The experiences of children diagnosed with a life-threatening or life-limiting illness

Estera Ciobanu (BS. MSW.)

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

August 2019

Faculty of Health and Medicine

Lancaster University

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

Thesis abstract

Title: The experiences of children diagnosed with a life-threatening or life-limiting illness

Background: Exploring children's experiences when diagnosed with a life-threatening or life-limiting diagnosis is essential in offering appropriate care for them. Although a number of studies have been conducted to explore the experiences of children diagnosed with serious illnesses, there are limited studies which explored the experiences of both children and parents who were from the same cohort in a palliative care setting. The study was conducted in Romania, which is situated in the Southeaster Europe, where paediatric palliative care is in its infancy.

Aim: To advance the understanding of the experiences of children diagnosed with life-threatening or life-limiting conditions through both their first-hand accounts and those of their parents in a palliative care setting.

Method: A qualitative study was conducted with ten children diagnosed with life-threatening or life-limiting illnesses using in-depth interviews. Interviews were also held with the parents who were the main carer for the child to give an additional perspective of the experiences of their children regarding their illness. The interview data were analysed using thematic analysis.

Findings: The data produced six major themes: awareness of the illness, death and dying, the spiritual response to illness, the emotional response to illness, striving for normality and independence and coping strategies. There is a gap in the child's experience and understanding compared to what their parents believe they know. Awareness contexts and developmental theory were used as frameworks to discuss the experiences of children diagnosed with a life-threatening or life-limiting illness from both their perspective and that of their parents. Results suggest that awareness contexts are not fixed and children can at times move back and forth from one context to another. Results also indicate that children are able to understand and describe their experiences related to their illness depending on their developmental stage as well as personal experiences.

Conclusion: This study makes a unique contribution to knowledge as it is the first study to present the perspectives of both parents and children diagnosed with life-threatening and life-limiting conditions in receipt of palliative care.

Acknowledgements

I am very grateful for certain individuals who assisted me throughout writing this project. Firstly, I would like to thank my main supervisor, Dr Anne Grinyer for the continuous support for my PhD studies, for her immense knowledge, advice and patience. I enormously appreciate all her contributions in writing my thesis. My gratitude also goes to my supervisor Professor Nancy Preston, who has been such a great source of motivation and encouragement for me. Her knowledge and guidance helped me enormously throughout writing the thesis. I have learned so much from both of them and I could have not imagined having better supervisors for my PhD. They have met all my expectations! I am also grateful to Dr Mark Limmer for his useful final suggestions when completing my thesis. I should also like to thank to the team who run the PhD in Palliative Care at Lancaster University.

My special thanks go to the children and their parents who were open to sharing their most profound thoughts, concerns about the experiences with the illness with me! Thank you!

I am grateful and I would like to express my gratitude to Gordon Lyon as well as to Susan Joy Strohschein for the great support they have offered me, for their encouragement and advice when writing my thesis.

I want to express my appreciation to the palliative care team that I work with, for their encouragement and support throughout my studies.

I would also like to thank my friends and family, especially to my brother Aurelian and his wife, for their love, prayers, encouragement, continued patience and the support I had from them in many ways.

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Chapter 1. Introduction

1.1 Aim of the research

The study aims to contribute to the understanding of the experiences of children and young people diagnosed with life-threatening and life-limiting illness through both their first-hand accounts and those of their parents receiving palliative care.

1.2 Defining terms

1.2.1 Children

For the purpose of this study children and young people were defined as being between 10 and 17 years old. This is consistent with the terms used most commonly in Romania where the word ‘children’ was used by my participants. There can be a variation in the terminology used to define children (WHO, 2013). The Association of Children’s Palliative Care (2009) defines ‘children’ as those who have not yet reached their 19th birthday. Children from 10 to 17 years of age were included in the research on the basis of the degree of homogeneity of their age.

1.2.2 Life-threatening and life-limiting illnesses in children

Childhood illnesses are multiple and cover a broad spectrum of diseases. Some are genetic which means that several members of the family can be affected. However, life-threatening and life-limiting illnesses in children are rare. The evolution of these diseases is difficult to anticipate because of the unpredictable issues related to the illness; therefore the duration of care is variable (EAPC Taskforce for Palliative Care in Children, 2009).

The Association of Children with Life-threatening to Terminal Conditions and their Families (2009) described life-threatening and life-limiting conditions in four main groups. A categorisation of life-threatening and life-limiting illness in children is not easy, and the examples used below are not exhaustive.

- Conditions that are threatening to life because curative treatment might not be successful in every case, e.g. irreversible organ failure and cancer;

- Conditions where treatment may extend life expectancy, but for which no known cure exists, e.g. muscular dystrophy and cystic fibrosis;
- Conditions which are progressive and for which there are no cure options and treatment is palliative, e.g. mucopolysaccharidosis and Batten disease;
- Conditions which involve severe neurological disabilities and deterioration may be rapid and unpredictable, e.g. cerebral palsy or brain damage (ACT Staff et al., 2009, p. 9).

1.2.2.1 Life-threatening illnesses in children

Life-threatening illness is one where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood such as with cancer (ACT Staff et al., 2009). Life-threatening illnesses continually and actively threaten children's lives. There may be effective treatment for these illnesses, but cure is not guaranteed. Children who followed successful curative treatment or who are in a long-term remission are not included in this category.

1.2.2.2 Life-limiting illnesses in children

Life-limiting conditions are defined by the Standards of Paediatric Palliative Care in Europe (2007) as conditions where ‘premature death is usual’ and where there is no reasonable expectation of a cure. Some conditions, for example Duchenne Muscular Dystrophy, can cause progressive deterioration, making the child increasingly dependent on their parents (ACT Staff et al., 2009).

1.3 Justification of the research

Being diagnosed with a life-threatening or life-limiting illness has an all-encompassing profound impact on a child’s life and presents many challenges for them. Kane et al. (2000) explain that serious illnesses affect all aspects of children’s lives, such as their sense of well-being, independence, daily activities, as well as their relationships. Adults are frequently unwilling to share with children information related to their illness or prognosis because they want to protect them (Bearison, 1991). However, children are able to read subtle cues or they may talk with other children to learn about their illness when information is not openly available to them (Bearison, 1991). Therefore, it is important to better understand how children process this information as well as how lines of communication can be improved between parents, children and healthcare professionals.

Listening to children's thoughts and feelings may contribute to the improvement of the services offered to children diagnosed with life-threatening and life-limiting conditions (Carney et al., 2003). One of the priorities in paediatric palliative care research, as James Lind Alliance (January 2018) recommended, is to find ways to emotionally support children diagnosed with life-threatening illnesses. This study makes a major contribution to research as it brings together the perspective of children diagnosed with life-threatening and life-limiting illnesses as well as the perspective of their parents in order to allow a comparison and to understand the children's perspective in the family context and in a palliative care setting.

1.4 The motivation for performing research

The impetus of exploring the experiences of children diagnosed with life-threatening and life-limiting illnesses was born out of the desire to learn more about what children go through, how much they know about the severity of their illness and how they can be better supported. In my practice as a paediatric social worker I have talked with children diagnosed with life-threatening or life-limiting illnesses about their illness and sometimes their impending death. In many instances, their medical professionals and parents were not aware of the children's understanding of the situation. These children had adjusted their conversation and behaviour to meet the expectations of their attending adults. My study can help both parents and healthcare professionals involved in the care of the children who receive palliative care understand these issues and address them.

1.5 Overview of the thesis

This thesis consists of seven chapters. This chapter covers the aim of the study, the terminology and the motivation for performing research. In Chapter 2 the background and context are discussed as well as providing a context for paediatric palliative care and developing the theoretical underpinnings of the research. Because the study was conducted in Romania, a brief description is included of Romanian palliative care services for children diagnosed with life-threatening or life-limiting illnesses. Chapter 3 presents a literature review of what is already known. Chapter 4 explains the underlying research philosophy of the thesis and discusses the methodology and methods used in this research and the ethical concerns related to researching children of this age. Chapter 5 provides an analysis of the findings obtained from the interviews with both children and their parents. Chapter 6 discusses the implications of the research, how they contribute to knowledge and the findings are discussed in relation to awareness contexts and developmental theory. Chapter 7 summarises the main findings of the thesis, discussing the limitations and strengths of this research, the implications for practice as well as recommendations for future research.

Chapter 2. Background and Context

2.1 Paediatric palliative care

Paediatric palliative and hospice care was developed in the 1970s and the first hospice facility for children was opened in 1982 in Oxford, England (Goldman et al., 2006) (See Appendix 1 for differences between palliative and hospice care). Paediatric palliative care was defined by the World Health Organization and adopted by IMPaCCT (2007) as follows:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family;
- It begins when an 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 (IMPaCCT, 2007, p. 2).

Although paediatric palliative care shares common goals with adult palliative care, there are many distinctions between them. Children who need palliative care services have a diverse range of illnesses. Some of these illnesses are rare and sometimes undiagnosed. Moreover, children's illnesses have unpredictable trajectories (Mellor et al., 2012). The organisation Together for Short Lives (2018) explains that another difference is that in childhood there is a continuing physiological, emotional and cognitive development and that paediatric palliative care professionals need to be aware of and responsive to each child's ability to understand their illness, treatments and prognosis as well as how children change their level of communication.

The International Children's Palliative Care Network (ICPCN) estimates that twenty million children could benefit from palliative care services worldwide, but not all children have access to these services. In the UK, where the population is over 65 million people, about 23,500 children require palliative or hospice care services annually (Gethins, 2012). In Europe a survey of 43 European countries, found 14 did not have any paediatric palliative care, and 24 had only some services. Only five countries (U.K., Germany, Italy, Belgium, Poland) had the highest level of palliative care provision (Gethins, 2012, Knapp et al., 2011). Knapp et al. (2011) explain that the countries with the highest level of services in paediatric palliative care experience integration with mainstream service providers that include multiple service types, impact of policy of palliative care, provide a high level of training and a national association.

2.2 Paediatric palliative care in Romania

Paediatric palliative care services were introduced in Romania in 1992 (Humphries, 2005), but they were only officially regulated in 2018 (Predoiu and Dumitrescu, 2018). With a population of over 19 million people, Romania has around 550 children diagnosed with cancer every year (Statistici Cancer, 2016). In Romania there are only four paediatric in-patient palliative care units, seven paediatric palliative home care services and five hospitals which have a paediatric palliative care ward (Predoiu and Dumitrescu, 2018). Some of the paediatric palliative care services are combined with adult services when there is an incomplete paediatric palliative care team. There are also limited statistics in Romania for children diagnosed with life-limiting illnesses, though statistics show that cancer is the second leading cause of death for children aged between 4 and 15 years. According to current estimates, over 5,000 children suffer from life-threatening diseases in Romania, but unfortunately fewer than 10% of them receive palliative care (Paliatia, 2016). Paediatric palliative care services have different sources of funding including donations, sponsorships and coverage by the National Insurance House (ANIP, 2014). The Healthcare System in Romania is mainly funded through state and local budgets. It also has private or charity funding sources which helps it to function (Parlamentul Romaniei, 2006).

The development of palliative care services is in its infancy in Romania which makes research difficult. As a result, there are no studies which explore experiences of children diagnosed with life-threatening and life-limiting illnesses in Romania. My study will have a significant contribution in the field of paediatric palliative care in Romania but findings are relevant to other countries.

2.3. Theoretical framework

A theory forms a conceptual basis for understanding and analysing data (Ravitch, 2017). Theories help to explain phenomena, moving beyond basic description to interpretation and explanation (Kelly, 2010). The theories of awareness contexts and children's development are used to guide and inform my research, to offer a framework for the analysis, as well as to generalise from the findings.

2.3.1 Awareness contexts

The theory of awareness contexts was developed in the 1960s by Glaser and Strauss (1965) to explain the interactions between dying patients, their relatives and medical personnel. Their study was conducted in six hospitals in San Francisco where they talked with dying patients, interviewed medical staff and observed nurses and physicians at work. Glaser and Strauss (1965) identified four types of awareness contexts:

- *closed awareness*, where the patients do not know their real condition while their family and medical personnel know it;
- *suspected awareness*, where the patient suspects the truth and tries to confirm it;
- *mutual pretence*, when both parties know the truth but act as if they don't;
- and *open awareness*, where there is a relatively open communication between the patient and the family or medical personnel.

Glaser and Strauss (1965) study shows that the awareness contexts have a significant impact on patients' interactions with their families and medical staff (Tom and Alvita, 2015). Bluebond-Langner (1978) used Glaser and Strauss' (1965) level of awareness to analyse the behaviour of dying children, their families and medical staff. Bluebond-Langner and Nordquest-Schwallie (2008) explain that children function in these four different awareness contexts, depending on how much they know about their illness and prognosis and how their parents and healthcare professionals relate to them. Children intuitively adjust to the way their parents talk about their illness and death, matching the carer's level of disclosure (Bluebond-Langner, 1978). Moreover, children become aware that they are dying even if they have not been told by their parents or healthcare professionals. She explains that children have different ways of acquiring information: from their experiences of the illness and the treatment as well as the knowledge the child receives of the illness and prognosis from family or healthcare professionals. Bluebond-Langner and Nordquest-Schwallie (2008) show that children know more than the adults think they do and these children manage their awareness by functioning in one of the four awareness contexts.

While investigating children's awareness of fatal illnesses, Waechter (1971) found that adults who frequently deny and try to protect their children from knowledge of their condition, do not actually guarantee that children will be prevented from experiencing anxiety. Adult silence, while aimed at protecting terminally ill children from their condition, results in children not expressing openly their awareness and fears about their disease. When giving them the opportunity to express they will communicate their knowledge and fears about their diagnosis and prognosis and they do not feel alone in their illness (Waechter, 1971).

The open awareness context has been divided by Timmermans (1994) into additional sub-contexts. The first one is the suspended awareness context where the patient and family ignore the bad news received from the doctor. The second is the context of uncertain open awareness, where the patient or the family members do not accept the bad news regarding the illness, instead believing that they will get better. The third is the active open awareness context, where both the patient and the family accept the bad news and live by what they know about the illness. However, Glaser and Strauss (1965) believed that open awareness happens only when the patient and their family or medical staff acknowledge prognosis in their actions. They explain that open awareness does not happen when one of the parties refuses to acknowledge the disclosure while the other party agrees with it.

The awareness context theory offers a valuable foundation upon which to study the experiences of children diagnosed with life-threatening and life-limiting conditions, providing the theoretical lens through which we can understand what children know about their condition, as well as parents' status in the context of their shared interaction (Lindesmith et al., 1999). The theory also contributes to understanding potential problems that could emerge because of functioning in a certain awareness context. The awareness contexts help us to understand the patterns of interactions among children, parents, and healthcare professionals and how these interactions are affected because of what they know about the illness and prognosis.

2.3.2. Developmental issues

2.3.2.1 Children's development theory

The classic work of Perrin and Gerrity (1984) report that Piaget and Erickson offer the best description of the expected developmental tasks of children according to their age group. The understanding of adolescent development started with Piaget's (1954, 1969) classic work, alongside Erikson's (1950) theory, which provide a model of *what* and *how* children think and feel. The development for healthy children between 14 and 17 years of age is briefly summarised below through both theories. However, these theories only act as a starting point since there has continued to be research. A discussion will follow of the variations in development expected for children diagnosed with life-threatening or life-limiting illnesses.

Erikson's (1950) theory of psychosocial development has five stages up to the age of 18 years. My study deals with the fifth stage, my subjects' age group. Erikson (1950) named this stage Identity vs. Confusion. Erikson shows that central to children at this stage is the successful attainment of identity (Perrin and Gerrity, 1984). During this stage, children look for personal identity and a sense of self (Kroger, 2007). For them, it is also extremely important to form a peer group. This group is part of a child's shift to independence from their parents. Thus, a natural divide is created between parents and children (Abrams et al., 2007).

Whereas Erikson's theory focused on individuals' social and psychological development and their adaption to society, Piaget primarily studied children's cognitive development (Abrams et al., 2007). Piaget described four stages of cognitive development through observing children: *Sensorimotor* (0-2 years old); *Preoperational* (2-7 years old); *Concrete operational* (7-11 years old) and *Formal operational* (11 to adulthood) (Feldman, 2004, Piaget, 1954). What follows, refers to children from eleven years of age to adulthood. For Piaget (1972), children at this age develop a greater level of cognitive complexity.

Piaget's (1954, 1969) theory shows that children are capable of abstract and conceptual thinking as well as deductive reasoning. They face internal cognitive and psychological changes and they also have to deal with the external pressures of school, peer relationships and dating (Perrin and Gerrity, 1984). This age range has significant physical and emotional changes (Grinyer, 2002) and for these young people autonomy, independence and sexuality are of increasing importance (Grinyer, 2007). Body image is another major issue for this age group. Appearance represents one of the factors which contributes to self-image which is so important at this age (Abrams et al., 2007).

