day to day, they don't know whether tomorrow, they would be able to cook dinner. They would be able to be able to have a dinner, because you may have to be at the hospital. So, it's bit of that lack of communication, understanding of the part. And We always think that the, everything should be perfect. And it's hard to admit that oh, we need a bit of help."*

Based on a mesosystem perspective of ecological systems theory, the mother's experience can be understood through the interactions within this interconnected system. As explained by the mother, this lack of support stems from the community's lack of exposure to individuals with critical illnesses and life-changing, physically disabling conditions. From a symbolic interactionist perspective, the mother associated the lack of support from her community to the collective meaning the community assigned to certain conditions like that of her daughter, Batten disease. As a result of these social interactions within a community, individuals can stigmatize illness and hardships associated with it. Accordingly, asking for help could be interpreted as a sign of weakness, since people are always inclined to reflect on the positive side of life and maintain the illusion of perfection.

> *"Some people would say I would never put my child through that. And they didn't say straight that why you did it. They said, I would never put my child through that. But probably they haven't been in my shoes. This is the one thing, they see everything from a perfect mirror, perfect glass. Whereas to me, I have whatever equipment Sumayra uses, a special needs chair, a special need bed, a special needs shower table, I always use it at some point for myself and try to see how she feels in it. And you know with the curvature of hundred-degree, spine curvature, is not easy even to breathe. So, it is hard for her. But I can't keep her here. But I...I would challenge anyone that if you sit in this chair for next three hours in that with that posture, then you have a right to decide. You know, it's like denying someone oh you have got heartburn, or you've got to eat this curry, even if you have a heartburn because I can't see the heartburn. So, it's hard for my child to be in that position. Although we can give her the medicines, but is it something right? It's not right."*

The mother's statement illustrates her direct involvement with Sumayra at the microsystem level. Because of her close relationship with her daughter, she is able to not only observe her daughter's distress, but also sympathise with her suffering. To further examine her daughter's circumstances, the mother physically experienced Sumayra's equipment, just to gain a sense of how it feels to be trapped in the chair, in a particular position. This illustrates a deeply involved and responsive microsystem. She is experiencing painful moments filled with pain and agony and feels helpless in what she can do. Therefore, this layer of the ecological systems theory captures how the mother works hard to improve the well-being of her daughter within their shared environment.

A macrosystem encompasses cultural and societal values, beliefs, and beliefs guiding a person's understanding of having a child with a disability. Taking a macrosystem perspective, it is possible to explain the indirect judgmental remarks made by some members of the mother's Muslim community, and their belief that they would have handled things more effectively. These ideologies and perceptions are likely impacted by societal views on caring for a disabled child, or by religious beliefs regarding what is deemed to be in the child's best interests. The statement '*say I would never put my child through that*' is a critical judgmental statement for someone who has no idea how it feels to be in that position. Individuals who pass such judgments are most likely to view withdrawal of treatments or termination of life-sustaining treatments as unnecessary, and cruel decisions. This can be offensive to a parent who is caring for a child with a disability or suffering from a life-threatening condition. The same is true for Sumayra's mother.

Through symbolic interactionism, it may be possible to explain the mother's experience by looking at how social interactions create meaning for disability and how caregivers are socially labelled. These meanings may reflect social stigmatization either of the disability itself or of the individual caring for someone with a disability. Sumayra's mother's narration illustrates her frustration with the way society, especially her Muslim community, labels her as a result of her choices for her daughter. Their judgemental framework: 'I would never put my child through that' implies that Sumayra's mother is harming her daughter, so her decisions are strongly rejected, and consequently, she is regarded as vicious. As the mother says: *'It is like denying someone that they have heartburn or that they have to eat this curry, even if they have heartburn because I cannot see the heartburn'.* This is a simple analogy using a common food item within their culture to convey a deeper meaning. In this analogy, Sumayra's mom intends to illustrate to others that regardless of the equipment used to manage difficult disabilities, they do not reflect comfort. In other words, Sumayra's mother is trying to challenge that if pain or discomfort is not physically visible to others, they tend to overlook it. Therefore, as the mother indicated in her reflection, a person has to go through the experience to know how it feels, as it is unfair to make judgements from the outside, while living what it may seem a problem-free life.

The mother shared heart-felt incidents where she felt neglected by those from her Muslim community, and experiencing similar circumstances of caring for a child with a chronic condition. Here is detail of her story:

> *"There was a lady in front of my…. front of Sumayra's bed in hospital. And they had all the curtains drawn. She passed by me several times, but did not share, she just smiled at me, did not say anything. So next time when she withdrew the curtain, and I said to her, I said, are you going home today? And she said Oh no, God has given us this. This challenge, but he will give us shifaa also. So we are, we are going to Saudia. Because my daughter is diagnosed with Type One Diabetes. So, I want to take her to Saudia for… to ask for God's help. So, I thought how sad. I felt really sad that I'm sitting next to you in front of you. My child is in worse, worse condition. But you did not…you did not communicate to me on a human level, but you are happy to travel that far with a poorly child and a bag of medicine to communicate with God who's not there. I really felt very…when I left that hospital ward, another next-door lady, she had a little child who was choking on something. But they did not withdraw the curtain at all. She passed by many times; she did not smile. Whereas, across the room, there was another English mom, and she had a little baby, and she was coming over to see Sumayra and I went over to see her child. I made some balloons out of the gloves for her child. Because he was crying. And... So, she… she chatted about Sumayra and everything. And I chatted about… so I learned a bit that there is a condition… about her child's condition. If I had to hold on to myself and just looked at Sumayra, and stayed in my own world, I would not have known. There are some other conditions also. And how she is coping with it, how she is managing things like these."*

In her reflection, the mother expressed disappointment with those who shared her religious background. Her interaction with another Muslim parent in the incident she described above was minimal and was often accompanied by negative connotations. By utilizing the symbolic interactionism theory to explain this incident, Sumayra's mother interpreted the Muslim mother's words and gestures as symbols of avoidance, such as passing by without saying anything. Traveling to another country to perform a prayer is another example of avoidance, which represents shutting down and avoiding contact with Sumayra's mother. Sumayra's mother interpreted this interaction as showing a lack of empathy on the part of the Muslim parent. As a result, Sumayra's mother felt disappointed, disconnected, and isolated. Unexpectedly, the mother felt a stronger connection with an English mother who was of a different religion and cultural background. Since the English mother was actively communicating with Sumayra's mother, this interaction was a sign of openness and a shared support.

Coping

Despite all the difficulties and obstacles Sumayra's mother came across through her journey of caring for her daughter, she was always keen on finding ways to move forward, while maintaining her energy to provide Sumayra with the care she needed. According to the mother:

> *"So, we opted for the next-door school [rather than travelling long distance for another special needs school], which is mainly autistic kids. And I thought that's what I have to do with these moms. My troubles are more bigger. But when I…I used to love going to the coffee morning so I said I want to come and help as a volunteer…going to attend Coffee mornings thinking that will make everybody a cup of tea, I will have a good time, and I will go home… my troubles are bigger than theirs. And I had the conversations with the moms, I came across how… how hard it is to have an autistic child. And how difficult the day to day, an hour to an hour slot is. God…God has definitely put me in a better position than I could, I wouldn't be able to handle that. And when especially one of the moms said that her son loves to escape through the windows. And the other moms out that her son loves the sound of smashing the crockery, and all that they have in their house is carving cups and carving pottery. I love myself because it is good, my troubles are not that much."*

Based on symbolic interactionism theory, one can explain the process the mother went through to come to a new understanding of her daughter's condition and to feel comfortable and at ease. Among the ways in which she achieved this was through social interactions with other mothers caring for children with a variety of critical and challenging medical and psychological conditions, including autism. The above narrative shows that one of the turning points occurred when she actively took the initiative to approach mothers of autistic children and interact with them closely. It was through these social connections and conversations that Sumayra's mother came to realize that her daughter's situation was not as bad as it appeared. She attached different meanings to the symbols in the stories shared by other mothers. Some of these symbols include children escaping through windows or smashing crockery which reshaped the mother's perception of difficulty and resilience. Therefore, attending such social interaction events helped the mother reinterpret hardship differently, allowing her to see the positive aspects of her situation.

Furthermore, these interactions are part of the mesosystem, since they occur between Sumayra's mother and other members of the community within the school environment. It was through these open communications that she was able to gain a new perspective on Sumayra. It was so difficult for her to see the other side because she was so concentrated on her daughter and observing close changes and significant developmental problems. She, therefore, only focused on the difficulties, without realizing there was another side to it. When she connected with other mothers, she had the opportunity to listen attentively to their perspectives, since they were close to their children as well. In this way, Sumayra's mother was able to notice the things she could not handle and became appreciative that God was not burdening her with anything she could not handle.