The theories of Piaget (1954) and Erikson (1950) are greatly respected and have had a significant influence in many areas of research. Their influence is found in paediatric palliative care studies, such as in Darcy et al. (2016) and Stillion and Papadatou (2002). However, society changes over time and people change with it, which means that the theories might not always be applicable. Context was central in Erikson’s development model (Kroger, 2007) because identity is formed as a result of how an individual responds to the opportunities and the environment of the cultural society in which the person lives (Jensen, 2011). There is an argument that the pluralistic diversity of modern society contributes to a loss of core values. Before the postmodern era, what was seen as objective fact by society is now seen as personal choice (Baumeister and Muraven, 1996, Jensen, 2011). This loss of core values places a great burden on children at this life stage who must find ways to make their life meaningful alongside those of others (Baumeister and Muraven, 1996, Jensen, 2011, Kroger, 2007). Influences from media play a significant role in the importance of finding themselves (Baumeister and Muraven, 1996, Jensen, 2011). This is no different for Romanian children who spend about seven hours of screen time every day, whether they are watching television, on the internet or playing video games. This has a significant impact on their development, behaviour and attitudes (Abraham et al., 2013). Crone and Konijn (2018) explain how media use can impact children in terms of brain development and related behaviour.

Another question that needs to be asked about Piaget (1954) and Erikson’s (1950) theories is whether they took the competence of the children into account. In UK competence has been addressed through the ‘Fraser Guidelines’ which is a term used to decide whether children under the age of 16 are able to consent to medical treatment without parental permission (Griffith, 2015). According to Fraser Guidelines, also known as ‘Gillick competence’, a child’s competency is demonstrated through their cognitive ability and experience. This experience may be enhanced by education or life experience (Larcher and Hutchinson, 2010). The Gillick ruling in UK defines a child as competent who ‘achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed’, and who has ‘sufficient discretion to enable him or her to make a wise choice in his or her own interest’ (Gillick, 1985, 3 All ER 423).

Slavin (2006) challenged Piaget's (1954) theory through research which investigated children's development (Siegler and Chen, 1998) and came to the conclusion that children are more competent than Piaget originally thought. Slavin (2006) also argues that Piaget (1954) and Erikson's (1950) theories rely on fixed and sequential stages. Analysing different studies such as Gelman (2000) and Overton's (1998) studies, Slavin (2006) came to the conclusion that children growing up in different environments can have different levels of development and their experiences influence their development.

Abrams et al. (2007) showed that although developmental theory sets the foundation for the issues that might arise for this age group, it does not take into account the challenges that might arise when a child is diagnosed with a life-threatening or life-limiting illness. Erikson's (1950) work was based on healthy children and his theories were sequential (Slavin, 2006). However, children diagnosed with a life-threatening illness or life-limiting illness, could have a different trajectory. These issues are discussed below.

Children's understanding of illness increases with age and is influenced by their level of cognitive development (Burbach and Peterson, 1986). Children's understanding of illness and death is also influenced by their experience with disease and if they have experienced the death of their peers, friends or adults (Kane et al., 2000). The contemporary advances in developmental psychology have led to the idea that the child is an expert on his or her life (Kiernan et al., 2005) and what matters to children may differ from what is seen as important by adults. Children are now seen as reliable witnesses about their lives (Clark and Statham, 2005). Kiernan et al. (2005) conducted a study with children whose mean age was 12 years. They explain that children can reliably share their thoughts about a wide range of topics.

2.3.2.2 Children's developmental considerations related to research

Kirk (2007) explains that data obtained from children was thought to be invalid before 1989 (Nairn and Clarke, 2012, Skelton, 2008) because children were considered too immature to understand their worlds. Deatrick (1990) shows that developmental perspectives of Piaget and

Erikson contributed to the view that children are unable to describe and understand their world and life-experiences because of developmental immaturity. Therefore, children were not involved in early research because of the assumptions about children’s inability to understand their illnesses. Piaget and Erikson had major contributions in developing their theories about children’s development (Slavin, 2006). Burbach and Peterson (1986) explain that it was assumed that children are not capable of understanding their illness in the same way that adults do and that children adhere to a logic which is different from that of adults.

In the UK, The *Children Act* (1989) represents the culmination of a shift from children being the passive subjects of parental rights to becoming legal subjects in their own right. This Act establishes that it is important to listen to children’s views and to consider their perspective regarding their illness and not only that of their parents. Also, *The Welfare of Children and Young People in Hospital* Report (Riessman, 1993) emphasised that children’s participation in research be recognised as important as well as that of their parents. Furthermore, The *Children Act* (1995) from Scotland advocated that when it comes to taking a decision that concerns children, their perspective must be taken into consideration (Carney et al. 2003). In Romania, The Law of Protection and Promotion of the Right of the Children (2004) gives children the right to freely express their views on any issues that concern them while adults should consider children's views, taking into account their age and maturity. Moreover, The United Nations of Human Rights Council adopted the Convention on the Rights of the Child (1989) which states that children who are capable of forming their views have the right to express them freely.

Another reason children were not included in earlier research was the ethical concerns regarding their vulnerability to be exploited by researchers (Kirk, 2007). Thus, there was a reluctance to research children based on adults wishes to protect children’s emotional well-being (Sartain et al., 2000). Singh (2007) explain that this reluctance to research children dates back to developmental psychology (Piaget, 1977).

Based on personal reflections on her own childhood and looking at childhood experiences of her college students, Waksler (1986, 2012) acknowledged this reluctance to research children in their social context. She challenged the belief that children were too incompetent and immature to participate in research. She also questioned the adult assumption that they understood the perspective of children regarding their illness. In contrast to previous assumptions, Waksler (1986) showed in her work that children are competent and their views should be studied.

Bluebond Langner's (1978) key study also challenged the theories that resulted in not taking children's viewpoints seriously. She conducted the first detailed study of the experiences of children diagnosed with cancer by observing and discussing their illness with these children. *The Private World of Dying Children* offered a different interpretation of children's capacity to understand their situation. Bluebond-Langner showed that children can develop theories about their sickness. She argued that children are aware of their treatment and its consequences even if adults who are concerned about them are reluctant to consult them. Through challenges like Bluebond Langner's (1978) early work and Waksler (1986), current thinking is that children should be included in research. Even if Bluebond Langner's (1978) study dates back to the 1970s, in her more recent works (Bluebond-Langner and Nordquest-Schwallie, 2008) it is seen that she has not changed her basic assumptions. Although there are studies relating to the experiences of sick children from their perspective such as Bearison (1991) and Bluebond Langner's (1978) study, there is still a need for research that includes the views of children diagnosed with life-threatening and life-limiting illnesses (Runswick-Cole, 2010).

Reasons for including children in research are many and varied. One is that children require different resources and experience different challenges than adults. Ullrich and Morrison (2013) consider that insights are needed into how children with severe illnesses understand and perceive their experience. Moreover, the palliative care needs of children are unique in comparison to the needs of adults (Ullrich and Morrison, 2013). Mahon et al. (1996) who reviewed two studies conducted with children, as well as with their main carer, explain that it is inappropriate to let adults represent children and that it is important to look for information directly from children. They saw that children can have completely different perspectives and experiences than their parents. This view had been supported by research which demonstrated that children experience events differently and that adults do not always give valid accounts of children's views (Beresford and Sloper, 2003, Dixon-Woods et al., 1999). Moreover, The European Association of Palliative Care in Children (2009) explain that research in Paediatric Palliative Care needs to be specific to children and cannot be extrapolated from the results of research in adults.

2.4 Summary of the chapter

The background chapter has established the context of care worldwide including Romania and describes paediatric palliative care services. The chapter explained how in the past there was a reluctance to take children's perspectives seriously and this was often understood through the voices of their family (Alderson and Morrow, 2011). This point of view has changed and children are now seen as competent to express themselves and to be included in research. Moreover, in this chapter, my research has been placed within the context of theories about awareness contexts and children's development. Awareness contexts along with the development theory provide a basis for understanding the experiences of children diagnosed with life-threatening or life-limiting illnesses. The next chapter presents a literature review of previous studies which explored the experiences of children diagnosed with a life-threatening or life-limiting condition, as well as the perspective of the parents on how their child is experiencing disease.

Chapter 3: Integrative Literature Review

Although the experiences of children diagnosed with a life-threatening or life-limiting illness have been studied over the past century, it remains an area which needs further exploration. Studies have been conducted to explore the experiences of ill children and some focus on the experiences of children diagnosed with serious illnesses; others use parents' perspective as a proxy to understand children's experiences. An integrative review was carried out to identify and assess evidence to determine what is known about the experiences of children diagnosed with life-threatening or life-limiting illnesses.

3.1 Literature review methods

3.1.1 Aim

The aim of this review is to identify and appraise prior research that focused on the experiences of children diagnosed with a life-threatening or life-limiting illness. The main focus is on studies that seek primarily the child's perspective. I have also reviewed papers that focus on parents' accounts and how they interpret the child's perspective. The objectives of this review were: to scrutinise the data of primary studies about the experiences of children diagnosed with life-threatening or life-limiting illnesses; to evaluate and extract data from these primary sources; and to identify and synthesise major themes.

3.1.2 Review design

This integrative review was conducted using the technique of Whittemore and Knafl (2005) to identify the included studies and to explore what is already known about the experiences of children diagnosed with life-threatening and life-limiting conditions as well as the experiences of children from their parents' perspective. An integrative review allows for a combination of methodologies and has been defined as a summary of the literature on a particular content area through which the research is summarised, analysed and overall conclusions are drawn (Whittemore and Knafl, 2005). This approach involves five steps that are completed sequentially including (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis and (5) presentation.

3.1.3 Problem identification

The first stage of the review was the identification of the problem: the need to explore the experiences of children diagnosed with life-threatening and life-limiting conditions. The purpose of this review was to identify and appraise previous research that explored experiences of children diagnosed with life-threatening and life-limiting conditions, as well as the perspective of the parents regarding their children's experiences.

3.1.4 Literature search

The next stage of the review included well-defined literature search strategies which are critical for enhancing the rigour of the integrative approach (Conn et al., 2003). The literature search process is clearly documented below for determining relevant sources for the review (Whittemore and Knafl, 2005).

Four electronic databases (PsychINFO, PubMed, CINAHL, and Cochrane) were searched, and no limits were applied to the date of publication. The following major palliative care journals were also searched by hand: *European Journal of Palliative Care, Palliative Medicine,* and *Paediatric Haematology and Oncology* (Centre for Palliative Care). The search was complemented by citation-tracking the included studies and checking their reference lists.

3.1.4.1 Database searches terms

Medical subject headings (MeSH) and free text were used to initiate the search. The SPIDER search strategy tool was used to identify the articles.

- **Sample (S):** children, parents, main carer;
- **Phenomena of Interest (PI):** children with life-threatening or life-limiting illnesses;
- **Design (D):** questionnaire, survey, interview, focus group, case study, observation, grounded theory, narrative, thematic, content analysis, ethnography;
- **Evaluation (E):** attitudes, views, perceptions, experiences;

- **Research type (R):** qualitative, quantitative and mixed method.

The whole list of search terms and the Boolean operators can be found in Appendix 2 which shows the construction of the SPIDER search tool. The search strategy for all databases used five sets of terms combined with AND/OR to ensure an appropriate subject coverage.

3.1.4.2 Inclusion criteria

Settings: Different settings, such as oncology wards, intensive care units, ambulatory clinics, children's hospices, paediatric palliative care settings. Studies have been included in the review if they focused on one of these settings.

***Participants**:* Children diagnosed with life-threatening or life-limiting illnesses. The review also includes studies which focus on the perspective of the parents regarding their children's experiences.

***Type of studies included**:*

- Any study which reported data on the experiences of participants diagnosed with life-threatening or life-limiting conditions, 18 years old or younger.
- Studies which focused on collecting data from children up to 18 years old who were diagnosed with a life-threatening or life-limiting illness.
- The data collected from children through a range of techniques including interviews, games, drawings, play therapy (Sartain et al., 2000).
- Articles which focused on children's or parents' views on the experiences of children diagnosed with life-threatening or life-limiting conditions.
- Articles with a quality score of 30 or above on the scoring tool created by Hawker et al. (2002). Articles with a summed score under 30 were excluded because they were graded as 'fair', 'poor' and 'very poor'.
- Publication language: Primary studies written in English and Romanian because the researcher speaks these languages.

3.1.4.3 Exclusion criteria

The following criteria for the exclusion of studies are used:

- Papers which explored the views of healthcare professionals;
- Studies in which children were healthy or diagnosed with conditions other than life-threatening or life-limiting.

3.1.5 Data evaluation and data extraction

Whittemore and Knafl (2005) agree that the inclusion of both qualitative and quantitative studies make the process of data evaluation complex and challenging. During this phase, the results were assessed critically whether the result was relevant for the review.

The review used Hawker et al.'s (2002) appraisal tool to gain insights into the quality of the studies which analysed the experiences of children diagnosed with life-threatening or life-limiting conditions. This tool was chosen because it can be used with both qualitative and quantitative data. Hawker et al. (2002) acknowledged that grading qualitative and quantitative studies with the same tool can be difficult. They have therefore designed the protocol to be as clear as possible. The guidance accompanied the ratings of good, fair, poor, or very poor. If the information provided was insufficient, the score was, *can't tell.* Overall the relevance of the studies was consistent, and even studies which were rated as fair in some areas contributed towards answering the research question (Sandelowski et al., 2007).

The Hawker et al. (2002) appraisal tool was chosen for assessing the quality of the studies. This scale was designed to assess heterogeneous studies. Cooper (1998) suggested the use of an evaluation list in the drawing of reliable conclusions. The list provided by Hawker et al. (2002) was used for data evaluation for each of the studies included. The evaluation was done in three stages: assessment of relevance, data extraction and scoring for methodological rigour. The overall rating for each study can range from 9 points to 40 points.

The preliminary synthesis consisted of extracting characteristics of the studies in a table and producing a textual summary of the results (Appendices 2, 3 and 4). The data extracted included details about the specific objectives, study methods, population, and outcomes of significance to the review question.

3.1.6 Results

In total, 16 articles met the inclusion criteria and were included in the review (Figure 1: Flowchart of the Literature Review). Of these, 13 were qualitative; one was quantitative, and two were mixed methods. The qualitative studies used predominantly semi-structured interviews; the quantitative study used a questionnaire, and the mixed methods studies used grounded theory methods of interview and observation. Three articles reported data collected from parents, three from a mix of parents and children/teenagers and ten from children alone. Each of the studies was rated from being ‘fair’ to ‘good’. Scores of the 16 studies included in the review ranged from 32 to 39 points.

Studies were conducted in the UK (four studies), Canada (five studies), Netherland’s (one study), Denmark (one study), Taiwan (one study), Sweden (one study), USA (two studies) and International (USA & UK) (one study). The age range of children included in the review was from one to twenty-six years of age. A wider age group of children was included in the review because of the limited studies available. Three articles included children above the age of 18, but they also included children from 14 to 17 years old, the age of my subjects. Only two studies included in the review analysed the experiences of children diagnosed with a life-threatening or life-limiting illness from both children and parents’ perspective who were from the same cohort. In most of the studies it was possible to extract data related to the age range of the participants included in my study.

While the participants included in the reviewed studies had life-threatening or life-limiting illnesses, they were recruited from different settings such as Paediatric wards, Epidermolysis bullosa Dermatology, Intensive care units, Cancer Registries, Paediatric Haematology/Oncology clinics, Inpatients wards, Ambulatory clinics and Teenage Cancer Trust Units rather than palliative care units or hospices. The interviews took place either in one of these settings or at their home. None of the participants were identified through a palliative or hospice care service although two qualitative studies (Flavelle, 2011, Grinyer, 2009), which analysed the experiences of children diagnosed with life-threatening illnesses mentioned that the children were receiving palliative or hospice care but it was unclear what proportion of the sample. Research in the area is scarce (Holge-Hazelton et al., 2016). There is a great need of research in a palliative care setting exploring the perspective of both the parent and their child diagnosed with a life-threatening or life-limiting illness.

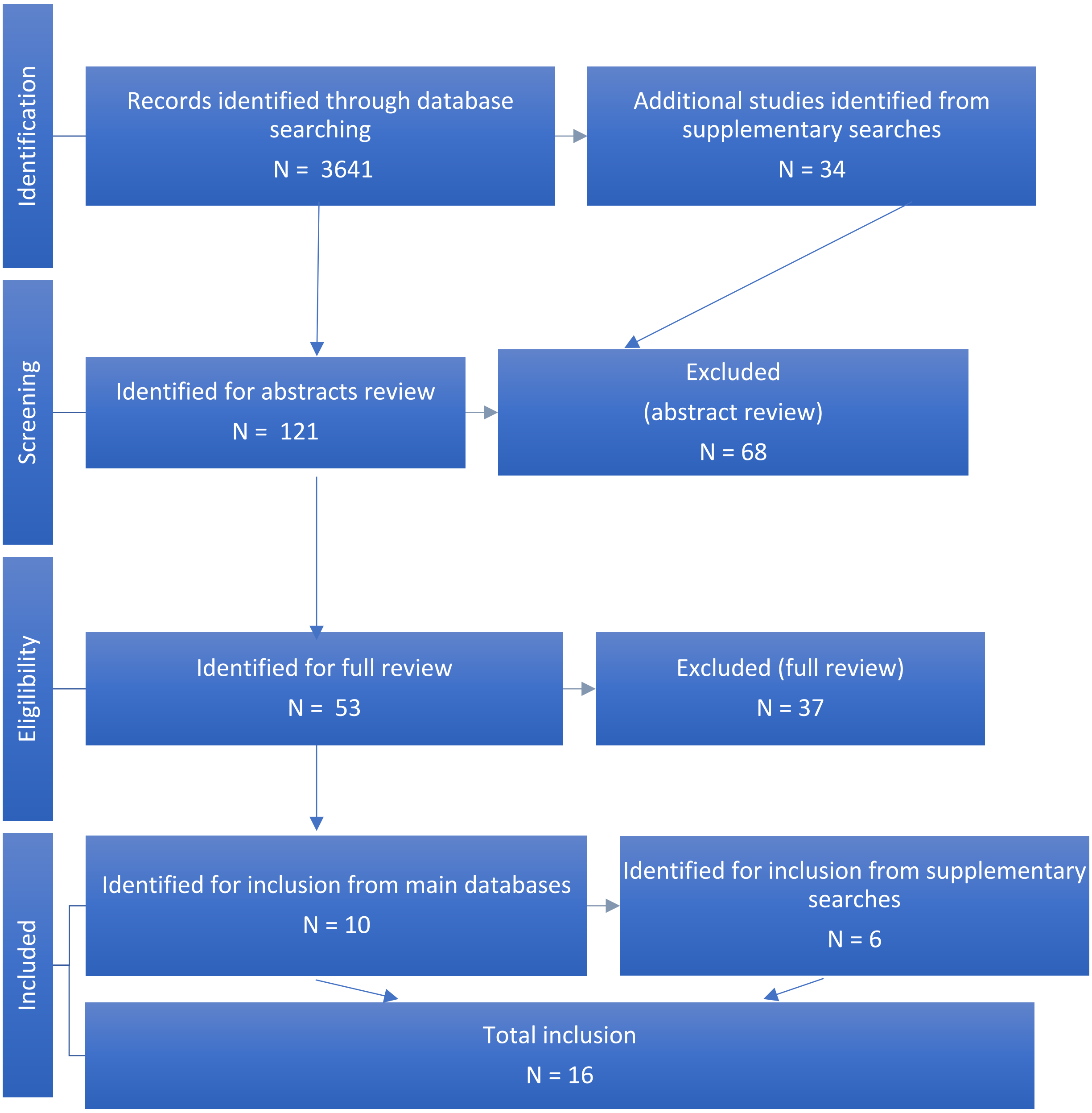

Figure 1. Flowchart of the Literature Review

3.2 Data analysis

On completion of the data evaluation, data analysis was carried out following the guidance recommended by Whittemore and Knafl (2005). This stage is defined by Cooper (1998) as 'reducing the separate data points collected by the inquirer into a unified statement about the research problem.' All data relevant to children's experiences were examined using a four-step process by Whittemore and Knafl (2005). These four steps are (1) data reduction, (2) data display, (3) comparison and (4) conclusion, which help to identify key themes. This approach facilitated recognition of patterns, variations and relationships from the data extracted.

Firstly, data reduction implied that the primary sources integrated into the review were divided into two subgroups according to the type of evidence. These subgroups of articles included in the review were articles where the views of participants were from (1) the child's perspective (Appendix 3), (2) the parents' perspective (Appendix 4) and (3) a mix of children's and parents' perspectives (Appendix 5). Predetermined and relevant data were compiled into a spreadsheet (Garrard, 2014). The second step involved data display. A table was created to view the comprehensive set of data extracted from each article. Phase three included the identification of patterns and themes (Appendix 3, 4 and 5). Once the patterns were discerned, the themes were identified. The final phase involved the synthesis of essential elements (Whittemore and Knafl, 2005).

3.2.1 Themes

The analysis produced six major themes and eleven subcategories as shown in Table 1. The key themes identified were the emotional responses to illness; the spiritual responses to illness; independence and normality; physical symptoms; treatment experiences and childhood development. Each of the themes produced a picture of the experiences of children diagnosed with life-threatening or life-limiting illnesses. Emotional response to illness was the only theme identified in all studies. Because findings were consistent across studies including life-threatening or life-limiting conditions, these are grouped together. An exception was the theme ‘Treatment experiences’ which was mentioned only in the articles where children were diagnosed with life-threatening illnesses from both children’s and parents’ perspective. Treatment experiences were mentioned only in the articles where children were in hospital. Also, children with both life-threatening or life-limiting illnesses were more prone to talk about their physical symptoms than their parents. A clear picture of how the themes were identified across the studies can be seen in Appendix 6.

Themes	**Subthemes**	**Papers related to each category**
Emotional responses to illness	Fears and Worries/Anger/Loneliness and isolation/Losing confidence/Mood and personality have changed/Escape from illness/ Forgotten/Insecure	Rollins (2005); Woodgate (1998); Anderzén-Carlsson et al. (2007); Carnevale and Gaudreault (2013); Montoya-Juarez et al. (2013); Moody et al. (2006); Wu et al. (2009); Holge-Hazelton et al. (2016); Flavelle (2011); Sartain et al. (2000).
	Withdraw from their families/Missing significant people/Having responsibility for others/Changing relationships/Lack of understanding from others/Adjusting despite challenge/Family tension	Bluebond-Langner (1978); Carnevale and Gaudreault (2013); Holge-Hazelton et al. (2016); Flavelle (2011); Scheppingen et al. (2008); Nicholas et al. (2011); Grinyer (2009).
Spiritual responses to illness	Viewing the future negatively and feeling hopeless/Fear of death/Uncertainty/The body feels alienated and deceitful/Finding meaning and purpose in life/Rebuilding hope /Spirituality- Coping strategy/Experiencing a transition process.	Holge-Hazelton et al. (2016); Rollins (2005); Montoya-Juarez et al. (2013); Flavelle (2011); Wu et al. (2009); Cataudella and Zelcer (2012).
Independence/ Normality	Maintaining normalcy/Living as normally as possible	Nicholas et al. (2011); Grinyer (2009); Sartain et al. (2000); Cataudella and Zelcer (2012).
	Appearance/Hair loss/The feeling of being different/Not feeling normal; The loss of a normal childhood	Grinyer (2009); Rollins (2005); Scheppingen et al. (2008); Moody et al. (2006).
	Restraining/Having difficulties with participation/ Dependency/Lack of autonomy/Barrier to normalcy/Independence	Woodgate (1998); Scheppingen et al. (2008); Montoya-Juarez et al. (2013); Sartain et al. (2000); Snethen et al. (2001); Grinyer (2009), Snethen et al. (2001).
Physical symptoms	Being in Pain/Hurt/Having an itchy skin	Scheppingen et al. (2008); Montoya-Juarez et al. (2013); Carnevale and Gaudreault

		(2013); Bluebond-Langner (1978); Woodgate (1998); Moody et al. (2006).
	Disability/'It takes extra effort'/Compromised mobility/Losing confidence (physical suffering)	Moody et al. (2006); Carnevale and Gaudreault (2013); Montoya-Juarez et al. (2013); Flavelle (2011); Woodgate (1998); Wu et al. (2009).
	Food or eating problems/Decrease pleasure of food	Carnevale and Gaudreault (2013); Moody et al. (2006).
Treatment experiences	Invasive interventions/ painful medical procedures/Surgical procedures/Chemotherapy/Needle/Discomfort/ Invasive technique procedures	Carnevale and Gaudreault (2013); Bluebond-Langner (1978); Rollins (2005); Wu et al. (2009); Montoya-Juarez et al. (2013).
Development	Developing knowledge about illness and involvement in treatment/The child's self-concepts change according to verbal and non-verbal cues from parents and conversations with peers/Adolescent development/Different ages – different fears	Nicholas et al. (2011); Cataudella and Zelcer (2012); Flavelle (2011); Bluebond-Langner (1978); Sartain et al. (2000); Anderzén-Carlsson et al. (2007).

Table 1. Themes and Subthemes

3.2.1.1 Theme 1: Emotional responses to illness

Children and teenagers expressed the stress of living with life-threatening illnesses in different ways. Some of the issues emerging from this theme relate specifically to the emotional response of children to illness. Moody et al. (2006) report that children expressed feelings of loneliness and isolation because they were not participating in social activities. Younger children reported feeling angry about their illness while teenagers were more concerned about death, the prospect of which produced much fear for them. Similarly, Rollins (2005) and Holge-Hazelton et al. (2016) explained how participants, aged between 7 and 21, expressed and experienced their fear of death. Results showed that most of the participants experienced worries and fears about dying, especially older children. The results also showed that one-quarter of them never talked with anyone about these thoughts.

Moody et al. (2006) identified loneliness and isolation. These concerns of the children and teenagers would make them view the future negatively and feel hopeless. Being confronted with cancer brings overwhelming feelings of uncertainty and diminished prospects of a future life (Holge-Hazelton et al., 2016). Anderzén-Carlsson et al.'s (2007) study, which analysed what the parents of children thought about their child's experience came to the conclusion that parents were aware of their child's concerns, but they were also aware that they were not always able to know their child's mind.

Carnevale and Gaudreault (2013) observed how participants experienced discomfort if they did not have access to the most significant person in their lives. Children highlighted being upset when their parents could not be with them, even if they were away only to eat or sleep. Teenagers said that they missed having direct contact with their friends, and if face-to-face visits were not possible, they would have liked to have contact at least through social media. This feeling of isolation was experienced especially when they had chemotherapy and were not able to be visited in the hospital because of infection risks.

Scheppingen et al. (2008) found that teenagers experienced a lack of understanding from most of the people in their immediate surroundings regarding their illness. This made them feel alone and also different from their peers. Hazelton et al.'s (2016) study explored how teenagers and young people have a feeling of responsibility for others and expressed their concern about not passing the illness to their family and friends. This made them feel even more upset even though their illness was not contagious.

The studies evidenced the childrens' struggle with different emotions related to their diagnosis, prognosis, their everyday life and how they viewed their future. There was a range of emotional responses such as anger, loneliness and worry.

3.2.1.2 Theme 2. Spiritual responses to illness

Some articles showed that spirituality could be a significant factor in the emotional response of the children. Three studies made direct reference to spirituality and one of the studies found that spirituality helped give the child a sense of peace, purpose, and belief about the meaning of life (Henoch and Danielson, 2009). Although Flavelle's (2011) study only analysed a single case examining data from a journal written by a dying teenager, the study provided valuable information because of its in-depth analysis. The study analysed 90 pages of the journal of a 15-year-old boy diagnosed with osteosarcoma; the journal spanned three months just before the death of the teenager, and many of the topics suggested that some of his experiences parallel those of other teenagers living with a life-threatening or life-limiting illness such as fighting for independence and existential suffering.

Holge-Hazelton et al. (2016) provide insight into existential issues as experienced by teenagers. Some of the participants indicated that since they became ill, they did not have control over their life. For that reason, they would enjoy time as much as they could. Holge-Hazelton et al. (2016) also reported that some of the participants said that they were not afraid to die. On the other hand, Rollins' (2005) reported that three children expressed their fear of death.

Other studies show that children and teenagers have spiritual concerns even if they do not make a direct reference to it such as a tension about the uncertainty of their future (Montoya-Juarez et al., 2013). Wu et al. (2009) identified two dimensions of teenagers' experience when diagnosed with life-threatening conditions; they may lose confidence, or they may start having hope again through envisioning hopeful images for the future. Wu et al.'s (2009) work is complemented by Holge-Hazelton et al. (2016) who found in their study that teenagers diagnosed with cancer viewed their future negatively and felt hopeless. For some of the teenagers and young people, it was hard to envision their future and being confronted with a life-threatening disease had resulted in an overwhelming feeling of uncertainty and diminished prospects of a future life. However, parents from a different study claimed that spirituality represented a coping strategy which demonstrated children's resilience in the face of illness or dying (Cataudella and Zelcer, 2012).

These studies have shown that spirituality is significant for many children diagnosed with life-threatening or life-limiting illnesses. While some of the teenagers felt hopeless with a gloomy view of their future, other teenagers expressed that spirituality was a means of coping with their illness.

3.2.1.3 Theme 3: Independence and normality

A significant feature of the experience of being diagnosed and living with life-threatening or life-limiting conditions was related to the striving of teenagers for independence and normality. There is a potential for family tension when a young adult strives for independence which is threatened by their illness (Grinyer, 2009). Many teenagers emphasised the importance of living as normally as they can regardless of their illness. (Grinyer, 2009, Nicholas et al., 2011, Sartain et al., 2000). Parents confirmed this, adding that this was a coping strategy which demonstrated their resistance to the prospect that they could die from their illness. Continuing to be treated as normally as possible had significant implications for their self-esteem and mood. However, parents were sometimes overprotective in their concern to keep them safe (Cataudella and Zelcer, 2012).

Other sources highlight the importance of appearance for teenagers which can be affected by their illness or by the treatment. The feeling of being different causes distress in teenagers (Grinyer, 2009, Scheppingen et al., 2008). For example, losing their hair made them feel different from others and from their former selves which could also lead to a loss of identity (Rollins, 2005).

Nicholas et al. (2011) study evidenced how children strove for normalcy, envisioned as living like others who are healthy. Hair loss after chemotherapy or weight gain from steroid treatment which could negatively impact their self-esteem and be distressing and demoralising for them (Grinyer, 2009, Rollins, 2005). Bluebond-Langner (1978) highlights that even young children could be concerned about their altered physical appearance because of medical treatment.

Children could also experience limitations or restrictions which would prevent them from having a normal life. This would mean that they struggled to find ways to accommodate the illness, so that they could participate in different activities (Woodgate, 1998, Scheppingen et al., 2008). Moreover, parents of teenagers with a terminal condition found that a significant cause of suffering for their sick children was their lack of autonomy (Montoya-Juarez et al., 2013). Teenagers were more prone than younger children to being frustrated because of losing control or when they could not participate in activities.

This theme encompasses some of the most important issues for teenagers: their striving for normality and independence, which could also lead to a tension with their family who needed to care for their ill child. 'Being normal' was defined by these children and teenagers as having an acceptable physical appearance as well as living a normal life not reliant upon support of others, particularly physical support.

3.2.1.4 Theme 4: Physical symptoms

A significant feature of living with a life-threatening illness was related to physical symptoms. Being in pain was mentioned by most of the children and teenagers, as well as their parents. Children diagnosed with a critical condition experienced distress and suffering. Children and teenagers expressed that pain often resulted from their illness (Moody et al., 2006) as well as pain experienced due to the effects of the disease on their daily lives (Woodgate, 1998).

For many children, their illness brought disability. Some of them described their illness as something that 'takes extra effort' for everything they want to do while also compromising their mobility (Flavelle, 2011, Woodgate, 1998). Teenagers were more aware of their physical condition than younger children in many situations. They would also experience not having enough energy to care for themselves, making them feel like a burden to their family (Flavelle, 2011, Wu et al., 2009). The small sample size in both Flavelle (2011) and Wu et al. (2009) studies offer a glimpse of how teenagers feel when their mobility is compromised.

Moody et al. (2006) also mentioned the limitation of physical function which teenagers consider a traumatic event. Children with restricted leg movement complained that they wished they could run and walk again (Moody et al., 2006). The parents who were interviewed in Montoya-Juarez et al. (2013) study offered their perspective about the physical suffering of their children and teenagers. Parents observed that the younger the child was, the higher the physical component of suffering was when compared to the emotional causes of suffering, which means that younger children were more affected by medical procedures like shots, than older children.

Other discomforts which appeared to bother children were the decreased pleasure of food or eating problems. They complained that they could not enjoy food because of their poor appetite, changes in taste and smell, chemotherapy, and restrictions in food choices (Carnevale and Gaudreault, 2013, Moody et al., 2006).

This theme evidences how physical symptoms impacted the well-being of children and teenagers diagnosed with life-threatening or life-limiting illnesses. Pain, as well as other symptoms such as weakness, caused a lot of distress in these children's lives.

3.2.1.5 Theme 5: Treatment experiences

Children and teenagers described how negative symptoms and side effects of the treatment dramatically interfered with their sense of well-being and with the ability to function normally. They depicted significant discomforts relating to painful medical procedures and invasive interventions such as needles and tubes which were their primary concerns. Needles were often the first thing mentioned when they talked about their discomforts, but tubes and catheters were also significant discomforts (Carnevale and Gaudreault, 2013, Bluebond-Langner, 1978). They also revealed their fear of chemotherapy and surgical procedures (Rollins, 2005). Even younger children were aware of the toxic side effects of drugs which created mood swings and weight gain (Bluebond-Langner, 1978).

Parents thought that the most concerning thing for their children regarding the treatment was pain (Montoya-Juarez et al., 2013). In this study indicators in terminally ill children were studied from the parental perspective. Parents felt that the invasive procedures such as ‘shots’ or blood tests which led to pain were the most disturbing for their children. Whether it was pain, nausea and vomiting, or fatigue, dressing changes, or stomach and mouth ulcers, every child and teenager mentioned one or more physical aspects of the treatment as being difficult for them (Rollins, 2005, Bluebond-Langner, 1978).

This theme evidences how much distress can be caused during the treatment experiences of children diagnosed with life-threatening or life-limiting illnesses. The main sources of discomfort, mentioned both by children and their parents, were the invasive treatments which included the use of needles or tubes, such as nasogastric or endotracheal tubes.

3.2.1.6 Theme 6: Development

The review identified that there were two perspectives held by researchers who study children: those who think children are unable to understand and describe their life experiences due to developmental immaturity and those who believed that children are competent interpreters of their world (Sartain et al., 2000). None of the studies included in the review would suggest that children were not competent or mature enough to participate in the research. An exception was Anderzén-Carlsson et al.’s (2007), who claimed that younger children were believed to not fully understand their illness, whereas older ones were thought to be old enough to do so. Based on parents’ understanding of their children’s experiences, Anderzén-Carlsson et al. (2007) found that parents considered age to be an important factor for children in understanding a serious illness like cancer.