Based on the structural functionalist perspective, Sumayra's mother's story shed light on the importance of collaborative efforts when there is a shared purpose or value. The mother shares her experience of volunteering, where she decided to take the opportunity to do something she enjoys. This enabled her to connect closely with other mothers, where their needs for support overlap, since they care for children with special needs. By creating that sense of community, that would enhance their support and contribute to maintaining their social stability and functioning in society.

Breaking the barriers: Finding comfort outside comfort zone

Among the major decisions made by the mother was the decision to send her daughter to a school that primarily caters to autistic children. Based on the above statement, it is evident that she chose this option due to its convenience, yet the outcome reflects one of the major milestones in her journey. Her experiences within a different community provided her with an opportunity to redefine her situation and look at its positive aspects. Continuing, the mother explains how she was able to make such a courageous change. According to her:

> *"When you go out of your… But it has only happened because I left my community. I left my…my comfort zone. I'm going out. To sit with them, with a lot of cultural barriers, a lot of religious, social barriers. And listen to them and think that oh,*

> *they are coping. But they were one best thing that I always say to everybody is, when you go out and meet them, they are always happy. They are always grateful. They don't…they're not church goals. They are, they are not as pretentious, religious as I am. But they are always happy, they're always happy in whatever God has given them."*

During the interview, the mother spoke of how she stepped outside of her comfort zone to connect with others who did not necessarily share the same cultural or religious background. In symbolic interactionism theory, people reinterpret and create meaning through social interactions. She explained that since she had been able to change her surrounding community, hardship was no longer automatically associated with negativity, sadness, and depression. Despite not being religious, they are happy and content, which means the meaning they interpret or reflect from their circumstances is not influenced by religion. Considering the ecological systems theory, this can be explained in terms of microsystems and mesosystems. Sumayra's microsystem includes members of the Muslim community. The mother finds it burdensome to be constantly in their presence with their negative remarks. As a result, as the mother stepped out of her comfort zone and introduced Sumayra to a new group of people, who are more on the positive side, it would positively affect Sumayra's microsystem. As for the mesosystem, the interactions between the mother and the new community would positively impact the mother, which would subsequently be beneficial to Sumayra.

It was very pleasing for Sumayra's mother to see how the community of families of non-Muslim religious backgrounds treated her. She stated that they are always striving to organize school events that will benefit the children. In her words:

> *"And they never say that…they never say no to help you even. And they will never judge you. Even… although they have got enough on their plates, they're always…they're always there to thinking of next thing, should we do this? Should we do that? Oh, can we help school in this thing? Can we do the fundraising? Can we come and do the summer school's camp?"*

They appear to be full of life despite their circumstances, and eager to participate in any possible opportunity to collaborate for the benefit and interest of the children. They are also friendly and supportive:

> *"And they will tell the other moms Oh, yes, this is my social media account. Just leave me a message there. And I will send you a message back. And they are very open to befriend each other to pass on messages and even pass on the equipment*

> *that has helped them. And even tell them how you can access the funding, and how you can approach the social services if you need."*

She enthusiastically explained that joining the community of her daughter's new school fostered a sense of belonging, respect, and support. As they all share a similar understanding of their struggles, they openly share resources and provide guidance to those in need without imposing any negative attitude. According to structural functionalism, for a family to be an active and effective member of society, they need to feel supported, and their basic needs must be met. For Sumayra's mother, for example, this sense of support and acceptance, regardless of what decision she makes, would contribute to her feeling of security and comfort. In this way, she will be able to make open decisions for her child's best interest without feeling judged. In turn, that would enhance her role as a mother and a caregiver, allowing her to provide effective care and support for her children.

As a means of providing a more complete picture, she explicitly compared the two communities and their respective approaches to their children's illness and distress resulting from it. She expressed the following:

> *"Whereas if I sit, when I used to go to [previous hospital, in another city in the UK], I used to sit in the waiting room, and all chats used to be focused on how hard life is. Which makes it harder; it makes you psychologically believe that you are the troubled one. And it doesn't give you an incentive to look for the brighter future. Doesn't give you that motivation, understanding there is a light and end of the tunnel…this on…the idea that this is your plate, be happy with it. Because you don't know the next-door person may have more trouble in his plate. So that is the biggest difference I have come across."*

Focusing solely on a child's illness would limit an individual's ability to find solutions to their problem. As Sumayra's mother mentioned in the excerpt above, focusing on the negative would be mentally distressing. It would cause parents to dwell on the worst possible outcomes, resulting in a much more difficult situation. As a result, from a structural functionalism theory perspective, the family's stability and functioning will be negatively affected as a result of their inability to function effectively. From a symbolic interactionist perspective, the social environment can have a significant impact on the meanings derived from a given situation. This means that social interactions within a highly negative environment, where the child's illness is viewed as a challenge or a test, would reflect these meanings in their attitude toward the illness As seen in the preceding examples, of the mother who decided to travel to another city to seek God's support, she is surrounded by negative thoughts, which adversely affect her and contribute to a feeling of isolation. Conversely, Sumayra's mother was supported by the positive attitude of the families in the new school community, who are always taking the initiative to help and support.

To conclude her story, the mother associated her ability to cope to her faith in God. As she emotionally, and strongly stated:

> *"They said God never gives you more than that you can handle, but I always say that we had this hardship, very bumpy ride in life. But when I speak with other people, and they tell that how they struggle to get the support, how they struggle to get the equipment, or the struggle in the day-to-day life or the this or that. I found that yes, God has taken away, not giving me a healthy child, but for the sake of that child God has put everything in place without me having to struggle for it. I've never had to struggle to get help from social services. nor I had to struggle to get help from the continuing health team of the community nurses, they are always there. I think, if you look things from that perspective, God gives you one item but then you got to look for how he has made other brighter points in your life. And my kids are really good. They're very, very good Mashallah."*

Based on a symbolic interactionist perspective, one may argue that the mother's sense of identity is strongly influenced by her religious beliefs. Using the phrase 'God never gives you more than you can handle', she frames her religious identity, which could be serving as a guiding symbol in her life, fostering her sense of resilience. The mother's negotiation of her circumstances also demonstrates symbolic interactionism. Seeing the symbolic meaning of having an extremely ill child as a positive transaction in which God has taken her child's health, but in return has provided her with the environment and equipment to assist her as she navigates such hardships. For this mother, religion is a symbol of comfort and a guide through the obstacles involved in dealing with a life-threatening condition and making life-altering decisions.

This narrative interview with Sumayra's mother was filled with overflowing mixed emotions reflecting the experience of a Muslim mother striving to provide the best possible care for her daughter. However, she is always motivated by her desire to ensure her daughter's quality of life, over prolonging her life, all while adhering to Islamic teachings and values. As reflected from the interview extracts, her remarks ranged from frustration, disappointment, and confusion. She was then raged by her family and community’s judgements, perceiving her decision as lacking trust in God's divine power. Throughout the above statements, mixed emotions, courage, and bravery prevailed. She went through a roller coaster of emotions, difficulties, and mental distress. But she found a solution, at least, one that align with her religious beliefs and moral compass, despite what others perceived of her. She continuously asked questions, and searched for answers, and settled on what she firmly believed to be in her child’s best interest.

She is holding firm to her decisions for her daughter despite the constant pressure that is placed on her by those around her. As she calmly stated:

> *“but this conference [Islamic conference] that I…this meeting that took place in an American school, they… they did all the faith, they did agree that end of life care decisions should be made in a way to be the understanding that the religion allows it. religion does not allow any kind of unnecessary pain even to the body. So, it was very comforting.”*

As expressed in the above statement, the mother affirms her stance on the importance of quality of life when it comes to her daughter's choices. Through seeking the advice of trusted Muslim scholars, she is comforted by their reassurance that she is making decisions within Islamic teachings. From a symbolic interactionist perspective, considering the mother's experience in seeking advice from Islamic conferences or schools can provide insights into how meanings of end-of-life care are shaped and negotiated within larger systems of social interaction. Sumayra's mother is reshaping her understanding of pain and suffering through such interactions and discussions. Religion is not just about individual practices, but also about community engagement, discussion, and mutual understanding. This statement from the mother reflects a symbolic meaning of religion derived from these social interactions, which is that it ‘does not allow any kind of unnecessary pain’. This is then used by the mother to guide her decision and justify their ethical and religious sanctity. Through symbolic interactionism, one can interpret the significance of such interactional incidents, in which individuals shared and created symbolic meaning around end-of-life care, which subsequently provided comfort and clarity to the mother as she is facing fatal decisions for her daughter.

Chapter 6: Discussion and Conclusion

This chapter will further discus the themes resulting from the interview with paediatric palliative care professionals and social work students. These themes collectively offer a comprehensive view of the barriers faced by healthcare professionals in delivering culturally competent palliative and end-of-life care to Muslim children and their families. They underscore the importance of diversity, training, communication, and family-centred approaches, while identifying areas for improvement in policy and practice.