Bluebond-Langner (1978) contradicted the developmental theory which stated that children were not capable of understanding their condition. Her study demonstrated that children are competent enough to comprehend their sickness (Bluebond-Langner, 1978). Anderzén-Carlsson et al.’s (2007) claimed that age was considered an important factor for understanding a serious illness. Bluebond-Langner (1978) included children as young as three years old in her research, and she also did informal interviews with the parents. She showed in the study that children could understand their illness and that they were dying. She explained that acquiring the information about the illness was a long and challenging process for the children.

However, the findings of Bluebond-Langner are contrary to Anderzén-Carlsson et al. (2007) in their study which aimed to highlight the parents' lived experience and understanding of their child's fear. Anderzén-Carlsson et al.'s (2007) study analysed the perspective of parents regarding their children's experiences. This study suggested that from the parents' perspective, as children get older it was easier for them to understand medical procedures as well as their disease which lessened their fear or other emotional responses.

This theme indicated that in the past children were not able to understand and talk about their illness. However, there is clear evidence that children have the ability to acquire information about their conditions and describe their experiences related to their illness.

3.3 Discussion

The aim of this systematic review of the literature was to identify what is known about the experiences of children diagnosed with life-threatening or life-limiting conditions. Results of this review are consistent with previous research and build upon the earlier findings of Bluebond-Langner's (1978, 1976) who undertook pioneering work on terminally ill children.

Ten of the 16 studies included in the review focused on the experiences of children diagnosed with a life-threatening or life-limiting disease such as cancer, epidermolysis bullosa or end-renal-stage-disease.

Following Bluebond-Langner's study (1978), literature has emerged that support her findings. She evidenced that children are able to understand and share their view related to their illness and that they adapt their behaviour depending on how much others share with them about their illness. Nicholas et al.'s (2011) findings are in agreement with Bluebond-Langner's (1978) results, that children can offer meaningful information about their experiences. However, her study concentrates on young children from 18 months to 14 years old. More recent research is needed as her study was conducted 40 years ago.

The ten studies included in the review show that children shared similar experiences such as their fears of medical procedures or about death and dying (Carnevale and Gaudreault, 2013, Rollins, 2005, Moody et al., 2006). A good observation is made by Bluebond-Langner (1978) who found in her study that young children information about relapses and prognosis. They acquire information based on their experience of the disease and changes in self-concept. Bluebond-Langner also observed that children were able to gain information about their condition even if parents wanted to keep them in ignorance.

Data on the experiences of children from their parents' perspective is provided in the other six of the 16 studies included in the review. Three of these studies include the perspective of the parents regarding their children's experiences and the other three studies include both the children and parents' perspective. The results from these six studies (Montoya-Juarez et al., 2013, Cataudella and Zelcer, 2012, Grinyer, 2009, Anderzén-Carlsson et al., 2007, Sartain et al., 2000, Bluebond-Langner, 1978) show that children may think differently from their parents in terms of how they experience their life-threatening or life-limiting illness. For some teenagers, quality of life was of greater importance while parents regarded the distress associated with aggressive treatment as a price worth paying for survival (Grinyer, 2009). Each disease has its own particularities and the children included in the studies had different types of illnesses including neurological, oncological or genetic. Even so, similar experiences have been identified in children diagnosed with life-threatening or life-limiting illnesses. For example, pain caused by the medical procedures and not by the illness itself is one of the main sources of suffering in children as perceived by their parents. Most of the studies included in the review mentioned pain as being a common issue in children diagnosed with a serious condition, which also includes existential suffering. Their suffering is described by parents and by children as sadness, apathy and anger which can be expressed towards their parents, medical professionals, or God (Montoya-Juarez et al., 2013, Anderzén-Carlsson et al., 2007).

Appearance, not feeling normal and disability were other similar experiences shared by children diagnosed with serious conditions (Montoya-Juarez et al., 2013, Grinyer, 2009, Cataudella and Zelcer, 2012). Many of them struggled because they were different from other children. They were also concerned about their appearance. These experiences were found in most of the studies included in the review and both children and their parents considered these factors disturbing.

Three studies (Grinyer, 2009, Sartain et al., 2000, Bluebond-Langner, 1978) included in the review analysed the experiences of children from the perspective of both children and parents. Grinyer's (2009) study analysed issues raised by teenagers/young adults treated for cancer and bereaved parents, but the parents were from a different cohort to the children. The results of these three studies evidence a difference between the perspective of the parents and that of the children. For example, the analysis of independence, especially in adolescents and young adults, differed between the parents' accounts and those of the teenagers and youths. From the parents' perspective, it is hard to allow their children to maintain their independence and autonomy. However, their children resent the reluctance of their parents to give them freedom (Grinyer, 2009).

It is surprising that from the 16 studies included in the review, only Sartain et al's (2000) did parallel interviews with children and their parents at the same time. But the study does not mention if the children were receiving palliative care services. Children were recruited through the National Health Service which provided primary or secondary care for children. In Bluebond-Langner (1978) study, parents of the children interviewed were included as well, but these interviews were informal. This is an important issue for further research which includes the experiences of children and adolescents diagnosed with life-threatening or life-limiting conditions from the perspective of both the parent and their child who is also receiving palliative care services.

Although parents' accounts may differ from those of ill children and teenagers (Grinyer, 2009, Bluebond-Langner, 1978), parental perspective can provide key information regarding the experience of suffering for terminally ill children (Montoya-Juarez et al., 2013). Interviews with both parents of the children/teenagers would have created an even richer context through which to understand and interpret these factors (Moody et al., 2006). Eisikovits and Koren (2010) confirm that bringing both sides together in research, children and parents, enriches the perspective of the phenomena.

Flavelle's (2011) study underlines that interviewing children about their experience regarding their life-threatening illness, will provide valuable information in the paediatric palliative care field in which the patient's perspective may be difficult to access.

3.3.1 Potential limitations and strength

This integrative review synthesises the current international evidence base regarding the experiences of children and teenagers diagnosed with life-threatening or life-limiting illnesses. Electronic search and review strategies were used to identify literature on the subject; however, the search has suffered some limitations. Databases were limited to the English and Romanian language; as a result, some studies may have been missed. Also, the inclusion criteria for this study focused on the perspective of children diagnosed with life-threatening or life-limiting illnesses and that of their parents; this excluded insights and valuable information from healthcare professionals working in a paediatric palliative care setting.

Although limited by the issues listed above, the included studies and synthesis approach goes some way to answer the review question. The main strength of this review is that most of the articles analysed in the review are qualitative in which the children were allowed to speak freely about their experiences. Another significant strength is the transparent approach adopted to identify and extract data from papers. As the review was conducted rigorously, the findings are useful for practice. One of the qualitative studies included in the review had only one participant which would seem like a limitation. However, the study provides in-depth insight into the experience of the participant. The majority of the themes reflect lived experiences, issues, and problems of children diagnosed with life-threatening or life-limiting conditions.

Given that the care of ill children occurs within the wider context of their family, the methodology is strengthened by linking parent and child studies of the illness experience. The themes identified in the studies included in the review occur in different countries and different populations. While the review may contribute to the knowledge of the experiences of children, the extent to which it can be generalised across cultural groups may be limited. Given that the children included in the studies reviewed had different types of disease like cancer, muscular dystrophy, epidermolysis bullosa, it makes it difficult to generalise the findings and apply the results to a variety of countries, hospitals and palliative or hospice care facilities.

3.4 Conclusion

This review aimed to identify studies which explore the experiences of children diagnosed with life-threatening or life-limiting illnesses. The studies included in the review describe issues related to children’s experiences which are explained through the six major themes identified. Each of these themes showed that there are similarities in children’s emotional and spiritual struggles in their illness, their striving for normality and independence as well as physical symptoms and treatment experiences. Some of the studies have shown that children are able to participate in research regarding their experiences which validates studies of their views regarding their illness. Thus, research about children’s experiences when they are diagnosed with a life-threatening disease should continue to develop which is an argument for their inclusion in the research.

As a result of this review, it is possible to identify that there are two main gaps in the literature where further research is needed. Although there are studies which analyse the experiences of children diagnosed with life-threatening or life-limiting illnesses, such studies remain narrow in focus dealing only with children; most do not include their parents in the research. Unlike most of the studies included in the review, which focus on children, my study brings the perspective of both children and their parents in a palliative care setting, thus allowing a comparison between the two in terms of what each party thinks the other does or does not know or understand about the illness and prognosis. There is a clear need for additional research on the experiences of children with life-threatening and life-limiting illnesses, from their perspective as well as how their parents think that their children are experiencing their disease. Including children in research has a significant impact on understanding their perspective about their illness because the child's view has been overlooked in the past (Ullrich and Morrison, 2013).

Additional research is also needed about children diagnosed with life-threatening or life-limiting illnesses who are also receiving palliative care. Some of the studies included in the review analysed children receiving palliative or hospice care (Flavelle, 2011, Grinyer, 2009) but they are not studying the same cohort of children and parents.

This thesis explores issues related specifically to children, from both their own first-hand perspective and from their parents' point of view (Eisikovits and Koren, 2010). All of the children included in my research receive palliative care services which will bring a new perspective on their experiences. Thus, this thesis helps to address gaps in current knowledge by having the perspective of both children and their parents in the same study. The study will have an important contribution to knowledge in the field of paediatric palliative care in Romania and other countries.

Chapter 4. Methodology

4.1 Background

This chapter explains the underlying research philosophy of the thesis and the rationale for choosing a qualitative approach. The research aimed to develop knowledge within the interpretivist paradigm; as it is particularly useful in facilitating the researchers' ability to obtain the understandings, views and perceptions of respondents (Berg, 2009).

4.2 Research Question and Objectives

This study asks the following research question 'What are the experiences of children diagnosed with life-threatening or life-limiting conditions and how do their parents interpret their child's perspective?' Gaining insight into both the child's and their parent's perspective will allow a comparison between the two groups.

The objectives of this research are:

(1) to develop an understanding of the illness as experienced by the children

(2) to explore the perspective of the parents on how their child is experiencing disease

(3) to compare and contrast the results of both groups.

4.3 Methodology

4.3.1 Research philosophy

The underlying research philosophy of this thesis relies on the interpretivist paradigm which is characterised by using subjective epistemology in which there are diverse interpretations of reality rather than seeking to reveal a general truth (Bunniss and Kelly, 2010). This perspective recognises that reality is socially constructed, subjective, interactive and changing, so the researcher aims to interpret the meanings others have about the world (Creswell, 2012). Within the interpretivist perspective the study endeavours to observe how the researcher's thoughts, feelings, opinions, and experiences might influence what he/she records (Bunniss and Kelly, 2010). Thus the researcher recognises that their background and experiences have an impact on the research (Mackenzie and Knipe, 2006).

The interpretivist paradigm was developed through the philosophy of Edmund Husserl, Wilhelm Dilthey and other German philosophers' studies of interpretive understanding (Mertens, 1998). Interpretivism is often combined with constructivism or social constructionism. Reality is socially constructed by the persons who experience it (Creswell, 2012), rather than being passively received by them (Ormston et al., 2014). Reality is shaped by the specific contexts in which people live and work; thus it is necessary to understand the historical and cultural settings of the participants (Darlaston-Jones, 2007). Berger and Luckmann (1967) who are among the main proponents of this approach claim that reality can be different for each of us based on how we understand and experience it. People create subjective meanings from their experiences (Creswell, 2012). Gergen (1999) explains that each person's reality is true for him/herself because each experiences it differently and each of them is independent in their interpretation of reality. Even though all the children in this study were diagnosed with life-threatening or life-limiting conditions, their experiences are individual and each of them has their own understanding and meaning about their illness. As an insider researcher I became part of my participants' experiences for the time in which I conducted the research. This means that their accounts of their experiences were a product of the context in which the interviews were taken, namely my relationship and interaction with these children and their parents. Also, children's and parents' perspectives are unique. While their accounts were different at times, it does not mean that one was more truthful than the other.

The goal of the research in the constructivist worldview is to rely on the participants' perspective on the subject being studied. Constructivist researchers address broad and general questions with the participants so that the participants can construct the meaning of the situation. The subjective meanings created by individuals are formed through interactions with others and through historical and cultural principles that function in every person's life (Creswell, 2012).

Studies based on the interpretivist paradigm are more likely to rely on qualitative data collection and analysis or a combination of both qualitative and quantitative methods (Mackenzie and Knipe, 2006). This research adopted an interpretivist position relying on qualitative data. The real-world phenomena are understood within the context in which they occur and the perceptions of those involved in the phenomena under study are analysed (Easterby-Smith et al., 2012). Understanding the setting of the participants and gathering the information personally from children diagnosed with serious illnesses as well as from their parents, enables engagement with the world my participants inhabit so that they can share their perspectives on their experiences (Crotty, 1998).

The advantages of using the interpretivist approach lie in the flexibility of the research process. Themes and patterns found in data may be different from the initial assumptions. These unexpected results can then be accounted for and included in subsequent interviews. There are also rich descriptions of the subjective experiences and results are based on understanding the views of the participants whose experiences are embedded in their social and historical context (Allsop, 2013).

Based upon these fundamental epistemological assumptions, a social constructivist paradigm underpins my research. Both the terms ‘life-threatening’ and ‘children’ are socially constructed concepts with different meanings which ‘illuminate the subjective meaning, actions and context of those being researched’ (Popay et al., 1998). Moreover, my professional experience in a palliative care setting has led me to adopt an epistemology which aligns with a qualitative approach.

4.3.2 Qualitative approach to research

The interpretivist approach, which uses qualitative research methods, has been selected as the most appropriate way in which to understand the experience of children when facing a life-threatening illness (Mojtahed et al., 2014). Braun and Clarke (2013) explain that the qualitative approach aims to do research by giving voice to a group or providing a detailed description of experiences.

The literature has emphasised that in qualitative research it is not necessary to have a large representative sample of a whole population. Instead, the focus of qualitative research is on in-depth information with a smaller group which is located in their context (Braun and Clarke, 2013). Therefore, the phenomena are viewed from the inside, which is the main feature of the qualitative research (Miles and Huberman, 1994).

There are various reasons why a qualitative approach is suitable for exploring the experiences of children diagnosed with life-threatening or life-limiting illnesses (Mantzoukas, 2008). A qualitative methodology was selected because it allows for a focus on participants' frame of issues important to them rather than the issues being pre-framed by the researcher (Braun and Clarke, 2013). Moreover, a qualitative approach allows the researcher to explore the meaning of children's experiences during illness, offer rich descriptions of phenomena being studied and interpret the experiences of children, their families, and their caregivers (Denzin and Lincoln, 2005, Berg, 2009, Creswell, 2012).

Another significant reason for the appropriateness of a qualitative approach is that it can be open-ended and exploratory (Braun and Clarke, 2013). Bearison (1991) argues that when conducting research with children, quantitative approaches can result in a loss of children's experiences, while using a qualitative approach can elicit unexpected findings (Braun and Clarke, 2013).

Woodgate (2000) shows that the primary philosophical principles of the qualitative paradigm should be seen as facilitating the access to children's thoughts and giving them a voice. Alderson (2000) claims that the best method of understanding a child's experiences is to ask him or her what their experiences are.

4.4 Methods

4.4.1 Setting/Population

Interviews were undertaken with ten children between 14 to 17 years old who had been diagnosed with a life-threatening or life-limiting condition and who are supported by hospice or palliative care services. Interviews were also undertaken with the parents of these ten children. This method offers a glimpse of the lived reality of the participants, gaining insight into their inner world.

Although I had originally planned to include children from 10 to 17 years of age, in practice only children between 14 to 17 years of age who volunteered to participate in the study. Even though three children under 14 years of age had been recruited for the study, they died before they could be interviewed.

The children were recruited from an organisation which cares for children from diagnosis onwards; thus not all the children were in a terminal phase. Moreover, the same children's parents were interviewed in order to understand how they interpret their child's experiences (Coad et al., 2015b). In all cases, the mothers were interviewed as they had self-identified as the main carers. The fathers could also have participated, but they chose not to; in most of the cases either because they were at work or because the parents were divorced. The exception was one father who attended the interview, but he did not contribute while I was interviewing the mother.

I have been working with children diagnosed with life-threatening and life-limiting conditions for over 10 years, thus I collected the data as an insider researcher (Kim, 2012). I had a prior relationship with the children as well as their parents in my role as a professional. These issues are addressed across this chapter as well as in the section about the challenges and benefits of being an insider researcher (See p. 60).

Inclusion and exclusion criteria were used to select research participants, and these were based on the research aim and research question (Oliver, 2010). The purposive selection was used to ensure that the participants in the study represented the phenomena under investigation (Wertz, 2005). The selection focused on specific characteristics of the children such as their age, diagnosis, the current state of the disease. Children and parents who were not Romanian speakers were excluded from the project. Participants were informed that they had been asked to be part of the research project because they receive palliative care services and that their contribution could help improve the care for future paediatric hospice or palliative care services.

The selection was made of children well enough and willing to participate. As I work with these children over a long time period, I could evaluate when they were well enough to participate and when their illness was at a point when they should be precluded. However, the selection was not based on my judgement alone. The doctor from my team verified my selection (Eiser et al., 1999). Some of the children who receive hospice or palliative care are unable to talk because they have severe cognitive problems or because they have a brain tumour or metastasis which severely affects their capacity to verbally express themselves. In these circumstances, they were considered unsuitable for inclusion in this research. Children with a severe level of intellectual delay were not included in the study as the research focuses on children who could understand and answer questions. Additional exclusion criteria included children who were very ill or distressed at the time of the interview (Eiser et al., 1999).

Inclusion criteria Children:	**Exclusion criteria**
(1) who were willing to be interviewed; (2) who do not have a severe level of cognitive impairment; (3) who received consent from their parents; (4) who gave their assent to participate in the study; (5) who agreed to be voice-recorded during the interview; (6) who were not actively dying.	(1) who were affected by their condition and not be able to talk; (2) who have a severe level of intellectual delay; (3) who were very ill; (4) who were distressed at the time of the interview.

Table 2. Inclusion and exclusion criteria

4.4.1.1 Recruitment process

Participants receiving palliative care services were identified by me through the database of a paediatric palliative care department. Afterwards, initial contact with the potential participants was made through the manager of a palliative care service which relieved them from the sense of obligation to me as a known person. The parents were contacted by phone by the manager of the programme and told about the purpose of the proposed study. They also received by post an information sheet about the aims of the project, interview arrangements and topics, as well as information on consent and confidentiality. An additional information sheet was modified to be more appropriate for the children (Appendix 7 and 8). Those who were interested in participating in the study were given several days to consider whether to participate. The manager of the programme then phoned the parents to ask for their decision.

With the parents' approval, I approached the child regarding participation in the study. If a child refused to participate, then I did not include their parent, even if the parent had originally agreed to participate. Both parent and child had to accept for inclusion purposes (Twycross et al., 2008, Coad et al., 2015a). In Romania, parental consent needs to be obtained on behalf of children up to the age of 18, therefore all the children included in the study needed their parents' consent.

4.4.2 Data collection

The method of data collection was through in-depth qualitative interviews, which tend to be very similar to a conversation (Bryman, 2012). This study employed in-depth semi-structured interviews because they enabled participants to express their thoughts and feelings in their own words, which enables the researcher to access various private experiences (Minichiello et al., 1992, Fossey et al., 2002). Franklin and Jordan (2008) point out that this approach enables a sufficient degree of structure for comparability among participants despite the disparities in the issues and topics that the participants might raise. A major advantage of this method is that it is suitable for children who are used to having ordinary conversations rather than answering survey questions (Woodgate, 2001).

The use of interviews as a data collection method is justified by its similarity with daily-life conversations and negotiation of meaning between two persons (Brinkmann and Kvale, 2015), which also corresponds to constructivist approaches to research. This method offered participants the opportunity to speak freely about the meaning of experiences. Each participant in the research study took part in face-to-face in-depth interviews which lasted from 30 to 70 minutes. Parents were interviewed first, after which children were interviewed. It was made clear that confidentiality would not be broken and information that the children and parents shared during the interview would not be disclosed to the other. For example, one parent had asked me for the information her child gave me during the interview and I explained to her that I could not divulge that information. However, they were told there were some limits to confidentiality; participants were made aware that I would have to break confidentiality if they indicated that they intended to cause harm to themselves or others (Twycross et al., 2008). In the event, none of the participants indicated an intention to cause harm to themselves or others.

Gaynard et al. (1990) claim that age development is imperative in determining a child's level of understanding and coping mechanisms. With younger children, the use of simple terminology and particular language is necessary. For instance, when eliciting information from younger school-age children, questions should focus on what the child would do in a given situation rather than how the child might feel, this approach is more likely to encourage a response (Instone, 2002). However, older children think more abstractly, and the interview can focus on the insight they are developing into themselves and their experiences. Open-ended questions, such as 'tell me how …', create a non-threatening opportunity for children to reflect on their experiences (Instone, 2002). Bluebond-Langner (1978) claims that critically ill children do not respond well to direct questioning. Thus, adult researchers should allow children to naturally engage in reasoning (Bluebond-Langner, 1978, Woodgate, 2001). Informal conversations are recommended when interviewing children (Woodgate, 2001) because when the interview has less structure, it will give greater control to the interviewees (Riessman, 1993).

4.4.2.1 The interview process

The location of the interview related to the participants' preferences. All the interviews were held face to face, and they were carried out either in the participant's room at the hospital or at home, depending on their wish. Two of the children preferred to go to a cafe for the interview.

All parents were interviewed separately from their children so that they would feel free to speak about personal aspects of their child's experience (Alderson and Morrow, 2011). Parents were invited, with their son or daughter's consent, to attend when their child was interviewed as it is normal for parents to stay beside their sick child. Parents can be useful in creating the connection between the child and the researcher (Scott et al., 2006). However, none of the parents wanted to attend when their child was interviewed and it was made clear that if they do not attend the interview I would not be able to divulge the information their child shared. All children were interviewed on their own. Literature has shown that interviewing children separately from their parents helps them express independent views (Alderson and Morrow, 2011, Gibson et al., 2005). Gardner and Randall (2012) also highlight that interviewing children away from their parents will allow children to express their experiences more openly. They also explain that the reasons a parent may choose to participate while their child is interviewed can vary from a desire to protect the child from distress to controlling the child's responses. Because the parents knew me before the interview, they trusted me and felt comfortable to leave their child alone with me for the interview.

A relaxed and private atmosphere was provided for the participants to talk comfortably about their experiences and perspectives (Braun and Clarke, 2013). Children are more likely to feel comfortable when they are in a familiar environment such as their home or at the hospital where they spend some of their time (Hennessy and Heary, 2005). In an attempt to make each interviewee feel as comfortable as possible, I asked the participants to choose the place for the interview so that they would feel free to speak in a private environment.

When interviewing children, topics should proceed from questions which are non-threatening such as questions about friends and hobbies, to more sensitive issues such as fears or concerns (Instone, 2002). Once the participant was greeted and thanked for agreeing to take part in the interview, the purpose of the research was again explained, and participants had the opportunity to ask questions. They were told that there was no right or wrong answer and that they had much to offer from their experience. After both the parents and the child had signed the consent/assent form (Appendices 8 and 9), the participants were asked if they were ready to start the interview. The interview topic sheet was used as a guide and not as set questions that needed to be followed. The ordering of the questions depended on how each participant responded to the questions. If the participant raised an issue which was going to be asked later during the interview, then the question was not asked subsequently. The discussions during the interviews were flexible and, even though the guide was planned carefully, the discussion was spontaneous. Once all the questions were asked, the participant had the opportunity to ask questions (Braun and Clarke, 2013). Because I have been involved in the care of the participants and they knew me before the interviews, this made a fundamental difference in their willingness to trust and share sensitive and personal information with me.

The interview guide contained a list of questions or topics to be covered which was designed to guide the interview in a focused manner but at the same time be flexible and conversational (Minichiello et al., 1992, Fossey et al., 2002). The topics included in the interview guide came from three different sources: the research literature, my pre-existing knowledge as a paediatric palliative care social worker and experience as well as from discussions with specialists in the research area (King, 2004) (See Appendix 11 for Interview Guide). As the participants had the opportunity to raise issues and topics that were not anticipated these were then added in the subsequent interviews (Braun and Clarke, 2013). Since the data from the children's interviews were compared with those of their parents, similar questions were asked of both groups.

Because I planned to compare parent/child experiences, it was important to have interviewed both the parents and the children, regardless as to the order of the interviews. If any of the children had worsened or died before they could be interviewed, then even if I had already interviewed the parent, the data gathered would not have been included in the study. Three of the children recruited for the study got worse and died before being interviewed; thus, their parents were not interviewed either. I did not encounter any situation where the parents were interviewed and afterwards I was unable to interview their children because of their worsening illness or death.

4.5 Data analysis

The interview data were analysed using thematic analysis which was used to identify the key themes (Braun and Clarke, 2013). This approach allowed for the description and interpretation of the participants' views (Smith and Firth, 2011). The benefit of choosing a thematic analysis approach is that it allows a comparison of results between the children's interviews and those of their parents (Bryman, 2012). Therefore, comparisons have not been made only between children and their parents, but also between children and between parents.

As Smith and Firth (2011) claim, qualitative research can lack transparency regarding the analytical process which in turn can lead to the failure of critically appraising the findings of the studies. To be transparent about the analytical process, details of the procedures are as follows.

The data analysis was iterative for each of the transcripts which were analysed initially throughout the data collection process. This allowed for the exploration of the concepts raised by the participants to be fed into subsequent interviews (Bailey et al., 1999). Subsequent data analysis involved the six-step process for thematic analysis outlined by Braun and Clarke (2006) which included familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

- Familiarising myself with the data included transcribing the interviews, reading and re-reading the data which was in Romanian and also noting initial ideas (Braun and Clarke, 2006).
- The next phase was the generation of the initial codes, features of the data were coded systematically across the entire data set, and relevant data to each code collated. The text from each participant was coded using NVivo programme and then annotated using comments to examine the passages that related to the research question (Mason, 2002) (see Appendix 12 for Coding Excerpt). According to Heidegger's circle of interpretation, analysis of the study involves a process of reading, re-reading and interpreting the transcripts (Taylor, 2014), which I have applied to my study as well.
- Searching for themes involves sorting the different codes into themes and gathering all data relevant to each potential theme. To identify patterns, the transcripts and coding frames were constantly reviewed (Braun and Clarke, 2006, Barbour, 2008).
- Themes were reconsidered; therefore some of the themes identified at an early stage were discarded or broken down into different categories (Braun and Clarke, 2006).
- The defining and naming phase includes the generation of clear definitions and names for each theme (Braun and Clarke, 2006).

- The results from the interviews of the children and parents were explored for similarities and differences (Barbour, 2008). The final phase produced a scholarly report of the analyses (Braun and Clarke, 2006).

Fossey (2002) says that qualitative analysis represents a process of reviewing, synthesising and interpreting data to describe and explain the phenomena or social worlds that are studied.

The NVivo data analysis programme was used because it provides a framework to structure the content of the interviews and offers an overview of the themes and how they recur in the separate interviews (Appendix 12). The NVivo programme uses powerful tools to organise and sort data in a single platform in a meaningful way to assist in categorising and in data analysis. Therefore data can be visualised better and connections can be explored (Bazeley and Jackson, 2019). In this way the use of the NVivo programme assures that the analysis process is rigorous (Richards, 2002, Maher et al., 2018).

Data were coded in Romanian and transformed into themes which were then translated into English. Nes et al. (2010) explain that the translation of quotes may be difficult because of the concepts for which specific culturally-bound words used by the participants. They recommend staying in the original language as much as possible to avoid potential limitations in the analysis as well as translating the most meaningful parts of the findings. Therefore, the data analysis was undertaken in Romanian, and only the quotes used in the thesis were translated into English.

4.6 Ethical Issues

Alderson and Morrow (2011) offer significant information about researching children. They comment that research and consultation with and about children raise ethical concerns which are addressed below. My research project was conducted in full compliance with Lancaster University’s ethical approval process. Ethical approval was obtained from a palliative care service in Romania (Appendix 13), and subsequently from the Faculty of Health and Medicine

Research Ethics Committee at Lancaster University (FHMREC) and Lancaster University Research Ethics Committee (UREC) (Appendix 14).

The project involved the participation of a potentially vulnerable population; namely children diagnosed with life-threatening or life-limiting conditions, as well as their parents. Therefore, it was essential for the project to be conducted in accordance to clear ethical guidelines. Children are especially vulnerable because they need protection and also because of the power relationships with the adult researcher (Einarsdóttir, 2007) who in this case was also involved in the care of the participants. However, Portenoy and Bruera (2003) claim that barriers are often imposed when conducting research with children, when, many children are capable of understanding the purpose of the study. Although children might not have the legal capacity to consent to participate in a research study, they still have the right to assent to participate if that is their wish (Masri et al., 2000). The children, as well as the parents from my study, were asked if they wanted to take part in the project. Understanding its purpose, they showed interest in participating because they understood that no one can explain better the experiences of children diagnosed with life-threatening or life-liming conditions. Participants can also find it empowering to be listened to and to be able to share their story even if there may not be any direct benefit to participation in the study.

Nairn and Clarke (2012) summarise the three most important human rights principles of research: (1) The well-being of the research participant; (2) The voluntary informed consent of the participants in a research project and (3) The commitment of the researcher to the confidentiality and privacy of the research participant. These principles were clearly explained to the participants and they were given the opportunity to ask questions about anything they did not understand.

According to the Research Governance Framework for Health and Social Care from UK (Department of Health, 2005), primary considerations in any research study are the dignity, rights, safety and well-being of participants. Researchers also have an ethical obligation to justify the benefit of their intervention, especially for the target population (Kane et al., 2000). All potential participants, whether they decide to participate or not in the research, must be informed about all relevant aspects regarding the research project (Oliver, 2010). After the interview, most of the participants said that it was therapeutic for them to talk about their experiences. The benefits of their participation in research will be for advancing the understanding of the experiences of children diagnosed with life-threatening or life-limiting conditions and for helping their families and healthcare professionals offer better care.

4.6.1 Information and consent/assent issues

Because I was involved in the care of the participants, initial contact with the potential participants was made through the manager of the palliative care programme who was not directly involved in their care. This measure was taken to remove any sense of obligation or coercion. The research required the parent’s consent and the child’s assent. Assent is defined as the child’s agreement to participate in research (Hammer, 2016, Department of Health, 2005) . Children are not able to give legal consent to participate in research, thus they needed their parents’ consent (Kumpunen et al., 2012). Initial consent was obtained first from the parents, then the children were asked if they wanted to participate in the study. In Romania, parental consent needs to be obtained up to the age of 18.

Before commencing the interview, participants were asked to read and sign the consent form. Participants were clearly informed of their right to withdraw from the study any time before or during the interviews and up to two weeks following the interview, without having to provide any explanations and without it affecting their care. If the child did not want to take part in the study, then their wishes would have been respected even if the parent gave consent. This was not the case as all the children approached decided to take part in the study. No incentives were used in the recruitment of the participants. Because children could have said that they were happy to participate, even if they were not, their body language was observed to assess if they felt uncomfortable with the research (Nairn and Clarke, 2012).

Participants were informed that their involvement in the study was voluntary. A detailed explanation was given explaining that the researcher is also a specialist involved in the care of the children. The participants were assured that they had no obligation to participate in the study and that their care would not be affected if they refused or withdrew. They were also told that the interview was for research purposes and that if they wanted to talk with the researcher as a member of their healthcare team, this would be done in a separate meeting or with another specialist. Arrangements were made to ensure that relevant information was provided in the appropriate form (Department of Health, 2005).

4.6.2 Patient Public Involvement Consultation

Being aware of how sensitive the inclusion of children diagnosed with life-threatening and life-limiting conditions in research is, particular attention was given to children and their families when recruiting them. Having worked with seriously ill children for over ten years I understand the difficulties in researching children’s experiences.

A major issue is how to sensitively approach children and their families about sensitive subjects particularly considering how potentially vulnerable they are. Nevertheless, Ireland and Holloway (1996) advocate that questioning children falls into the category of ‘minimal harm', and they consider the risk involved is minimal if the interviews are carried out in a sensitive way and the child/adolescent assents or consents to participate in the study. It is well known that many challenges are encountered when conducting research with children in a healthcare context, such as obtaining a child’s willing cooperation/consent or assent and safeguarding against distressing the child during the interview (Carnevale et al., 2008).

Being aware of how sensitive and potentially fragile children and their parents are, I conducted a Patient Involvement Consultation with three parents who had a child diagnosed with life-threatening or life-limiting conditions and who also receive hospice or palliative care. These parents were identified through the database of a palliative care setting which was caring for seriously ill children. Firstly, I explained to them that the research project was about exploring the experiences of children diagnosed with life-threatening or life-limiting conditions and I also showed them a draft Participant Information Sheet. I then asked them what they thought about the research project and if they believed it would be acceptable to potential participants. I also asked them if they thought it was too cumbersome.

One of the parents expressed her gratitude because someone was taking an interest in what a child with a serious condition feels and not just how healthy children feel. Another parent told me that professionals have a lot to learn from her child. The last parent that I talked with told me that her child would not be able to open up to talk with a stranger about his illness and how he feels about it. She said: ‘He would not talk to a new person, but he would share with you because you know him very well and he knows you.'

When I asked the parents about using words like ‘serious condition’ during the interview or in the information sheet, two of the parents thought they were suitable terms, but one of them said it would be better to avoid using these words. She suggested replacing ‘serious condition’ or ‘seriously ill children’ with words like ‘children attending palliative care’, which I changed as advised. Even though it was only one parent who suggested it, I chose to change the terminology. It was wise to be cautious with the terms used, as not all the children were aware of the seriousness of their illness. All three of these parents offered to take part in the study, thus I included them in the research after I had the assent from their children.

4.6.3 Balancing risks and benefits as a practitioner researcher

As an experienced paediatric palliative care social worker, I interviewed participants in a sensitive way. Being an insider researcher has many benefits in studying children because they are better placed than an outsider who does not know the children and does not understand the context of the medical condition. Children are open to sharing information with an insider researcher which would otherwise be difficult to share with a stranger (Alderson and Morrow, 2011).