Theme 1: Diversity in the Workforce

In terms of diversity in the workforce, this study highlighted the importance of enhancing diversity within healthcare teams. This cultural diversity would contribute to improving cultural competency, enhance inclusivity, and quality of care provided to patients from all backgrounds. Findings from a study by Alim-Marvasti et al. (2023) agree that in multicultural societies, having a diverse group of physicians who represent various cultures and religious beliefs is crucial for better health outcomes. According to Sullivan (2004), diverse workforces would improve understanding and identification of cross-cultural challenges at the provider level, allowing for effective management of such challenges and ensuring high-quality patient care. In fields like Anaesthesia & Intensive Care, where ethical decisions are often complex, this diversity can help address different perspectives and improve decision-making and patient consent (Alim-Marvasti et al., 2023).

Such diversity in the workforce, within social work, for example, as it would facilitate culturally sensitive care to Wales' increasingly diverse populations, which includes children and young people. Diversity in a workplace is not just about representing cultures and backgrounds; it is also about giving all racial and ethnic groups equal opportunities, resources, responsibilities, and power, and including cultural elements that would positively impact the experience of those receiving care (Sullivan, 2004). Findings of the study also suggested that there is a need to increase cultural representation in healthcare workforce. Accordingly, Jackson and Gracia (2014) concluded that increasing the representation of underrepresented groups in the healthcare workplace would ensure that a range of values and beliefs are represented, and that cultural awareness is increased. Findings also suggest that increasing diversity within social work and healthcare requires a targeted approach to reach underrepresented communities. Flores and Combs (2013) argue that to increase diversity in workforce, there needs to be targeted approach to intentionally attract individuals of racial and ethnic minorities. This type of recruitment should be done actively and systematically (Flores & Combs, 2013). This approach should focus on understanding where and how potential minority applicants find and process job information (Flores & Combs).

Moreover, this study suggests that increasing diversity within social work programs require revaluation of educational pathways to make social work programs more accessible. Similarly, a study looking at ways of increasing diversity within environmental health program suggested some measures need to be in place for those individuals. This includes ensuring adequate financial support for these students (Boyapalli et al., 2023). Other things include having mentors to students of diverse backgrounds to assist them in navigating cultural differences in a new environment and to meet challenges they may encounter (Boyapalli et al., 2023). Furthermore, recruitment and admission processes should include students from diverse backgrounds (Boyapalli et al., 2023). In order to attract students from diverse cultural backgrounds, Boyappalli et al. (2023), suggest that collaborations with other majors and widely accepted health programs can be of significant benefit (Boyapalli et al., 2023). Collaboration with high schools and promotion of environmental health programs through the school's science programs are also important to increase awareness of environmental health programs (Boyapalli et al., 2023).

Theme 2: Building Relationships

Insights of the study emphasize that providing culturally sensitive and effective care requires building genuine, long-term relationships with communities and ensuring that information and services feel trusted and embedded within community norms and values. A patient-centred approach where healthcare services are delivered in culturally sensitive, community-integrated ways. Building trusted, long-term relationships with communities and engaging respected local figures in communication can help bridge gaps in understanding and trust, particularly around end-of-life care. Reflections from the study highlight a significant need for consistent, multi-faith, and particularly Muslim chaplaincy support within palliative care. Participants express that having access to religiously and culturally aligned resources and advisors would help bridge gaps in understanding and support, enabling healthcare providers to deliver care that respects the religious beliefs and cultural practices of diverse families. These cultural liaison officers and outreach workers play a vital role in making hospice care more accessible, trusted, and culturally sensitive for Muslim and Asian communities. Through proactive outreach, culturally informed communication, and community engagement, they help bridge gaps in understanding, ensuring that diverse families feel welcomed and supported in hospice settings.

Theme 3: The Role of Training in Enhancing Cultural Competence in Healthcare

While general cultural competency and equality, diversity, and inclusion training are accessible, there is a need for more focused and detailed training on faith-specific practices in palliative and end-of-life care. Such training would enhance healthcare providers' ability to respect and support the religious beliefs and customs of families from diverse backgrounds, fostering a more inclusive and compassionate care environment. Findings of the study highlight an opportunity to expand palliative care training beyond Christian-centric and medical-focused content. Integrating a comprehensive approach that includes multi-faith education and culturally respectful care practices would help healthcare providers meet the diverse spiritual and cultural needs of patients and families in end-of-life settings. These insights reveal that existing cultural competency training is often too generalized, leaving significant gaps in knowledge that directly impact the quality of care and support provided. The participants advocate for more specialized and tailored training that addresses specific cultural, religious, and situational needs within diverse communities. Such training would empower healthcare and social work professionals to deliver more nuanced, culturally appropriate, and effective care across varied demographic groups.

Findings of the study also reveal that healthcare and social work professionals often take on the responsibility of self-education and problem-solving to address cultural and religious needs in patient care. While this initiative is commendable and shows dedication to providing culturally respectful care, it also underscores a gap in formal training that, if filled, could ease the burden on individual staff members and enhance care quality across the board. These reflections underscore that while formal training is important, the combination of listening to families, seeking external guidance, and gaining experience through hands-on practice are equally valuable in developing cultural competence. The participants recognize that openness and an eagerness to understand different beliefs are essential for providing compassionate, culturally sensitive care that resonates with families' deeply held values. In summary, these reflections highlight a significant need for comprehensive and practical cultural competency training in end-of-life care. Creating accessible resources, like a Learning Hub, providing experiential training, and involving religious leaders in educational sessions are all potential strategies to help healthcare providers deliver respectful, culturally appropriate support that honours the diverse beliefs of the families they serve.

Theme 4: Communication Barriers

The study highlights the complex, often emotional nature of end-of-life decision-making in paediatric care, where conflicts can arise between medical recommendations and family wishes, especially when religious beliefs or cultural values shape families' choices. Key themes from the participants' perspectives include prioritizing the child's best interests, the role of multi-professional collaboration, the impact of ethical panels, and the emotional toll of these decisions on both families and healthcare providers. In summary, these reflections reveal the importance of a multi-layered approach to resolving conflicts in paediatric palliative care. Prioritizing the child's best interests, fostering collaborative discussions that involve trusted figures, and ensuring open, compassionate communication can help bridge the gap between medical recommendations and family beliefs. Ethical panels, while sometimes necessary, add complexity and can be traumatic for families; however, they may also offer a sense of closure for families who feel they have advocated fully for their child. In summary, these insights reveal the need for a nuanced approach to end-of-life discussions that respects cultural and religious values while considering medical perspectives on quality of life and compassionate care. Enhanced training in cultural competence, alongside skills in empathetic, open communication, could help healthcare providers better navigate these deeply sensitive and complex situations.

Theme 5: Language Barriers

In this study language barriers were discussed in terms of the limitation of translation services that impact the family's experience. Generally, when providing services for Muslim families and individuals of various ethnic backgrounds, language barriers significantly impact the quality of care and support that healthcare and social work professionals can provide to families from diverse linguistic backgrounds. These barriers can be mitigated by readily available and well-trained interpreters, along with culturally competent staff who are sensitive to the additional complexities that arise when language and cultural differences intersect. Recognizing and addressing these language challenges is essential for providing respectful, effective, and compassionate care.

Some participants in the study, highlighted the various tools and resources that healthcare and social work professionals use to overcome language barriers and support effective communication with families from diverse linguistic backgrounds. these insights reflect a proactive approach in healthcare and social services to bridge language barriers through various interpreting tools and services. The increased reliance on professional interpreters, both by phone and in person, as well as the translation of key documents, demonstrates a commitment to ensuring that language is not a barrier to effective, compassionate, and culturally respectful care. These resources help professionals support families in making informed decisions and feeling fully included in the care process. Moreover, they emphasised the significant challenge that language barriers present in providing effective, culturally sensitive care, particularly in palliative and social work settings. Language differences can complicate communication, lead to misunderstandings, and add emotional stress for both families and healthcare providers.

Overall, these insights from the study reveal systemic issues related to interpreter access in healthcare and social work, especially in settings with limited funding. The reliance on informal solutions, such as joining other professionals' visits to share interpreter access, points to the need for more consistent, funded interpreter services. Increasing availability and funding for language support in these settings would ensure that all patients and families, regardless of language, receive equitable, high-quality care and communication. Yet, it is not a convenient solution. Therefore, there must be a sustainable solution to allow health professionals readily access translation services as needed. That would help meeting the requirements of Muslim families encountering language barriers, as well as any patient from ethnic minority group.

As the study revealed, consistency, cultural alignment, and emotional support in interpreter services within palliative care, emphasizing the need for tailored solutions that respect the sensitive nature of end-of-life care. Findings illustrate the need for a more personalized approach to interpretation in palliative care. This includes consistent, face-to-face interpreters, culturally aligned language support, and professional interpreters who relieve family members of this role, enabling them to focus on their emotional well-being. Implementing such practices would enhance the quality of care, facilitate more empathetic communication, and better support families in navigating complex end-of-life discussions.