Gans (1997) and Shah (2004) explain that a practitioner researcher has advantages over the outsider researcher because of the familiar patterns of social interactions which are required when it comes to having access to information and assigning meaning. My interactions with participants confirm what the literature demonstrates because parents, as well as their children, showed interest in taking part in a study with somebody they knew.

In a detailed study of communication between children with leukaemia and the researcher, Bluebond-Langner (1978) explains that the researcher's relationship with families and children makes a significant difference in what information the subject is willing to share. Francis (2006) highlights that the exploration of children's experiences of illness is only possible when the investigator has established a relationship of trust and openness with the child. This was found in my experience as children shared with me information they would not have shared in a different context. The data obtained from them and from their parents was specific to the context in which it was shared. As explained in the Methodology chapter, the knowledge produced was a result of my prior relationship and interaction with the participants.

According to Palmer (2006), an insider researcher is perceived as less likely to cause harm to the participants, especially because of the familiarity and comfort with the participants (Sikes and Potts, 2008). Sikes and Pots (2008) also claim that it is crucial for the child to be familiar with the investigator so that the child feels free to speak honestly with him/her. The parents felt at ease in leaving their children alone with me for the interviews and I found that it was comfortable for the children to share sensitive information as well. After the interview, many of them offered to share more with me if I needed more information from them.

Lobe et al. (2007) state that when adult researchers study child respondents, there is an asymmetry in power regarding the status, control and knowledge. Paus-Hasebrink (2007) claims that children should know that they are taken seriously, and they should have the opportunity to express their own understanding regarding their illness. This approach requires much empathy from the researcher which provides the opportunity for confident and free expression of thoughts and feelings on the part of children. Before the interview, I explained to the children that it was very important to have their perspective regarding their experiences and that what they were sharing would be extremely useful for healthcare professionals. Children felt privileged that they could be part of the study and make a contribution to a better understanding of their unique experiences.

Nevertheless, Clark (2003) argues that the uneven relationship between a chronically ill child and an adult caretaker or researcher can muffle the child's voice and perspective. In a research setting, children are subordinate to the research process. On the other hand, Davis (1998) claims that power relations between the adult and the child exist whether being insider or outsider researcher. However, Davis then goes onto explain that a non-authoritarian and friendly position of the insider or outsider researcher would make the child feel confident and secure. I used a friendly approach with my participants, as explained by Einarsdottir (2007), by telling them that they were my collaborators in my research and also talking with them in a relaxed manner to minimise any power imbalance.

Mercer (2007) points out that there are some drawbacks as practitioner researcher. It is possible that parents might feel compelled to participate in the research project because they want to maintain a good relationship with the specialist and they might also fear that refusing to take part in the study would negatively affect the services that their child receives (Flewitt, 2005). Children can also become vulnerable when a researcher approaches them, creating an obligation for children to please the adult (Alderson et al., 2004). Parents, as well as children included in the study, were told that their participation in research was entirely voluntary and their care would not be affected if they refused to be part of the study or if they wished to withdraw during the interview if it became distressing. They were also made to feel at ease with the process of the research and that the interview was a safe place.

4.6.4 Privacy and confidentiality

Confidentiality and anonymity are central to the ethical conduct of research. Some of the participants wanted to ensure that their data would not be identifiable. The majority said I could choose a pseudonym to protect their identity but some of the children chose their own pseudonym (Grinyer, 2009). The participants were assured that if any quotes from the interviews were used in publications, no personal or identifiable data about them would be divulged.

Special attention was given to the use and protection of participants' data. Data were managed in accordance with the Romanian National Ethics Council (2004) and also with the UK Data Protection Act (1998). Participants were assured about the confidentiality of their personal information and that a secure system would be used to protect their data. Each interview was conducted in the Romanian language and recorded using an encrypted audio device. Audio recordings were transferred in a password protected laptop which was also encrypted and I was the only one with access to the data. I was responsible for carrying out the transcription and anonymising the data.

Audio recordings were deleted from the audio recorder as soon as they were downloaded onto a password protected and encrypted laptop. The recorder was stored securely until data were transferred to a secure medium. The data were transcribed, anonymised and the voice recordings will be deleted from the password protected computer once the thesis has been examined.

At the end of the study, hard copies of the interviews will be kept in a locked filing cabinet in my office and destroyed by me after ten years time. I do not anticipate that I will change my job but if I do, I will remain responsible for the data, and I will take the hard copies with me and store them securely.

4.6.5 Assessing distress and support resources

It was anticipated that when discussing sensitive subjects, participants might experience some psychological discomfort. The parents and the children were informed that they could refuse to answer any question if it was a sensitive issue about which they did not feel comfortable or to withdraw from the interview. The interview would have been stopped if I observed any distress or if the participant had requested. They would have then been referred to counselling services (Department of Health, 2005). The Participant Information Sheet provides information on how the interviewees could access counselling services if they felt distressed as a result of taking part in the interview. During the interview, all the parents cried, but when they were asked if they wished to stop, none did. Most of them said it was therapeutic for them to talk about the experiences of their child. Some of the children cried as well, but none of them wanted to stop the interview.

Support resources were established to help me manage the stress involved in doing research in such an emotionally demanding and sensitive area.

4.7 Summary

The qualitative methodological approach allowed for significant data to be obtained from parents and children. The results obtained from the analysis are described in the following chapter, which is structured in two sections: the first presents the themes resulting from the experiences of children diagnosed with life-threatening or life-limiting illnesses; the second presents the same themes but from the parents’ perspective.

Chapter 5. Findings

5.1 Themes

This chapter presents the analysis of the data obtained from the interviews with both children and their parents. The chapter is structured around the six major themes which emerged from the data: (1) Awareness of the illness, (2) Death and dying, (3) The spiritual response to illness, (4) The emotional response to illness, (5) Striving for normality and independence and (6) Coping strategies. While physical condition, the medical procedures and the difficulties of living with their condition could be separate themes, because they are so integrated into every aspect of the children's lives, they are threads which run through the analysis. The first theme 'Awareness of the illness' is divided in two categories, given the clear difference between children diagnosed with life-threatening as opposed to children diagnosed with life-limiting illnesses. In the following themes there is an integrated discussion about children with either life-threatening or life-limiting illnesses.

5.1.1 Participants

Twenty individuals participated in the study, ten children and ten parents. Of the ten children who participated in the study**,** four of them had cancer and six were children with other life-threatening and life-limiting diseases (Table 3). All ten parents were the mothers of these children and were their main carers. All participants have been allocated pseudonyms. The interviews were conducted individually, with each child and each parent.

Children	Age	Diagnosis	School	Family context
Victoria	17	Muscular Dystrophy	Attending normal school	Parents together
Melissa	16	Epidermolysis bullosa	Attending normal school	Parents together
Paula	14	Autoimmune thrombocytopenia/Common variable immunodeficiency	Low frequency – normal school	Parents together
Patrick	17	Mixed Connective Tissue Disease/Dermatomyositis	Low frequency – normal school	Parents Divorced
Alisia	15	Dystrophic Epidermolysis Bullosa	Attending normal school	Parents Divorced

Denis	16	Duchenne muscular dystrophy	Not attending	Parents Separated
Flaviu	17	Stg IV Lymphoma	Not attending	Parents together
Damian	17	Abdominal lymphangioma	Attending normal school	Parents together
Anton	17	Acute lymphoblastic leukaemia (Relapsed)	Not attending	Parents together
David	16	Non-Hodgkin Lymphoma (Relapsed)	Not attending	Parents Separated

Table 3. The children's characteristics

5.1.2 Theme 1. Awareness of the illness

5.1.2.1 Children's perspective

The data indicated that there were a variety of awareness contexts across participants. 'Awareness of the illness' can be defined as simply knowing the diagnosis or the more complex understanding of what it means to be diagnosed with a life-threatening or life-limiting condition. Knowing the name of their illness does not necessarily mean that all the implications of the illness or the prognosis are understood.

Some of the children did not know the name of their illness, while others were more aware of not only its name but the long-term consequences regarding life expectancy. Some children found out directly from their parents or doctor about their diagnosis while others searched on the internet, or overheard family members and professionals talk, which enabled the children to know more about their disease.

The first part of this theme addresses the data from the children diagnosed with cancer who tended to focus on the severity of their illness. These children reported that they learned their diagnosis from the oncologist. They assumed it had been too difficult for their parents to communicate such a serious diagnosis. As Anton said: *'My mum couldn't tell me from the very beginning that I have cancer … she was too shocked, so I found out from my doctor.'* Most of the children diagnosed with cancer were not informed by their parents. There tended to be a delay of a few weeks after they were diagnosed before they were told. This delay was because the parents were not ready to tell their child the shocking news. This was confirmed by both children and their parents during the interviews. After Anton found out his diagnosis, he also realized that even if he is receiving treatment he can relapse. But he refused to accept the idea, saying: *'I knew I could relapse, but I thought it cannot happen to me as my bone marrow was clean.'* After he relapsed twice, he was more aware of the severity of his illness.

David received his diagnosis from his doctor two weeks after he had been diagnosed. He learned how serious his illness was from the long periods in hospital, the difficult treatment he had, as well as from seeing other children on the ward with the same condition. He spent almost a year in hospital having chemotherapy and during this time he saw some children getting worse and others dying. After a period of remission, he relapsed at which point he was even more aware of the severity of his condition: *'It is an extremely difficult and dangerous illness. It spreads rapidly, and there are high risks if it is not treated on time and even if it is treated, there are lots of risks during the treatment as well.'* Another child explained that he knew from the beginning the severity of his disease:

> *'After the doctor told me that I have cancer, I realised I would never be OK. She said that the treatment might work, but I didn't believe her. I have seen so many people with cancer on TV and I told myself it is not going to be OK. The doctor told me that I have no chance of survival.'*
>
> (Flaviu, Stg IV Lymphoma)

It can be seen how some children diagnosed with a life-threatening illness realized from the very beginning the severity of their illness while others saw how severe their illness was only after their experience with symptoms and the treatment.

While children diagnosed with cancer found out about their illness a few weeks after their diagnosis, children diagnosed with life-limiting illnesses other than cancer, experienced a different process**.** This is due to them being born with their disease, or diagnosed at a young age. They learned their diagnoses as they grew up which meant that it was a less straightforward process. Because they were born with a life-limiting illness, they tended to have a gradual realisation of their illness as it is illustrated in the examples below. They grew up accustomed to their condition and as little children, they gradually learned their limitations were not shared by other family members or by their peers.

While some of the children were not sure what their diagnosis was, others were knowledgeable about having a serious condition and what it was. The illness experience consisting of distressing symptoms, pain, physical limitations, prolonged periods in hospital, meant that they understood the implications of having a life-threatening or life-limiting illness.

Some comments from the interviews indicated that there were children who had never heard their diagnoses directly from their parents or from the doctor. Denis was diagnosed with a life-limiting condition at the age of ten, but he was never told what disease he had. His mother tried to hide the diagnosis from him to protect him. Knowing that it would upset his mother, he learned not to show interest in learning more about his illness: *'I don't remember how I got ill, I never asked my mum about this ... I was never interested in finding out more about it and I kind of got used to the way I am … I know mum avoids discussing my illness, so I leave things as they are.'* Denis acted as he believed his mother wanted him to act in order to protect her. He did not want to add to her burden of being separated from her husband and also of being on medication for depression.

Similarly, Melissa was never told her diagnosis. However, she learned more about it as she grew up, as she said, *'when my mum was talking about me with her friends*' and '*as I grew up, I realised how serious my condition is.'* She explained that she was not sure if she had been born with her illness or if she got ill when she was very young. Her mother would often cry and be distressed during the conversations she had with friends about Melissa's condition. However, she had not been aware that Melissa was paying attention and overheard. Along with the clues she got from her mother's conversations as well as her deteriorating physical condition she progressively understood the severity of her illness.

Unlike Denis, who claimed that he did not want to find out more about his illness, Melissa expressed her desire to know more: *'It was only after my teeth fell out that I knew it was because of the disease. I would have liked to have known beforehand.'* After she realised that her illness could be unpredictable, she started to live with the fear of the unexpected things her illness could bring: '*When I was little I was not aware how it was going to be and what would happen to me … now I worry about what could happen next.'*

Even children who knew more about their condition had the same fear of the unpredictability of its course. Alisia, whose mother was trying to be open with her daughter about her condition, said '*You never know what tomorrow brings … I could be worse than I am right now, or I could be bette*r'. Patrick also confessed: '*I often think that my condition could get worse. I don't know why but I am that kind of person who always thinks of the worst.'* Alisia and Patrick were aware that their illness could have complications because it was explained to them by their parents.

Other children lived with the uncertainty of an unconfirmed diagnosis. Victoria was suspected of having a form of muscular dystrophy as she had all the symptoms and complications of this disease. However, she never had the final test to confirm the diagnosis.

> *'Some of the doctors say that a child diagnosed with this disease lives no more than a year. It means that there are not too many chances for survival … they were saying that the longest survival with this disease might be no more than seven years. And that's why I didn't want to believe that I have this disease. Then I was in the hospital and the doctor told me that it might not be this disease … So, right now I am not sure about my diagnosis.'*
>
> (Victoria, Muscular Dystrophy)

While Victoria had been told by some of the doctors that it was likely her symptoms indicated that she had muscular dystrophy, she resisted having the tests that would confirm it. As long as she did not have confirmation of her illness she could deny it. She had her suspicions regarding her diagnosis, but because it was not verified, she was able to ignore her diagnosis to some extent.

She became suspicious that she had a life-limiting illness because of her unusual bodily appearance and repeated periods in hospital due to complications she had. Victoria vacillated between ignoring her diagnosis and the desire to know more about it. She was not content with her doctor's explanation, and she realised her mother would not tell her more, so she searched the internet for the diagnosis of the illness she suspected she had. It seems it was easier for her to search the internet than to have a test to confirm the illness, maybe because her mother did not encourage her to do the test.

> *'Honestly, mummy never wanted to scare me; she didn't want me to see other children like me because she didn't want me to be shocked … so I was curious and I searched on the internet and I found the disease.'*
>
> (Victoria, Muscular Dystrophy)

It was surprising that even though she said that she did not want to know her diagnosis, she sought information and as a consequence, lived with the fear of having a form of muscular dystrophy and all it implied for her future.

5.1.2.2 Parents' perspective in comparison to their children's accounts

The results of the interviews with the parents related to this theme showed that they assumed either that their children did not know much about their illness, or that their children knew more about their illness than they had told them. Parents of the children with cancer were more likely to hide the diagnosis from the child but knew that their children would eventually find out.

Almost all the parents of the children diagnosed with cancer tried to hide the diagnosis from their children when they first learned about it. Damian's mother stated: '*I couldn't tell him that he has cancer. The doctor told me that his illness is critical and that he doesn't know what will happen … I did not have the courage to tell him about it.'*

Some parents were so shocked about their children's diagnosis that it made it difficult for them to be truthful with their children. Some of the parents even chose to give their children misleading information. Anton's mother explained how angry her son was when he found out that she had hidden the diagnosis from him:

> *'He asked me what he has, and I told him it's anaemia. He started to search on the internet right away. Because of the internet you cannot hide anything. The doctor told him the diagnosis three weeks after he was diagnosed. That was the moment when he became so angry with me, and he kept asking me why I lied to him?!'*
>
> (Anton's mother, Acute lymphoblastic leukaemia)

Because my participants were between 14 and 17 years of age, their doctors considered them mature enough to understand their illness. Therefore, the oncologists communicated the diagnoses directly to the children when they saw that the parent had not told them the truth. This caused a delay of several weeks before they were told their diagnosis.

However, even if children with cancer were told their diagnosis by their oncologist, parents still hid some information about their disease to protect their children. Damian's mother confessed:

> *"I couldn't tell him what was going on. When we were in the hospital, I pretended to take a shower so that I would be able to cry alone. Then, when I calmed down a little bit after the shower, I told him, 'They took out part of the tumour, but not all of it.'"*
>
> (Damian's mother, Abdominal lymphangioma)

The doctors could not remove any part of his tumour, but Damian's mother struggled with her fears which led her to hide information from him. Some parents believed it would have been too difficult for their children to handle information about their illness, so they decided to conceal the reality from them up to the point when the doctor communicated directly to the child. As in Anton's case, children would get upset and angry about being misinformed.

Another example was David who was aware of his diagnosis and the potential complications. David's mother collapsed when she learned that he had relapsed. When she tried to explain what her son knew about his diagnosis she said: *'I don't know what he knows. You need to ask him, or I can ask him. I told him that he doesn't realise how dangerous his illness is and that he can die because of it.'* She could not stand his calm attitude toward his illness which made her try to frighten him with the worst. David was able not only to handle information about his illness, but he was able to handle his mother's attitude toward his illness. While he struggled with his fears, he kept a calm demeanour in front of his mother. David realised that his mother did not cope well and he tried to protect her by assuring her that she did not have any reason to worry. The interview with the mother revealed that she interpreted his attitude as not realising how serious his condition was, rather than David protecting his mother. However, she admitted her son was better than she at handling information about his illness.

Regarding children diagnosed with life-limiting illnesses, parents proved to have misconceptions about their children's beliefs when comparing their responses to those of their children. Victoria's mother claimed that she did not do all the investigations to confirm her diagnosis because she was terrified of what she might have learned. She was not even aware that her daughter knew more about the disease than she assumed. When she was asked about what worried Victoria, she explained: '*I cannot say too much because we don't know much about the diagnosis, we were not really interested to know more … we were concentrating about her immune system because she had lots of complications.'* While Victoria's mother said that neither of them was interested to '*know more about the disease*', Victoria said that she searched the internet to learn more. Victoria’s mother was unaware of how much her daughter knew about her illness. From the previous section, we can see that Victoria was resistant to having her diagnosis verified. However, her mother’s comments suggest that Victoria’s attitude was likely to be shaped strongly by her mother’s advice or reluctance to find out more about her illness.

Another example is Melissa's mother who believed that her daughter knew more about her illness than she had explained to her. She said:

> *‘I think she knows almost everything about her illness, but she does not talk too much about it. She doesn’t ask too many things about her illness. She doesn’t often ask me to give her explanations. Or maybe she doesn’t know too much, but I think she knows.’*
>
> (Melissa’s’ mother, Epidermolysis bullosa)

Melissa explained that she would have liked to have known more about her disease, but she had not searched on the internet to find out more. Instead, she gathered information when she heard her mother talking with her colleagues or friends about her illness. Her mother admitted: ‘*I didn’t spend time with her talking about this terrible illness that is tormenting her.’* The reason her mother concealed information is explained in the following comment:

> *‘When she was not feeling OK, I always tried to tell her that everything was going to be all right. When she was fearful, I tried my best to get her out of that mood. I have never gone with her into the depth of the disease. I once searched on the internet, and I felt sick after reading. So, I said to myself I would never search again. It affected me so much to read about her illness … So, I don’t want to tell her because it consumes you a lot mentally. And even if she is aware of some things about her illness, I don’t want her to understand everything about it.’*
>
> (Melissa’s’ mother, Epidermolysis bullosa)

Melissa’s mother thought she was protecting her by not explaining her condition, not realising that it made Melissa more anxious not knowing the truth.

In contrast, there are comments from the data which illustrate that some children were aware of the severity of their illness and they also knew that they could not be cured:

> *‘He hears about his illness from different people, or even from the doctor, and he knows that he has a very rare disease and it is incurable. He already knows that there is no treatment in the world … the treatment he is doing is not curative … you know that with his condition no two days are the same. Today he might be feeling OK and tomorrow may be his worst day. He has grown accustomed to that and was even at peace with the daily changes.’*
>
> (Patrick’s mother, Mixed Connective Tissue Disease)

However, while Patrick claimed that he was aware that his condition could get worse, his mother thought that he only knew that his illness was incurable, but not that he was also aware that he could get worse. Having a close relationship with her son she thought she knew everything about him. It seems that not only do parents try to protect their children from distressing information, their children sometimes pretend not to know they could get worse or in some instances die, to protect their parents. Patrick was used to talking about everything with his mother, but he realised it would be hard for her to handle knowing that he was aware that his condition was so unstable that he was likely to get worse or even die.

Denis was never told he had been diagnosed with a form of muscular dystrophy and his mother thought it would be for his own good to hide the reality from him. There were rare occasions when he would ask if he would ever be able to walk again and his mother pretended that she did not know the reason his muscles had weakened. ‘*Muscular dystrophy is such a hard illness, so I did not want him to know he would progressively get worse. I always tried to change the subject and make him think of other things. Now he is not asking anymore because I have* *taught him not to ask.'* Denis's mother recognised that her son would not ask anything about his illness because she had closed down open discussion with him. She admitted that she refused to talk with him and avoided having discussions about sensitive subjects related to his illness.

While some children matured early because of their illness, Denis seemed to regress because his mother always treated him like a child. His mother recognised that because she protected him he did not have the cognitive age of his peers. Though she was trying to protect him, her attitude did not allow him to mature, moreover, it estranged him from her. She confirmed that she thought she was protecting him by keeping him in ignorance, but the result was he *'withdrew into himself'.* As a result, she was unsure if it had been the best decision to hide information about his illness.

5.1.3. Theme 2. Death and dying

5.1.3.1 Children's perspective

Another theme found in the interviews were the children's thoughts about death and dying. This makes an interesting contrast with parents' perspective on their children's view on death and dying. Each child talked about death without being directly questioned about it. Specifically, many of the children's comments evidenced their awareness that they could die from their disease or exposed their worries about death and dying. Several children expressed their desire to die because of the difficulties they faced from their disease. Patrick, who struggled with lots of pain and whose daily activities were profoundly affected by it, explained:

> *'There are times when I have so much pain and I concluded that I cannot stand it anymore. I said to myself that I'd be better off dead so I would not have to suffer any more. I would not have to stand so much pain. I thought that it is useless. There is no reason to struggle like that! It's not worth it!'*
>
> (Patrick, Mixed Connective Tissue Disease)

Patrick's comment evidenced how much suffering he faced because of his illness. He also said that if he did not have a specific reason to live, he would have considered death a welcome escape. The relationship with his girlfriend was a source of support for him and it gave him a reason to live.

Similarly, Melissa reported that *‘It would have been better if she had not existed’* because of the pain she experienced daily. Melissa experienced deep wounds all over her body as well as joint and tooth pains which often prevented her from attending school or home activities. As a result of these experiences, she thought ‘*when it hurts me so badly, I think I cannot continue to live like that’.* She found herself overwhelmed by the issues related to her illness, like the blisters and painful sores on her ultra-sensitive skin caused by even minor contact. She also said she did not talk openly with her mother about her concerns. Having thoughts about dying and not sharing them with her mother made Melissa feel alone in her concerns and worries about it. It was not that she would not be open to talking with her mother about it, but she was aware that her mother would not be able to handle painful conversations about her thoughts and feelings regarding death.

While children like Patrick and Melissa almost welcomed the prospect of dying because of their pain and other issues related to their illness, there were children to whom the fear of death affected their wellbeing. Unpredictable experiences linked to Victoria’s illness, such as loss of consciousness, repeated colds that could be fatal, or the inability to breathe normally had led her to confess that she had panicked at times because *‘who knows what is going to happen with me!?’*. Victoria was afraid of a sudden and unexpected death which was why she was afraid of being left alone for even short periods of time. For example, Victoria and her mother once visited her grandparents in the village; while Victoria was left alone in the house for a short time, she was not able to breathe normally; when her mother returned she found her blue and unconscious. Fortunately, the ambulance came in time to help her. This experience caused her an ongoing fear of sudden death.

However, not all the children openly admitted their thoughts and concerns about death and dying. Paula refused to think about death as she claimed:

> *'I do not think about death … because you know how it is with death ... you do not have to think about it, because if you think, you do not live your life. Why do we have to think about it?! Leave it alone as it will come in any case.'*
>
> (Paula, Autoimmune thrombocytopenia)

She compared herself with children diagnosed with cancer: '*those who have leukaemia and cancer stay in the hospital for eight months or so and if they don't die, they heal. But I am not healed! I still have to go to the hospital.'* While Paula was aware that the children with cancer who did not respond well to the treatment had died or would die, she constantly had to go to the hospital for treatment and knew she would have to do this her whole life. This meant that her pain would never be over. As a result of her repeated periods in the hospital and related complications to her illness, she admitted: *'I am not sure if I will die because of my illness, or if I will die because of the other complications of my disease.*' Initially, as shown in her first comment, she refused to think about death, however, later during the interview, she revealed that she was aware she could die because of her illness.

Unlike Paula who was comparing herself with children with cancer, Alisia compared herself with healthy people and tried to avoid thinking about death:

> *'I've seen many healthy people who were well and maybe the next day they died because of a car accident. You cannot know what the future brings. You must live the present and enjoy everything. There is no point in thinking what will happen tomorrow!'*
>
> (Alisia, Dystrophic Epidermolysis Bullosa)

Several children diagnosed with cancer discussed how they started to view their future negatively as well as feeling hopeless because they were aware that their illness threatened their lives. Their whole life was shaken at the diagnosis and as Flaviu expressed it, *'I was terrified that I would die'*. After he started chemotherapy, he vacillated between fear and hope; fear that the treatment would not work and the hope that he would get better.

Anton did not acknowledge explicitly that he could die because of his illness, but his comments indicate that he was tired in his fight for life:

> *'I was thinking that I had tried for two years to do the treatment and it did not work. Why should I try doing the treatment again if it did not work in the last two years when I have struggled so much?'*
>
> (Anton, Acute lymphoblastic leukaemia)

Anton conveyed that he did not want to fight for life but at the same time he confessed that he wanted to live: '*I was not so scared by the thought of dying but what I want is to live and have a normal life.*'

This 'normal life' that he was longing for might never be achievable for him. If we look at Anton's experience through the lens of Paula's earlier quote, that children with cancer don't stay for extended periods in the hospital as she does, then we see that her assessment is skewed. While there was a long process of treatment and periods in the hospital for children with cancer, both Anton and Paula were tired because of the even longer treatment and repeated periods in hospital.

Damian compared himself with healthy people when he talked about dying. We saw in the previous section that he was in shock and very afraid that he was going to die because of his condition. As he started treatment and he processed all the information he had about his illness he tried to normalise his thoughts about dying:

> *'Anything bad can happen to me. My condition can get worse; I can die … but I guess it's normal to think about dying. I think anyone can think about that because you see so many problems happen to even healthy persons.'*
>
> (Damian, Abdominal lymphangioma)

In contrast, David refused to think about death. He could not imagine himself dying even when he was in the hospital while several children with a similar condition to his had died:

> *'I cannot think about dying … I am responding well to the treatment; the blood tests and the biopsy are OK. I don't expect anything bad happening to me. I am trying to do everything the doctor is asking me and to be good … I have never asked myself what the worst would be.'*
>
> (David, Non-Hodgkin Lymphoma)

His mother often reminded him of how serious his condition was, but he refused to think *'the worst'*.

5.1.3.2 Parents' perspective in comparison to their children's accounts

The interviews with the parents bring a different perspective to what their children said about death and dying. The interviews revealed that the parents were not always aware of their children's thoughts about death.

For example, dying was a recurrent thought for Melissa, but her mother was not aware of it. For her, Melissa was still the *'little girl who cannot think of such serious things'*. Her mother recognised that she avoided having sensitive conversations with her daughter:

> *'I have tried to run away from the reality we live in; that is what I do, I am running away to escape. I know she can die from her illness, but I would go crazy if I would think of that all-day long … it is too painful for me to think of that and my soul aches more than anything. It is too much for me to keep that thought in my mind that when would she die.'*
>
> (Melissa's mother, Epidermolysis bullosa)

There were also parents and children who focused only on discussions which were positive. Alisia's mother claimed that she started to encourage her daughter to be positive at a very young age, '*I always tell her not to think of the worst. We don't talk about death at all.*' The attitude of Alisia’s mother encouraged her to look on the positive side of the things regarding her illness. While they had a close relationship, her mother did not allow any conversation about Alisia’s fears. Some parents avoided telling their children the truth even as they asked direct questions. Damian’s mother explained how difficult it was for her when her son asked her if he was going to die:

> *‘He was wondering if he was going to die, then he would ask me ‘Mummy, I am dying, am I not?’ … And I told him he would be all right, even if I didn’t believe what I was saying, but I was just trying to encourage him.’*
>
> (Damian’s mother, Abdominal lymphangioma)

While Damian’s mother was trying to deal with her feelings she had to answer his *‘dozens of questions about dying’.* As she said: ‘*He was so afraid that he was going to die. That thought was a torture for him. He was always thinking about what was going to happen to him.’* Damian was truthful with his mother about his fears and she realised it would be difficult for him to hear directly from someone that he could die, so she tried to conceal the truth from him to protect him.

Similarly, Anton’s mother was not able to talk with him when she received bad news from the doctor about his medical condition. When he eventually found out the truth from the doctor or sometimes from his mother, he tried talking openly with his mother about his thoughts. When he relapsed, Anton did not want to do chemotherapy again: ‘*He told me he was only doing the treatment for me as he knew how much my husband and I were suffering.’* At the second relapse he revealed again to his mother his deep feelings:

> *‘He does not want to go through the difficult treatment again. He was saying that he would rather die. He did not have any confidence that the treatment would work for him... but he still had the power to talk, eat and also do the treatment.’*
>
> (Anton’s mother, Acute lymphoblastic leukaemia)

Anton’s mother confirmed his ambivalent thoughts about the desire to fight for life or to give up. This depended on his medical condition and how he was feeling, ’*When he found out about the third relapse he felt terrible, hopeless … he didn’t care if he would die. It was so hard to convince him to do chemotherapy again.’* His mother confessed that when he saw her collapse, he would try to encourage her:

> *“When the doctor told me to expect the worst, I cried a lot and I called my husband telling him I don’t want our son to die. And I thought Anton was asleep, but he heard me and he asked me: ‘Why are you crying? Do you think that I am going to die? I am not going to die.’”*
>
> (Anton’s mother, Acute lymphoblastic leukaemia)

As it can be seen, some parents were either trying to conceal information about the diagnoses or prognosis from their children, or they were not aware of what their children knew about their illness. In both instances, the communication between parents and children was not open. The consequences are described in the theme about the emotional response to illness.

5.1.4 Theme 3. The spiritual response to illness

5.1.4.1 Children’s perspective

Comments on spirituality were offered spontaneously during the interviews. Some of the participants mentioned spirituality as a source of support and other participants turned their anger and frustrations on God. Most Romanians identify themselves as being Christians even though Romania is a secular state and does not have a state religion (WorldAtlas, 2017). The largest religious denomination in Romania is the orthodox church with over 80% of the population declaring to be Orthodox Christians but only 1% of the population claim to go to church regularly (Stan and Turcescu, 2000, WorldAtlas, 2017). Nevertheless, Stan and Turcescu (2000) explain that orthodoxy represents an essential and vital function of Romanian culture which may explain why God was mentioned in almost all the responses of the participants as being a source of support or the reason for their suffering.

Some children tried to find a purpose for being ill and not being able to find a reason was a great discomfort for them. Melissa said, *'I am often sad and upset, wondering why do I have to be like this?'* She was aware that God is good and He would not harm her, but this did not offer much support because she couldn't find a personal reason for being so ill. Anton also wondered why he had to be sick, but he said that '*there is no answer to that question.*' He was upset and angry as he asked: *'Why would God allow me to suffer and take my life while other teens are killing themselves or don't drive carefully?'.* He thought that God was unfair and unjust, so he turned his anger toward divinity. He put all the blame on God for him not being healthy, for losing his adolescence in the hospital and fighting with the illness.

Similarly, Patrick had many unanswered questions and thought life was unfair to him. He could not find a reason for being so ill:

> *'Sometimes I wonder, why do I really have to be like this? Why do I have to be so ill? There are so many healthy people who don't have to worry about anything and they have money and they have all they need and their life is so much better compared to mine and some of them are bad people.'*

(Patrick, Mixed Connective Tissue Disease)

Patrick expressed his anger and frustration at being ill. This was similar to Melissa and Anton.

> *'When I am in excruciating pain, I feel so upset! I am already tired of it and I cannot think clearly in those moments! I cannot stand it and I am getting really upset. Honestly, I am getting upset at God wondering why He would allow so much pain in my life. I think that He doesn't care about me and He can't be bothered to look after me. In my pain, I feel very scattered in my thinking and I don't know what's wrong with me. I know I'm not thinking right, but that's how I see it.'*

(Patrick, Mixed Connective Tissue Disease)

Patrick had ambivalent thoughts about God. Sometimes he had overwhelming feelings related to his illness, accusing God of not relieving him of his troubles, but he also thought God was just.

> *'I couldn't find any answers to my questions. I have not received any sign from above to explain to me that this is how it should be, or this is what is ordained for me. I mean, I am aware that God gives us as much as we can bear and He never allows more in our lives than we can carry. But why would He give me this illness? He loves us all the same, so why would He want some of us to suffer and deal with all these hardships? It is so hard! You have one life to live and you would wish to do things and go here and there, you want more from this life because you are young, but you cannot because you are ill.'*
>
> (Patrick, Mixed Connective Tissue Disease)

At the same time, there were children like Damian, who was raised in a Christian community and who said that he found much comfort in putting his trust in God. He also said that he could not imagine himself going through this experience without God's help, his family, and friends. He explained how the church had provided a lot of emotional and spiritual support for him. He hoped and wished that either new technologies would be discovered to treat his illness or, as he said, '*I pray that God would heal me and make my tumour disappear.*' His trust in God was rooted in the way he was raised in the family, inspired by the examples in the Scripture of people who put their hope in God in their suffering.

Other children came to the conclusion that medication was not helping them to heal so they believed that it was only God who could heal them. Paula, who acknowledged that there was no cure for her illness and that all the treatment she took was for her symptoms, believed that if she did not respond well to the treatment, *'there is another way, to believe in God who can do miracles.*' Trying to picture herself in the future she said:

> *‘I know that I will be ill all my life … my illness is so unpredictable; I don’t know how I will be in the future. I think that I will be fine, that I will still be able to paint and I will live like this and one day I will be healed. But not healed by the treatments but with God's help. That's how I see it!’*
>
> (Paula, Autoimmune thrombocytopenia)

Victoria had a strong faith in God. She came to the conclusion that it did not help to complain and be upset about her illness and she decided to live her life the best way she could. She thought that her illness helped her to become a better person and she would live a meaningful life despite her difficulties.