Theme 6: The Role of Faith and Culture in Shaping Personal and Social Identity

This study reveals the deep impact of culture, religion, and family dynamics on end-of-life care within Muslim families, highlighting both the strength derived from family and community support and the potential tensions or pressures that can arise. Key themes include the role of faith in coping, family networks as sources of strength, community pressures, and family dynamics in decision-making. The study, therefore, highlight the supportive and complex roles that culture, religion, and family networks play in end-of-life care among Muslim families. While faith and community support provide comfort and practical assistance, they can also create challenges, particularly when extended family members have strong opinions on treatment decisions. Healthcare providers who understand these dynamics and work sensitively within them can help families navigate the difficult balance between meeting cultural expectations and making decisions aligned with the child’s best interests. This approach allows for more compassionate and culturally responsive care, supporting families both emotionally and practically through the end-of-life journey.

Theme 7: Family Dynamics

As for the theme of family dynamics, the study shown certain aspects within the family that can impact the family’s decisions. Certain aspects pertaining to gender role differences within Muslim families is what plays a significant part in impacting the family’s decisions. For example, gender roles between a husband and a wife. Also, the impact of gender on autonomy, and the relationship between gender and English proficiency. The study revealed that, males, within Muslim families appear to have more power authority. As the findings indicated, mothers are usually reluctant to take on the responsibility, and lead within the family. Leaving major decisions, such as end-of-life decisions for a child to be contemplated, and decided by the father, or the male-figure in the family.

In summary, these findings highlight the importance of recognizing and addressing the gender-based dynamics that can influence caregiving, access to support, and decision-making within certain families. Healthcare providers working in palliative care may benefit from approaches that empower mothers by providing culturally sensitive support, offering tailored language assistance, and actively engaging them in decision-making processes. By understanding and responding to these gender-based nuances, healthcare providers can foster more inclusive, supportive environments that respect each family's structure while ensuring that primary caregivers have the resources and autonomy needed to provide effective, compassionate care.

Theme 8: Family-Centred Care

Findings of the study shown the importance of providing individualized, culturally sensitive care in palliative settings, highlighting themes of adaptability, avoiding assumptions, active listening, and the potential impact of overlooking cultural and religious needs. As part of family-centred care, participants emphasized the role of advanced care planning (ACP) in paediatric palliative care. ACP is an individualised plan for each child, that families can have to incorporate their wishes for the child, the child's needs and wishes; along with including religious or cultural needs that pertain to death and dying. Having an ACP is a continuous process that can occur at any time of the journey of the illness. It helps ensure that end-of-life care is aligned with the family's and child's values, providing comfort and dignity in difficult times.

The theme of family-centred care is consistent with the findings of a study by Muskat et al. (2017), where they stressed that when working with families of children at end-of-life, social workers offer ongoing support to families throughout the stages of the child's illness, up until the child's death, and even after the child's death, providing grief support and community resources (Muskat et al., 2017). This emphasis on person centred care is a theme in paediatric palliative care policies and strategies which emphasize patient and family-centred care. As shown in the National Services Framework (NSF) (Essex et al., 2004) for children and young people in Wales, care for children and young people should be centred around the needs of children and families regardless of their circumstances.

While child and family centred care is universal for all children and young people, needs may vary depending on the family and the child. Hence, the NSF establishes standards of care that are specific to children with disabilities, children with acute and chronic illnesses, and children in special circumstances, such as those cared for by authorities, refugees, or asylum seekers (Essex et al., 2004). As one of the standards of care described in the NSF, children and family centred services are used to encompass various aspects of support for children, young people, and their families. Children and their families need to be assessed holistically to form the foundation for a care plan that is tailored to their needs and takes families into consideration (Essex et al., 2004). Children and their families need services personalized according to their needs, which includes ensuring that disabled children are included, and inequalities are addressed, as well as providing accessible spaces that are suitable for their needs (Essex et al., 2004). As part of All-Wales palliative care standards for children and young people's specialized healthcare services, location of services is added as part of child and family centred care. Family-centred care refers to a comprehensive approach to care that considers the personal needs of families to facilitate treatment decisions (Essex et al., 2004). This means catering to the specific needs of the caregivers, separate from the child's needs. As a result of the findings of this study, a social work student identified person-centred care as something independent of the child's needs that would enable the family to plan for various things, even after the child's death.

Theme 9: Accommodating Rapid Burial Rituals

Islamic principles and teachings are more of a guide to life. In Islamic teachings, Muslims are provided with comprehensive guides that assist them not only in navigating life events, but also in understanding death and its meaning (Jahangir & Hamid, 2022). Hence, the way the dead body is prepared for burial is all dictated by Islamic teachings. Then, to prepare the body for the burial, it should be washed, shrouded by a white sheet, and then facing the deceased towards Mecca, the holy city for Muslims (Madni et al., 2022). According to the study findings, rapid burial is one of the most important post-mortem practices in Islam. It is strongly believed by Muslims that that the quick burial of the body signifies mercy on the body. As it is required to be treated with respect, even after death (Madni et al., 2022). Therefore, Muslim individuals require a quick release of the deceased, to be able to proceed with the burial (Madni et al., 2022). In this study, healthcare professionals discussed the importance of supporting Muslim families in ensuring a quick burial for their deceased children. Nevertheless, some healthcare professionals in this study have indicated that the process is not always smooth.

This study revealed that healthcare providers take proactive measures to minimize delays, often going to great lengths to ensure a smooth post-death process. As part of this process, advanced planning and coordination with other services is required, such as arranging for imams, arranging funerals, and keeping documentation so that death certificates can be obtained more quickly. Healthcare providers often face unavoidable obstacles that prevent them from meeting families' burial timing expectations, which can be distressing for both the families and the staff. Healthcare providers feel a strong responsibility to support families' cultural practices, but systemic limitations, including limited coroner hours or public holidays, add to the emotional strain of end-of-life care. It is common for healthcare professionals to advocate for families during this time, which is consistent with previous findings of Muskat et al. (2017), highlighting that advocacy for patients and their families is one of the essential elements of social workers' roles, along with providing culturally appropriate care for patients.

Among the themes that emerged from this study, accommodating rapid rituals was the most controversial. While Muslim families require that their children be buried within 24 hours, it is not always convenient to do so. Despite this, healthcare professionals remain committed to facilitating burials within 24 hours of the request. The experience can be distressing for both the healthcare professional and the patient's family. As a result of this tension, the immediate family may experience an emotional burden as they attempt to balance their own needs with the cultural expectations of others.

Conclusion

The purpose of this study is to examine the perspectives of healthcare professionals and social work students regarding the barriers they face when providing culturally sensitive care for Muslim children and their families. Among the objectives of this study is to understand the lived experiences of Muslim families who are caring for children suffering from a life-threatening condition and facing imminent death, and how their Muslim faith is impacting their ability to make decisions. The findings were addressing the following:

Research Question:

How can the Islamic culture and religious teachings impact paediatric palliative care and end-of-life (EOL) decision-making for clinicians, and parents of children with life threatening illness?

Objectives of the study

- To examine the extent to which faith and culture influence the decision-making process of Muslim parents whose children are diagnosed with life-threatening illnesses.
- To examine whether faith or culture can serve as coping mechanisms for parents and shape their views of their children's conditions.
- To explore the challenges that pre-qualified students and health care providers face in understanding the culture and traditions of their patients in regard to paediatric palliative care and end-of-life care in relation to their Islamic faith and culture.
- To identify and analyse the institutional factors that facilitate or hinder the inclusion of the Islamic faith and culture in paediatric palliative care and end-of-life care.

Summary of the study’s findings in relation to the research question:

Islamic culture and religious teachings significantly influence paediatric palliative care and end-of-life (EOL) decision-making for healthcare professionals and parents of children with life-threatening illnesses in several ways:

Guiding Decision-Making:

In this study, Islamic beliefs shaped the views of the mother in this study on medical treatments, EOL care, and ethical considerations around suffering and life preservation. These decisions were heavily influenced by the mother’s religious beliefs, even when she was facing judgments, she continued to refer to Muslim scholars for help in giving her adequate answers about end-of-life care. Sumayra’s mother continuously relied on religious guidance when making decisions about Sumayra’s care, which impacts choices around interventions and comfort measures. Clinicians aware of these beliefs can better respect and support the decision-making process.

Providing Coping Mechanisms:

According to some of the healthcare professionals participating in this study, faith and community support serve as critical coping mechanisms for Muslim families, offering emotional strength through religious practices, prayer, and support from extended family and community networks. Recognizing the role of faith in coping enables clinicians to offer more compassionate support and respect families' coping needs. Additionally, it allows them to reevaluate other areas that are needed to support the families.

Challenges in Cultural Understanding:

Clinicians may face challenges due to limited knowledge of specific Islamic traditions, such as the importance of rapid burial, dietary laws, and gender roles in caregiving. As highlighted in the study, among some Muslim families, males and male-figures sometimes appear to be dominating and authoritative.

Importance of Institutional Support:

Systemic barriers, like limited access to Muslim chaplaincy and interpreters, can hinder the provision of culturally appropriate care. Institutions that support cultural liaison officers, partner with community leaders, and fund consistent interpreter services can facilitate a more inclusive healthcare environment.

Culturally Sensitive Advanced Care Planning (ACP):

ACP that involves religious leaders and respects Islamic practices, such as rapid burial, helps align care with the family’s beliefs and priorities. Clinicians who engage with these cultural values can foster trust, honour religious requirements, and provide care that resonates with families’ deeply held beliefs, ultimately improving the palliative care experience.

In summary, Islamic culture and religious teachings influence decision-making, coping, and the need for culturally aligned support in paediatric palliative care. For healthcare professionals, understanding and integrating these cultural dimensions enables more respectful, compassionate, and effective care for Muslim families facing EOL challenges with their children. Also, addressing these gaps through targeted, culturally specific training can enhance health professionals’ ability to deliver culturally sensitive, respectful care.

Implications of findings

Practical Implications:

- **Enhanced Cultural Competence Training**: Healthcare providers require deeper, specific cultural competence training that goes beyond a general understanding of diversity. This means incorporating experiential learning and practical resources focused on Islamic beliefs and end-of-life practices, helping caregivers respond with respect and understanding to the unique needs of Muslim families.
- **Policy Adjustments to Support Cultural Needs**: Revise existing health institutional policies and make the needed adjustment to meet the requirement for inclusive workforce or to incorporate best practices that consider accommodating rituals like rapid burials. Consider what is currently existing regarding ensuring culturally sensitive care, and reevaluate it as needed, to meet the needs of Muslim families to better their experience.
- **Improved Translation and Communication Tools**: Given the importance of clear communication in navigating palliative care, institutions must refine translation services to ensure they are culturally sensitive, consistent, and of high quality. This could involve assigning dedicated interpreters, training them in medical terminology and cultural nuance, and creating pathways for compassionate, personalized communication that fosters trust with families.
- **Collaboration with established local and global Muslim organisation**: At the local level, it is a physical space for individuals to go to when needing support from the community. They should be easily accessible, with possibly a social media platform, to connect with youth. This organisation could have ties globally, where they can reach out to Muslim scholars whenever needed, to provide efficient and accurate Islamic knowledge about different life and death matters.
- **Reconsidering Recruitment Strategies for a More Diverse Workforce:** Build an effective strategy to promote health programs that are not well reputable among individuals of different cultural backgrounds. Individuals from certain cultures are keen on pursuing certain programs and are not aware of different career pathways. Therefore, such strategies will bridge the gap between people of ethnic minorities and healthcare workforce. Also, consider targeted recruitment in communities where are dominated by one specific cultural background.

Although these implications are directed towards Muslim families in paediatric palliative care, they can also be considered with health services users from various cultural background.

Limitations of the Study

This study has only looked at Muslim families. Also, the sample size was small, and possibly saturation of data was not reached. There was no comparison between the perspective of families of other faiths and culture, to find out the similarities or differences in services provided to them or the lack of them. Also, the study focused on certain participants and the findings are not generalised to all everyone from the same religion or professional background. This study looked at the perspective of one mother, which may or may not be similar to others. Therefore, it is suggested that other studies to look in depth at the perspectives of different cultural backgrounds within the Muslim communities since each culture or background may follow a different interpretation of the religious teachings.

Recommendations for Future Research

- Future research can focus in one of the barriers and consider branching it out to improve it. For example, look at the specific translation services assess their effectiveness, and ways into making them more advance. Explore the experience of translators and what needs to be done to ensure the smooth and effective implementation of new translation services.
- Qualitative study exploring ethnic minority children taking on the role of the caregiver, as their parent is navigating a chronic or terminal illness.
- Replicating this study but expanding on the number of participants. Consider various Muslim cultural groups and compare the cultural perspective on care, as each culture could have a different interpretation of illness and coping with it.

In conclusion, this study could be the initial idea where other recommendations can branch from it. They can focus on one the implications, like diversifying the workforce and measuring the effectiveness of current strategies. While another research can focus on the mental distress on healthcare providers as they are heavily involved in sensitive matters about death and what is rewarding about being in such a profession.

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Appendix A: Participant Information Sheet for Healthcare practitioners

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TITLE OF RESEARCH: Islamic teachings and culture in making end-life- decisions for children living with life-limiting illness

You are being invited to take part in research that is undertaken as a part of a PhD study. Joining the study is entirely up to you, before you decide whether or not to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part. Then we give you more detailed information about the conduct of the study.

If anything is unclear, please do not hesitate to ask questions.

What is the purpose of the research?

We are conducting research on the Socio-Cultural dimension and communication of children's palliative care in the healthcare system; with specific attention to end of life care for children with life threatening illness and their families.

The purpose of the study is to explore the impact of the Islamic faith and culture's teaching on end-of-life (EOL) decisions made by Muslim parents of children with life-threatening illnesses. Additionally, looking at communication between clinicians and other support staff, and parents in paediatric palliative care within a multicultural setting; where culture/faith, and language, may create barriers for parents pursuing EOL care for their children.

You are being asked to take part in this research study because you are a health care professional or support staff working in paediatric palliative care or hospice care; to explore your perception as a healthcare provider on how culture and faith play a part in Muslim parents' ability in decision making for their ill children.

Your participation in this study comprises of 1 interview, through a video communication APP, like ZOOM, Microsoft Teams, or a telephone interview which is intended to take approximately 30 minutes, at a time and location mutually agreed on.

Who is organizing and funding this study

The data are being collected by Eiman Nabag, School of Health and Social Care at Swansea University; the study is being supervised by Dr Tracey Maegusuku-Hewett and Dr Wahida Kent, School of Health and Social Care at Swansea University.

What happens if I agree to take part?

After agreeing to participate in this study, you will be asked to engage in one telephone, or virtual interview that will last approximately 30 minutes. Interviews will take place at a day and time suitable with your busy schedule. Interviews will be audio-recorded with your permission.

If you do not wish to be audio-recorded, that will not interfere with your participation; in this case the researcher will write down your responses to the questions being asked in order to refer to your answers at later stages of the study.

The interview will be semi-structured; where you will be asked open-ended questions about your role, understanding of faith and culture, institutional guidelines that take into consideration culture and religion in dealing with patients, your experiences of caring for children at end-of-life from Muslim faith and culture, and the barriers you face as a healthcare provider caring for children in a multicultural environment.

Will I receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

As this is a PhD study, with very limited resources, it will not be possible to reimburse you or provide you with any incentives or financial benefits as a result of your participation. Also, travel expenses will not be covered. However, if travel time or expenses are of a concern, your interview as a healthcare provider, can take place at your work location and at a convenient time.

What are the possible benefits of taking part?

You will not be benefiting directly; however, listening to your perspective on caring for children from diverse Muslim backgrounds will help in the further development of good practice and training programs for healthcare practitioners and support programs for children and families.

Are there any risks associated with taking part?

There are no significant physical risks associated with participation. However, it is possible that some participants may experience anxiety or emotional distress during the interview; in such cases, please inform the researcher and appropriate measures will be taken in consideration.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw at any time, without giving a reason and without penalty. However, you need to notify the researcher that you wish to withdraw from the study no later than a month after your participation, because after this period once the data is anonymised, it will not be possible to identify and remove your data.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team.

All electronic data and audio files will be transferred and deleted from the digi recorder and will be stored on a password-protected computer file that will be kept in a computer that is part of the University facility. All paper records and transcription will be stored electronically in a password-protected computer in the University as well.

Any paper documents such as consent forms will be stored within a secure locked filing cabinet within the University and only accessible by the researcher.

Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for our study will be made anonymous. You will not be identified from your answers in any way. To ensure your confidentiality and anonymity, code names or numbers will be used on all research notes and documents of the study; thus it will not be possible to identify and remove your data at a later date, should you decide to withdraw from the study. Therefore, if following your interview you decide to have your data withdrawn, please let us know within one month of this date.

Swansea University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Swansea University will keep identifiable information about you for 10 years.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

In cases where data is likely to be used for future research; information published by sponsor unit/department/organisation

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

What will happen to the information I provide?

An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be anonymous and unidentifiable.*

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by an NHS Research Ethics Committee.

Date protection officer and ICO Data Protection Privacy Notice statement

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office: dataprotection@swansea.ac.uk

Your personal data will be processed for the purposes outlined in this information sheet.

Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the departmental Research Ethics Committee.

Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

NHS/hospices and the study's sponsor (Swansea University) will collect information from you for this research study in accordance with our instructions.

NHS, hospices and Swansea University (the study's sponsor) will keep your name, NHS number and contact details confidential and will not pass this information to other *organisations.* NHS, hospices, and Swansea University *will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from sponsor organisation and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Sponsor organisation will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.*

NHS, hospices and Swansea University will keep identifiable information about you from this study for 10 years after the study has finished.

Who to complain to for Data/Management/Health issues?

Data Issues

If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the University Data Protection Officer using the contact details below.

Any requests or objections should be made in writing to the University Data Protection Officer:-

University Compliance Officer (FOI/DP)

Vice-Chancellor's Office

Swansea University

Singleton Park

Swansea

SA2 8PP

Email: dataprotection@swansea.ac.uk

Health Issues

If you have experienced health issues and would like further assistance or would like to make a complaint, you can contact your local community health council.

Health watch dog contact details

Abertawe Bro Morgannwg Community Health Council

First Floor

Cimla Hospital

Neath

SA11 3SU

Tel: 01639 683490

http://www.wales.nhs.uk/sitesplus/902/home

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

If you remain dissatisfied then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner’s Office,
Wycliffe House,
Water Lane, Wilmslow,
Cheshire, SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

Eiman Nabag

Department of Public Health, Policy and Social Sciences

College of Human and Health Sciences

Swansea University

Email:
[redacted]

Dr Tracey Maegusuku-Hewett

Department of Public Health, Policy and Social Sciences

College of Human and Health Sciences

Swansea University

Email: [redacted]

Appendix B: Participant Information Sheet for Pre-qualifying Students

TITLE OF RESEARCH: Islamic teachings and culture in making end-of-life decisions for children living with life-limiting illness

You are being invited to take part in our research that is part of a PhD study. It is entirely up to you if you would like to join the study; to help you decide whether you want to be part or not, we are providing you with the following information so you can understand why the research is being done and what it would involve for you.

Before you decide, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research?

I am conducting this research on the Socio-Cultural dimension and communication of children's palliative care; with specific attention to end-of-life care for children with life threatening illness and their families.

The purpose of the study is to explore the impact of the Islamic faith and culture's teaching on end-of-life (EOL) decisions made by parents of children with life-threatening illnesses. Additionally, looking at communication between clinicians and other support staff, and parents in paediatric palliative care within a multicultural setting; where culture/faith, and language, may create barriers for parents pursuing EOL care for their children.

Who is carrying out the research?

The data are being collected by Eiman Nabag, a PhD student at Swansea University, Department of Public Health, Policy and Social Sciences within College of Human and Health Sciences; the study is being supervised by Dr Tracey Maegusuku-Hewett and Professor Fiona Verity, Department of Public Health, Policy and Social Sciences within College of Human and Health Sciences at Swansea University.

Why have I been invited to take part in this research project?

You have been invited to take part because you are a pre-qualifying student in social work, nursing or a medical student; to explore your perceptions on caring for children from diverse cultural backgrounds and faiths. Also, to discuss the possible challenges arising because of the family's cultural and religious beliefs during times when they are required to make decisions about their child's treatment plan or end-of-life care.

What would taking part involve?

After agreeing to participate in this study, you will be asked to take part in 1 interview via Zoom or telephone which is intended to take approximately 1 hour, at your convenience.

You will be engaged in a casual discussion about the role of culture and religion in a health care setting. As well as you will be presented with a case study of a terminally ill child of Muslim faith and have a discussion about the decisions made by the mother regarding the child's care, and the various ways culture and religion impacted the decisions making process.

Your privacy and confidentiality will be ensured to allow you to express yourself freely.

The interview will be audio-recorded with your permission. If you do not wish to be audio-recorded, your responses will be manually recorded.

Will I receive any payments, repayment of expenses or any other benefits for taking part in this research?

Your participation is voluntary, you will receive a £10 voucher for your participation in the study, as a thank you for your time and effort contributed to the research.

What are the possible benefits of taking part?

You will not be benefiting directly; however, listening to your perspective on caring for children from diverse backgrounds, and particularly those of the Muslim faith, will help in the further development of good practice and training programs for healthcare practitioners and support programs for children and families.

Most likely findings from the study will benefit others with similar conditions, in the future, rather than you as a participant. However, you will be able to express your concerns and limitation in care regarding caring for terminally ill children from of Muslim faith.

What are the possible disadvantages and risks of taking part?

There are no significant physical risks associated with participation. However, some participants may find the discussions around children's end of life care, to be emotionally distressing; in such cases, please inform the researcher and appropriate measures will be taken into consideration. For example, you can take a break or withdraw at any point.

What if something goes wrong?

If anything happens that makes you uncomfortable, or you feel upset after taking part in the study please contact the researcher Eiman Nabag at [redacted] or any of the supervisors, Dr Tracey Maegusuku-Hewett at [redacted], or Professor Fiona Verity at [redacted]

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw without giving a reason and without penalty.

Will my information be kept confidential?

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team.

All electronic data and audio files will be transferred and deleted from the Digi recorder and will be stored on a password-protected computer file that will be kept in a computer that can only be accessed by the researcher. The data will be stored on the researcher's password-protected laptop due to COVID-19's restrictions that prevent the researcher from accessing a computer that is part of the University's facility. All electronic consents and transcription will be stored electronically in the researcher's password-protected computer as well.

Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for our study will be made anonymous. You will not be identified from your answers in any way. To ensure your confidentiality and anonymity, code names or numbers will be used on all research notes and documents of the study; thus it will not be possible to identify and remove your data at a later date, should you decide to withdraw from the study.

What will happen to the results of this study?

An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be anonymous and unidentifiable*.

How long will your information be held?

Data will be preserved and accessible **for a minimum of 10 years after completion of the research**. Records from studies with major health, clinical, social, environmental or heritage importance, novel intervention, or studies which are on-going or controversial should be retained for at least 20 years after completion of the study. It may be appropriate to keep such study data permanently within the university, a national collection, or as required by the funder's data policy.

Who has reviewed this study?

The research has obtained approval from an NHS Research Ethics Committee for any patients recruited via the NHS. Also, for your involvement, the study has been ethically approved by the Research Ethics Committee, College of Human and Health Sciences, Swansea University.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data and can be contacted at the Vice Chancellors Office: dataprotection@swansea.ac.uk

Your personal data will be processed for the purposes outlined in this information sheet.

Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be processing is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer:

University Compliance Officer (FOI/DP)

Vice-Chancellor's Office

Swansea University

Singleton Park

Swansea

SA2 8PP

Email: dataprotection@swansea.ac.uk

How to make a complaint:

If you are unhappy with the way in which your personal data has been processed, you may in the first instance contact the University Data Protection Officer:

University Compliance Officer (FOI/DP)
Vice-Chancellor’s Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email: dataprotection@swansea.ac.uk

If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner’s Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

Researcher:	**Supervisors:**
Eiman Nabag	Dr Tracey Maegusuku-Hewett
Department of Public Health, Policy and Social Sciences	Department of Public Health, Policy and Social Sciences
College of Human and Health Sciences	College of Human and Health Sciences
Swansea University	Swansea University

Email:
[redacted]

Email: [redacted]
[redacted]

Tel: [redacted]

Professor Fiona Verity

Department of Public Health, Policy and Social Sciences

College of Human and Health Sciences

Swansea University

Email: [redacted]

Tel: [redacted]

Appendix C: Participant Information Sheet for Parents

TITLE OF RESEARCH: Islamic teachings and culture in making end-of-life decisions for children living with a life-limiting illness

Hello, my Name is Eiman Nabag and I'm a PhD student at Swansea University. I'm exploring the influence of Islamic faith and culture on the every- day experiences and end-of-life (EOL) decisions made by parents of children diagnosed with a life-threatening illness. The study will also look at communication between parents and healthcare providers, and the possible barriers created by culture/faith, and language when discussing EOL care plans for their children. The intention is to understand and raise awareness of your experiences so that families may benefit from improved services and support in the future. For example, to enhance communication with Muslim parents, and importantly, to provide care and support specific to the need of each family with respect to their cultural and religious beliefs.

You are being invited to take part in this research study and participating is entirely up to you. Before you decide, I have provided some important information about the study. Please take time to read it carefully. If anything is unclear, or you would like more information, please do not hesitate to ask. Many thanks for your time.

Who is carrying out the research?

The data are being collected by myself, as a PhD student at the Department of Public Health, Policy and Social Sciences within the College of Human and Health Sciences. The study is being supervised by Dr Tracey Maegusuku-Hewett and Dr Wahida Kent, School of Health and Social Care at Swansea University.

Why have you been invited to take part?

You are being asked to take part in this research study because you are a Muslim parent caring for a child with a life-threatening condition or a life-limiting condition.

What will taking part involve?

Your participation in this study is made of 1 interview that is intended to take approximately 1 hour. The interview will either be through a video communication APP, like ZOOM, or a telephone interview. The time of the interview will be decided according to your preference and convenience, taking in consideration your circumstances caring for an ill child.

What happens if I agree to take part?

If you agree to take part in the study, you will be involved in one video (or phone) interview that will last approximately one hour. The time of the interview will be based on your preference and convenience. Virtual interviews will be in a private setting to ensure your privacy and comfort as you share your stories.

The interview will be audio-recorded. But, if you do not wish to be audio-recorded, that will not prevent you from participation; in this case, I will write down your responses to the questions being asked in order to refer to your answers at later stages of the study.

The interview will be a little like a conversation, in which I will help you talk about yourself; as well as your experience of caring for a child with a life-threatening or life-limiting condition; what it means to you, and what are the challenges and benefits you have experienced in your journey.

You will be asked questions about your Islamic faith and how it influences your daily life and any decision making around your child.

While you may find it helpful to talk about your experience, the interviews are not intended to be like therapy or counselling sessions. However, you will be given a sheet with contact information to services that you may find beneficial and give you more help if you want.

Will I receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

Unfortunately, it will not be possible to reimburse you or provide you with any incentives or financial benefits as a result of your participation.

What are the possible benefits of taking part?

There is no direct benefit for you as a participant taking part in the research. But the findings may benefit future children and their families in similar issues and challenges they may face. This could result in better services provided.

What are the possible disadvantages and risks of taking part?

As a participant in the study, you will not be subjected to risks of physical harm. However, due to the nature of the topic, it is possible that some participants may feel upset; in such cases, we can stop the interview, take a break or come back to it another time. You can also withdraw at any time, no problem.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw at any time, without giving a reason and without penalty. Though you would need to let me know within one month of the interview. After this point I cannot guarantee that your information will be retrieval as it will have been analysed and made anonymous.

Will taking part be confidential?

Yes. Your personal information, or your personal stories will not be shared with anyone who is not part of the research team, unless we think you may be hurt or in danger. If so, we will talk to you first about the best thing to do to protect you and your child from any harm.

Will I be anonymous?

Yes, we will hide your identity in any reports produced.

How will you look after my information?

Any audio recordings made will be typed up and made anonymous. The digital file will be deleted at this point.

Any information you provide will be securely stored within Swansea University and encrypted with a password. Swansea University is the sponsor for this study based. Under the university guidelines, we are responsible for looking after your information and using it properly. Swansea

University will securely keep identifiable information about you for 10 years after the study has finished.

What will happen with the results of the study?

Once all the interviews are completed, the information collected will be analysed to write a report at the end of the study and may be presented to interested groups such as support organisations, health and social care professionals. It may also be published for educational purposes such as in journals and related media.

Note that all information presented in any reports or publications will be anonymous and unidentifiable.

Who should you contact for further information?

If you have any question about the study, please do not hesitate to contact Eiman Nabag at [redacted] or Dr Tracey Maegusuku-Hewett at [redacted]

Who has reviewed this study?

The research has obtained approval from an NHS Research Ethics Committee for any patients recruited via the NHS. Also, for your involvement, the study has been ethically approved by the Research Ethics Committee, College of Human and Health Sciences, Swansea University.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data and can be contacted at the Vice Chancellors Office: dataprotection@swansea.ac.uk

Your personal data will be processed for the purposes outlined in this information sheet.

Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be processing is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer:

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email: dataprotection@swansea.ac.uk

How to make a complaint:
If you are unhappy with the way in which your personal data has been processed, you may in the first instance contact the University Data Protection Officer:

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email: dataprotection@swansea.ac.uk

If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner's Office,

Wycliffe House,

Water Lane,

Wilmslow,

Cheshire,

SK9 5AF

www.ico.org.uk

What if I have other questions?
If you have further questions about this study, please do not hesitate to contact us:

Researcher:	**Supervisor:**
Eiman Nabag Department of Public Health, Policy and Social Sciences College of Human and Health Sciences Swansea University Email: [redacted]	Dr Tracey Maegusuku-Hewett Department of Public Health, Policy and Social Sciences College of Human and Health Sciences Swansea University Email: [redacted]

Appendix D: Participant Consent Form for Pre-qualifying Students

Project title: Islamic teachings and culture in making end-of-life decisions for children living with a life-limiting illness
Principal researcher Eiman Nabag: [redacted]
Supervisor: Dr Tracey Maegusuku-Hewett [redacted]

		Participant's initial
1.	I (the participant) confirm that I have read and understand the information sheet for the above study (dated) which is attached to this form.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons.	
3.	I understand that in case I decide to withdraw from the study my medical care will not be affected in any way.	
4.	I understand what my role will be in this research, and all my questions have been answered to my satisfaction.	
5.	I understand that I am free to ask any questions at any time before and during the study.	
6.	I have been informed that the information I provide will be safeguarded.	
7.	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs.	
8.	I am willing for my information to be audio recorded.	
9.	I have been provided with a copy of the Participant Information Sheet.	
10.	I agree to the researchers processing my personal data in accordance with the aims of the study described in the Participant Information Sheet.	

Thank you for your participation in this study. Your help is greatly appreciated.

Print name of participant	Signature	Date
Print name of parent/guardian	Signature	Date
Print name of researcher	Signature	Date

This study is being conducted by Swansea University, College of Human and Health Science.

When complete: Original copy will be kept by the researcher, and one copy to be given to participant

Appendix E: Participant Informed Consent for Parents

Project title: Islamic teachings and culture in making end-of-life decisions for children living with a life-limiting illness
Principal researcher Eiman Nabag: [redacted]
Supervisor: Dr Tracey Maegusuku-Hewett [redacted]

	Participant's initial
I confirm that I have read the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
I understand what my role will be in this research, and all my questions have been answered to my satisfaction.	
I understand that I am free to ask any questions at any time before and during the study.	
I have been informed that the information I provide will be safeguarded.	
I understand that the information I provide will to be used (anonymously) in academic papers and other formal research outputs.	
I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.	
I am willing for my information to be audio recorded.	
I have been provided with a copy of the Participant Information Sheet.	
I agree to the researchers processing my personal data in accordance with the aims of the study described in the Participant Information Sheet.	

Thank you for your participation in this study. Your help is very much appreciated.

Print name of participant Signature Date

Print name of researcher Signature Date

This study is being conducted by Swansea University, College of Human and Health Science.

When complete: Original copy will be kept by the researcher, and one copy to be given to participant

Appendix F: Participant Consent Form for Healthcare Professionals

Project title: Role of Islamic culture and faith in end-of-life (EOL) decision making for children, parents and healthcare providers in paediatric palliative care (PPC)

Principal researcher Eiman Nabag: [redacted]
Supervisor: Dr Tracey Maegusuku-Hewett [redacted].

		Participant initial
1.	I (the participant) confirm that I have read and understand the information sheet for the above study (dated) which is attached to this form.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons.	
3.	I understand what my role will be in this research, and all my questions have been answered to my satisfaction.	
4.	I understand that I am free to ask any questions at any time before and during the study.	
5.	I have been informed that the information I provide will be safeguarded.	
6.	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs.	
7.	I am willing for my information to be audio recorded.	
8.	I have been provided with a copy of the Participant Information Sheet.	
9.	I agree to the researchers processing my personal data in accordance with the aims of the study described in the Participant Information Sheet.	

Thank you for your participation in this study. Your help is very much appreciated.

Print name of participant Signature Date

Print name of researcher Signature Date

This study is being conducted by Swansea University, College of Human and Health Science.

When complete: Original copy for patient, one copy to be retained by researcher.

Appendix G: Interview questions for healthcare professionals

1. *Does the culture or the religion play a part in them making decisions or talking about the illness in general?*
2. *How do you deal with issues like that (pertaining to culture and religion)*
3. *what are the existing mechanisms or the training, or policies that are incorporated to… that incorporates faith and culture when you're… when you're dealing with… with parents of different backgrounds?*
4. *What are the changes that you feel needed? If there's any when you're faced with such challenges when… when talking to Muslim parents, and culture and religion can be clash or conflict with medical decisions? And what changes do you feel like, for you as a clinician, you would like to do or trainings that you need to deal with situations like that?*
5. *(for you as a clinician what changes you feel are needed, if there are any, when you're facing some challenges caring for children with different cultures?)*
6. *do you think are there any specific things that you would like to have in that in the trainings?*
7. *can being culturally insensitive create a barrier when communicating with parents?*
8. *what are the barriers you face when you talk to parents from different… different cultures or Muslim parents? If there are any.*
9. *And your role as a provider, how does it impact…for example, if a parent is not accepting the medical decision, how do you deal with it?*
10. *Does religion or culture play a big role in their reluctance?*
11. *to what extent do you think sensitivity to culture is important when you're caring for children and especially at end-of-life?*
12. *do parents continue seeking your support even after the child dies?*
13. *from your perspective how can culturally sensitive care be improved if it needs an improvement?*
14. *What are the existing trainings or policies that help support that?*
15. *what are the changes that you feel needed to make practitioners ready when dealing with certain barriers and challenges?*

16. *Do you feel like families from the Muslim faith, they're different in dealing with religious matters?*

17. *Does the culture or the religion play a part in them making decisions or talking about the illness in general?*
18. *How do you deal with issues like that (pertaining to culture and religion)*

19. *what are the existing mechanisms or the training, or policies that are incorporated to… that incorporates faith and culture when you're… when you're dealing with… with parents of different backgrounds?*

20. *What are the changes that you feel needed? If there's any when you're faced with such challenges when… when talking to Muslim parents, and culture and religion can be clash or conflict with medical decisions? And what changes do you feel like, for you as a clinician, you would like to do or trainings that you need to deal with situations like that?*

21. *(for you as a clinician what changes you feel are needed, if there are any, when you're facing some challenges caring for children with different cultures?)*

22. *do you think are there any specific things that you would like to have in that in the trainings?*

23. *can being culturally insensitive create a barrier when communicating with parents?*

24. *what are the barriers you face when you talk to parents from different… different cultures or Muslim parents? If there are any.*

25. *And your role as a provider, how does it impact…for example, if a parent is not accepting the medical decision, how do you deal with it?*

26. *Does religion or culture play a big role in their reluctance?*

27. *to what extent do you think sensitivity to culture is important when you're caring for children and especially at end-of-life?*

28. *do parents continue seeking your support even after the child dies?*

29. *from your perspective how can culturally sensitive care be improved if it needs an improvement?*

30. *What are the existing trainings or policies that help support that?*

31. *what are the changes that you feel needed to make practitioners ready when dealing with certain barriers and challenges?*

32. *Do you feel like families from the Muslim faith, they're different in dealing with religious matters?*

Appendix H: Interview Questions for Pre-qualifying students

Introduction to the study and process of the interview.

Hi. Thank you for taking the time to take part in the study. Your time is appreciated.

I am Eiman, and I am conducting this PhD study to explore the perspective of health care professionals and pre-qualifying students on the impact of religion and culture on decision making for parents of children diagnosed with life-threatening conditions. The interview will entail two parts. First part will consist of questions about cultural sensitivity. The second part will consist of a partially fictional case study (the names are changed for anonymity purposes), that was created using data I collected from interviewing a parent, and part of the case is fictional and is related to the literature on children end-of-life care and children palliative care policies.

Part A:

1. The concept of 'cultural sensitivity' is used in health and social care practice. How do you understand cultural sensitivity?
2. What do you think you require to develop cultural sensitivity?
3. From your perspective what supports 'cultural sensitivity' in health and social care?
4. From your perspective what are challenges in supporting 'cultural sensitivity' in health and social care?
5. Can you please tell me about your discipline and how your studies to date prepare you for working in a culturally diverse society?

Part B:

For this part of the interview, I will give you a case scenario that is fictional but partially based on interview data from my study. However, I have changed the names of the people involved for purposes of confidentiality and anonymity. The case also includes evidence from the literature, policy and practice guidance. The context of the case study is as follows:

Fateema is an 11-year-old child, of a Muslim family, who came from Pakistan and settled here in the UK. Her mother did not grow up in a religious household, but her dad did. At the age of 4 or 5, she was diagnosed with a rare case of Batten disease, which is a neurodevelopmental disorder, and the most common cause of childhood dementia. Children with Batten disease have short life-expectancy. Fateema was given a 12-year life expectancy, and her family was forced to make difficult decisions.

- If you had to care for Fateema, what kind of challenges do you think you might face?
- What do you feel you would need to know in order to help you do that sensitively?
- How would you go about building rapport with the family?

The case continues:

As the illness progressed, the mother gave full authority to the medical team to turn off equipment, since she is fully aware of her child's suffering and she thought it is the best way to end her suffering. But the father opposed the decision and said they can't turn off the machine. As the mother stated in the interview: "But dad, when came on the scene, he had this question, he had these questions that, what would I say to the Imam? that I turned off the machine, myself, so I had actually no hope in God? I have taken the life of my own child. And so, he had those hard questions"

- What do you think of this dilemma?
- If you have to provide care at end of life for Fateema, what do you feel you would need to know?
- What challenges do you think you may face in this case scenario? What could you do to overcome them?
- What might be some of your anxieties when dealing or engaging with families giving their circumstances, and cultural or religious backgrounds?

At a time of Fateema's illness, her mother discussed with the siblings their sister's health condition and the changes that are happening. She had conversations about Fateema's imminent death, and her place in the cemetery. The mother was judged by members of the Muslim community and even Muslim leaders for her decisions. She was accused of making irrational decisions, and not accepting God's decree.

- From your perspectives, what impact would the community's perceptions be on the mother?

In this case the child is non-verbal and unable to communicate but has the ability to feel emotions.

- How would the conflict between the parents impact the child?
- If the child was verbal and able to communicate, to what extent do you feel the child has the right to know about their condition?
- What might be some of the challenges of caring for the child and including them in decision making processes.

The case continues

Since Fateema is at end-of-life, her mom was preparing for the death. Planning for the burial was not an easy task, because Fateema would be the first Muslim child to be buried in the cemetery where they live. Fateema's mother got a permission to bury Fateema in the cemetery, but they must be on a separate section because she will be facing a different direction. Fateema's mother had to fight for her daughter's right for the burials and faced many criticisms from Muslim leaders in her community. She was blamed for planning ahead; she was accused of not having enough knowledge about the religion to ask for someone to perform the prayers upon her child's death.

* *The following questions will be asked to participants, but in case they are not able to answer, the researcher will give the answer and then start a discussion about it**

- What are the Islamic rituals that must be followed when a Muslim person dies?
- What are some of the bereavement services that can support Fateema's mother and siblings after her death?
- What are the ways to promote the engagement of Muslim communities, or other faith groups health care providers to understand the need of the patients from these faith communities?

Thank you for your time and engagement in this interview.

The result of this study will be presented at seminars and conferences; as well as articles written in relevant publication.

All the information you have provided will be confidential and anonymous. By that I mean, no one will know your identity and what you have shared with me because you will be given a number and will not be known by name throughout the research and at any point where findings are shared.

If you decide that you want to withdraw, there is no problem at all. Just send me an email with your wish to withdraw, no later than 3 weeks from today, and you will be removed from the study. This will enable me to retrieve any data you provide and destroy it, as it will be difficult to remove your information afterwards because all the information will be anonymous.

If you have any questions regarding this study, please feel free to ask me at any time. Otherwise, if you wish to make a complaint about anything that you didn't like or find acceptable about me as the researcher you can raise this at any point by contacting my supervisors Dr Tracey Maegusuku-Hewett and Professor Fiona Verity.

I will email you a debrief sheet with all the contact information and email addresses.

Thank you again for participating.

Appendix I: Interview topic guide with parents

Hi, my name is Eiman. Thank you for agreeing to take part in the study and do this interview.

As you may recall this study is about the impact of culture and religion in palliative care and the decision-making process you go through as you decide on certain aspects of your child's care and treatment.

This will be an informal chat about your experience caring for your child; feel free to stop me at any time if you feel distressed or uncomfortable.

Let's start by you describing a day in your life caring for your child. *

- *If participants have difficulty describing their experience, I will start by asking questions that will encourage and help participants to start. Questions such as:
- How did you feel when you first found out about your child's diagnosis?
- How has that changed today?
- What motivates you at times when you are overwhelmed?
- How do you cope on days that are more challenging than others?
- Do you feel supported by the community?
- What kind of support do you have? Is there anything else you feel is needed?
- How have you found the care and support from health and social care professionals? To what extent do you feel they have been inclusive/ knowledgeable about your cultural religious practices? What advice could you offer to another parent just beginning to go through this experience?
- do you have anything else to add?

Appendix J: List of study participant

Healthcare Professionals					
	Name	**Role**	**Hospice/NHS**	**Location**	**Type of interview**
1	Tamara	Clinical Nurse	Children's Hospice	England	Microsoft Teams
2	Ebon	Nurse	NHS	England	Telephone
3	Nasima	Nurse	NHS	England	Telephone
4	Sharon	Clinical Nurse Specialist Paediatric Palliative Care	NHS	Wales	Microsoft Teams
5	Natalie	Clinical Nurse Specialist	Children's Hospice	England	Microsoft Teams
6	Lynda	Paediatric Palliative Care Consultant	Children's Hospice	England	Microsoft Teams
7	Ross	Consultant in Paediatric Palliative Medicine	Children's Hospice	England	Telephone
8	Catherine	Clinical Nurse Specialist	Children's Hospice	England	Microsoft Teams
9	Denise	Nurse	Children's Hospice	England	Microsoft Teams
10	Alison	Nurse	Children's Hospice	England	Microsoft Teams
11	Catherine	Children's palliative care Nurse Specialist	NHS	England	Telephone
12	Catriona	Consultant Paediatrician	NHS	England	Telephone
13	Abbie	Senior Community Paediatric Palliative Care Nurse	NHS	England	Telephone
Social Work students					
	Name	**Year**		**Location**	
1	Emily	MSc	University	Wales	Telephone
2	Ginnie	Year 2	University	Wales	Telephone
3	Rhian	Year 1	University	Wales	Telephone
	Total number of participants (Healthcare professionals and social work students) is 16				
Parents					
	Name	**Relationship to child**	**Child**	**Location**	**Type of interview**
1	Faiza	Mother	11-Year-old daughter (Batten Disease)	England	Face-to-face (Participant's home)