> *‘I realised that God made me like this with a purpose. And my purpose now is to show everybody that someone can live like this and all you need to do is not to complain, but to persevere. I have to be thankful!’*
>
> (Victoria, Muscular Dystrophy)

She had ups and downs, so she would not always be so positive, especially when she thought that she might not live long or when she was panicking at the thought of what might happen to her. However, she encouraged herself and found comfort in what she believed to be God’s plan for her life. She realised that she had control over her feelings and she did not want to let herself down. She stated:

> *‘I know that God has a plan for me … and that I cannot change His plan for me. I can change what I am doing with my life, but I cannot change how I am going to die; this is not up to me! I want to do it the best I can for the part that depends on me!’*
>
> (Victoria, Muscular Dystrophy)

5.1.4.2 Parents’ perspective in comparison to their children’s accounts

Parents, like their children, brought spirituality into the discussion without direct questions which suggests that it was a significant aspect of their experiences. They shared their children’s anger and frustration about their illness as well as being angry with a God who could allow such suffering. Nevertheless, some parents said that their child trusted God or found comfort in Him.

Some of the parents' accounts of their children's experiences coincide with what their children shared about their spiritual insights. However, some parents offered even more detailed accounts of their beliefs regarding their children's thoughts. Anton's mother explained the rage he had because of his illness and how he thought God was responsible for his suffering.

> *'He is so upset that he must fight for his life instead of enjoying being a normal child, going to school, learning, taking his college entrance exams. He gets angry at God that he has to fight for his life when he hears that there are young people who get drunk, who use drugs … one of them had a car accident after drinking too much and he lost his life … and he was only 20 years old.'*
>
> (Anton's mother, Acute lymphoblastic leukaemia)

His mother described how Anton perceived God: *'He beat me up!'* She thought Anton felt that God unfairly allowed him to get sick: '*He thought there was no point in praying to God because God does not answer, especially when he had his second and third relapse. He is so furious; his fury is as big as all of China.'* Knowing that his mother prayed for him to get better, he made it clear to his mother that he was sure medication helped him and that God had nothing to do with him getting better.

The anger felt by some of the children toward God was recurrent in their responses and was reflected in the parents' responses. The anger accompanied by the question *'Why me?'*, was mentioned by several parents who explained their children's frustrations about their illness. Damian's mother said that her son often asked her: '*Why do I have to be so ill? Are the other children better people than me? Am I the worst of them all?'* His mother also explained that in his agony, he would find comfort through prayer and the minister from the church who helped him to see his illness from a different perspective.

While Alisia did not mention spirituality being her comfort, her mother explained that for Alisia, '*her trust in God's sovereignty over her life brought her much comfort'*. Her mother was encouraged by her daughter's attitude, but she often wondered why God would allow so much suffering in her daughter's life.

5.1.5. Theme 4. The emotional response to illness

5.1.5.1 Children's perspective

The stress of living with a serious illness was evidenced by a variety of emotions. Children explained how they felt scared, depressed, upset, angry, stressed, disappointed or anxious about different issues related to their illness.

A recurrent feeling of sadness accompanied by depression, mood swings and anxiety was identified by the participants.

> *'I often have a bad mood. I mean, I am upset, uneasy … it can easily be seen on my face how I feel; I don't wanna talk to anyone, I just want to be with my thoughts. I feel horrible … sometimes I cannot cope and it is like depression. I find it hard to live with the idea that I am so ill.'*
>
> (Patrick, Mixed Connective Tissue Disease)

Patrick was overwhelmed by his illness which was shown in his depressed mood. He would try to cover up his feelings by doing things that would bring him joy, but he was often overwhelmed by his intense negative emotions which he could not control. Fluctuating emotions would make him withdraw from his normal activities and make him want to be alone with his suffering. However, the more he withdrew the worse he felt. He claimed that his *'bad mood'* prevented him from enjoying the moments when he was not feeling so sick. He also explained that when he could cope with his feelings, he was able to come out from that *'bad mood'*.

A depressed mood was also mentioned by Victoria who had a form of muscular dystrophy. She said that she was perceived by her family and the people around her as a cheerful and a positive person, full of desire to confront the difficulties brought by her disease. She confessed that *'once in a while I feel depressed … disappointed.'* These feelings were triggered by specific situations in her life. For example, not being able to use her hands as she used to, made her feel ashamed and *'overthinking it'* made her feel depressed.

It was common for the children to struggle with sadness because of their condition but they showed it in different ways. Melissa, who was also a participant with a life-limiting condition, confessed her internal turmoil: *'I am sad many times because of my illness … too many times … I am worrying and troubled inside and I usually cry for about an hour. Then I calm down.'* Melissa, a shy and sweet-natured girl, who endured pain and struggle because of her illness, was very cautious in talking about herself with her peers and other people. On the outside, she would have shown people a beautiful and bright smile even if her visible wounds and physical appearance indicated a life full of suffering.

The children were aged between 14 and 17 and thus considered mature enough to understand what it means to be diagnosed with a serious condition: *'I got really scared when I was diagnosed, I was shocked and I thought the worst,'* explained Flaviu. Because it was so difficult for him when he was told his diagnosis, he could not talk with friends and family members about his condition. From then, he decided to be silent about his thoughts and feelings regarding his illness. As he could not talk about his feelings with family and friends it made him feel alone. He said that sometimes he talked with other children with cancer from the hospital about issues related to their illness. What was surprising was that he offered to talk about his illness with other children who had been diagnosed with cancer and needed some encouragement, because he knew how difficult it was to be alone. I explained that I would investigate the possibility and that we could talk about it after the interview.

Anton expressed how tough it was for him when he learned that he had relapsed *'it was so disappointing and I was so upset and angry about it'*. He realised that he had to stay isolated for the transplant and he confessed: *'I am terrified of staying in one place for so long, I hate that I have to be away from everybody.'* He was so angry that teenagers who were careless about their lives were free to live as they wished. Meanwhile, he, who had complied with everything the doctor had asked him to do and who wished so much to live, had to start another round of chemotherapy and would not be able to enjoy life and to go out with his friends.

Some children claimed that they felt like they were '*in prison'*, isolated and alone in the hospital and also stressed, fearful and anxious because of treatment and medical procedures: *'The medication makes me feel so irritated … I feel like I cannot control myself, I feel like yelling and getting angry with everything'* (Paula, Autoimmune thrombocytopenia). For those reasons, Paula often refused to go to the hospital. She was so exhausted and emotionally burdened because of the frequent periods in the hospital, that she would be resistant when she had to go to the hospital. She commented that the frequent periods in the hospital '*makes me have nervous breakdowns and be a different person.'* She would not refuse treatment directly, but she would initially refuse to go to the hospital almost every time she had to go. Even though she did not want to go to the hospital, her mother would always have the last word and they would eventually go for the treatment. Paula's reaction was understandable because she was exhausted by these repeated hospital stays and she sometimes missed special occasions because of it. She also compared herself with children diagnosed with cancer: '*I saw so many things in the hospital, children who are not able to cope with their illness and die and I think I become stronger because of that.'* Paula considered herself a '*happy case'* because she was *'better than the other children.'*

Denis denied his suffering when he claimed several times that his *'illness doesn't bother me'* or '*I am OK the way I am'*. However, his statements were not consistent with his behaviour as he refused social interactions. This could imply that he was not as comfortable as he professed.

Non-cancer children were more worried than cancer children, that they would not be able to get a job when they grow up. They sometimes lost hope in their ability to accomplish different things for their future. As Alisia commented: *'I cannot do many things … for me it is so difficult.'* They expressed their desire to do things they knew they were not able to do. However, they could not picture themselves performing them, or even hope to do them in the distant future.

While children's worries and fears made them live with many negative emotions, at the same time they could be hopeful that something good might come. Most of the children interviewed reported their desire to get better. Talking about his hopes, Damian, whose tumour was inoperable said:

> *'I often think how it would be if my tumour would just disappear. I wish that the scientists would find a method for making it disappear or that a miracle would happen. At the very least I wish that my tumour would not get worse.'*
>
> (Damian, Abdominal lymphangioma)

An interesting finding in participants was hope, which Damian mentions in the quote above, for medical science to discover a cure for their disease. Denis, a 15-year-old boy diagnosed with a life-limiting illness, reported that he was looking forward to a cure for his illness. Their hope for a treatment to be discovered gave the children the determination they needed to fight their fears and the strength to move forward. Alisia dreamed of the day when she would not be hindered by her wounds in her daily activities:

> *'I wish I didn't have so many blisters because they are so painful. It's harder when I have them on my feet because it makes it difficult to walk and it hurts a lot. I would*

> *like to have fewer wounds, or I don't know, to find a special ointment for my wounds.'*
>
> (Alisia, Dystrophic Epidermolysis Bullosa)

Patrick, diagnosed with Mixed Connective Tissue Disease, also said: *'I'd like to get to a competition on TV. That's what I'd like to do when I will feel better.'* He started to learn to play guitar and take canto lessons to pursue his dream. Children's hopes and wishes helped them cope with their illnesses and this issue is developed under the theme about coping strategies.

5.1.5.2 Parents' perspectives in comparison to their children's accounts

The insights provided by parents regarding the emotional responses of their children to illness show that they were aware of their children's emotional struggles. But parents also brought a new perspective to what the children shared about their emotions.

While Patrick's mother thought the hardest thing for him was his struggle with the pain, he was more troubled by the waves of sadness that came over him from time to time which would prevent him from fighting with his illness. As she said:

> *'He is often in so much pain … that's such a painful disease. As you see now, that's what eats him up, his pain! ... it hurts him so badly that sometimes he wants to scream. He is always complaining because of the pain.'*
>
> (Patrick's mother, Mixed Connective Tissue Disease)

Patrick and his mother had a close relationship**,** and he shared with her his *'deepest concerns'*, as she indicated. However, she was not always aware of his sadness. She knew about his struggle with the pain because it was something evident that she could see.

Some parents had a greater understanding, such as Anton's mother who confirmed his rage towards his illness**,** and she was able to articulate his rage in the following quote:

> *'He is angry, so angry because the illness forced him to stay in hospital … anger, anger, anger and I can say this a thousand times. He is angry because he does not*

> *have a normal life, because he is not a normal child, because he is different from the others, because he suffers terribly. He is also angry because he has no certainty that he will be all right. That's what he always says, you know, rage, anger, anger!'*
>
> (Anton's mother, Acute lymphoblastic leukaemia)

Anton was angry because of his illness but also because his mother and his family were determined that he would continue chemotherapy after his second and third relapse and also have a cell transplant. He thought that if he could give up chemotherapy and start natural cancer treatment, such as detoxification and juicing, his medical condition would stabilize. His mother explained how he would respect her decisions to continue chemotherapy even if he did not want to go through all the difficulties of the treatment again.

Some parents were more aware of their children's anger. This was true in Anton's case because his mother allowed him to express his feelings. For other children, their anger was hidden, though sometimes they expressed anger without realising it. A good example is Denis, who told his mother many times he was all right, but he burst into tears several times because of his illness, as his mother explained. It was difficult for him to talk about his strong emotions.

> *'I think there were two times when he had outbursts and I got really scared when I saw his reactions. Not long ago, I remember it was about 10 o'clock in the evening and he started crying really bad. I didn't know what was happening with him and I sat down beside his bed to talk with him. I asked him what was going on and if something was hurting him. I asked him to explain to me why he burst out like that! And then he asked me when will he be able to walk again.'*
>
> (Denis, Muscular Dystrophy)

Denis was not used to talking about his feelings with his mother; she admitted that she did not encourage him to express his emotions and to be upset because of his illness. She claimed that *'for sure he is not all right with his illness and he is the only one who knows his struggles, only* *he knows what is deep in his soul.'* It seems that his mother's attitude encouraged him to deny his feelings and pretend that he was all right. However, as we have seen in the quote above, Denis could not hide his feelings. He adjusted his behaviour to his mother's expectations, but he had moments when he would burst out, as he was not able to cope alone with his emotions. His mother also claimed that he would do anything to protect her because he knew she was suffering because of him: *'He lost 11 pounds only to make it easier for me to lift him.'* He saw that losing weight would make it less difficult for his mother when she needed to lift him.

As shown above, there were several situations where children's affirmations did not correspond with what their parents reported regarding their children's emotions and experiences. Paula's account was inconsistent with her mother's story about her. While Paula had stated that she had accepted that she would not grow and would never be as tall as her peers, her mother explained that Paula complained frequently that she was bothered because she was so short compared to her peers. Her mother also revealed that Paula behaved like a child when she had to go to the hospital for treatment or to the emergency room because she had frequent bleeding. However, when it came to comparing herself with her classmates, she would consider herself superior to them because she was older. Paula was often troubled, as her mother quoted her, that *'no one wants to spend time with me, no one loves me, I'm so swollen and deformed'* (Paula's mother, Autoimmune thrombocytopenia).

Many of the children revealed different worries related to their illness. Some of them talked about their fears of getting worse**,** and their parents confirmed these worries. Victoria's mother claimed that '*she got used to the fact that she cannot use her hands. But still, she is worried because she is not able to use them as before'.*

Other parents indicated that they were not sure if their children were worried about issues related to their illness or not. Alisia's mother claimed: '*I don't think she has fears related to her illness, or I might not see if she has fears.'* David's mother also believed that she knew very well when her son was content because his behaviour would indicate that he was content. However, she could not say if he was worried about issues related to his illness: *‘I don’t know what his fears are because he doesn’t show them to me, there is no way he would. But he is excited when the doctor allows us to go home for a few days.’*

Other parents confirmed the fears their children shared and moreover they brought new insights into their children’s feelings. Melissa’s mother gave an example of an issue which would trigger her worries and fears regarding her daughter’s life-limiting illness:

> *‘She's afraid the illness will get worse. For example, when she has anaemia, she feels very dizzy for a long time, and she needs to stay in bed a lot because she feels the house turns upside down with her. Then I see that she panics.’*
>
> (Melissa’s mother, Epidermolysis bullosa)

The children’s emotions were significantly triggered by their wishes and desires. Some of their strong emotions were related to wishes regarding their illness while others had nothing to do with their health. For most of the children, it was more comfortable to share with their parents their positive desires regarding their illness and wishes for the future, than to express their fears.

Denis would barely talk with his mother about his worries and fears regarding his illness. But his mother spoke of how Denis told her he saw himself in the future.

> *‘He would like to be a farmer; he watches Digi Life or Discovery, where tractors are adapted for disabled people and he thinks he can do that … to have a farm and animals, to climb and things like that. That’s his dream!’*
>
> (Denis’s mother, Muscular dystrophy)

Denis’s mother was aware that he would not be able to accomplish his dream, but she did not want to discourage him.

Similarly, Paula's mother said that *'She hopes to attend the Faculty of Art … now, I don't know what the future holds for her but that's what she hopes for. She would love to do either art or acting'.* Just as in Denis's situation, Paula's mother was not optimistic about her future, but she never tried to take away her dream by telling her that she would not be able to do that because of her illness.

Other children would see themselves *'getting married, having a family, even with children'*, as Alisia's mother claimed. She wished to have a family like everybody else, but her mother explained that her daughter was realistic because she also admitted several times that she would never get married and have children because of her illness.

Parents were encouraged that their children had hopes. Children's wishes for their future would bring them hope and strength to fight their illness. This aspect is developed in the final section which covers the coping strategies of the children diagnosed with a life-threatening or life-limiting illness.

5.1.6 Theme 5. Striving for normality and independence

5.1.6.1 Children's perspective

A variety of issues described by the children revealed that they were striving for normality and independence. 'Normal' was a term used by my participants as they described the world around them in comparison to their own experiences. This term also defined their aspirations as they described what 'normal' people would do. Despite the value judgement implied, I have consequently used the term 'normal', as that was the terminology used by the children.

The most difficult issue affecting normality and independence was medical treatment. This was mentioned by the children as being 'the most awful thing' not only because of the difficulties of the medical procedures but also the impact on their ability to participate in 'normal' activities.

> *'Since I am sick, and I need to do chemotherapy I am not like the other children, and my life has been changed radically. I don't have the same freedom; I cannot do things that a healthy child would do*.'
>
> (David, Non-Hodgkin Lymphoma)

It is clear that there has been a shift in David's life since he got ill. From the child who used to enjoy *'going out with friends, riding bikes, going to gym class'*, he was forced to interrupt his usual activities because of chemotherapy and its effects. When David compared himself with healthy children, he felt his life did not follow a 'normal' pattern.

The comparison of seriously ill children with healthy children was experienced by children with cancer as well as by children with other life-limiting illnesses. However, normality is perceived differently by these two groups of children. Children who had been born with life-limiting illnesses had never experienced 'normality' in contrast with the children diagnosed with cancer who had lived a 'normal' life before their diagnoses. Victoria, a 17-year-old teenager diagnosed with a life-limiting condition and who was not able to walk or use her hands because of her condition, explained that it would have been much more difficult for her to be born 'normal' and then not to be able to walk any more.

Unlike children who never experienced 'normality', children diagnosed with cancer experience a shock at the diagnosis, as they feel like their 'normal' life as well as their independence had been stolen from them. They had a degree of independence before their diagnosis, but after being diagnosed with cancer, their life trajectory changed unexpectedly. Anton's account illustrates how disturbed he was because of the sudden interruption of his life since he was diagnosed with cancer:

> *'I used to go to the gym, to school, to go out anytime. All at once I had to stay in the hospital, chained like a dog to the infusions and not being able to meet with my*

> *friends. I wish I could go back to living normally, to do what I used to do before I got sick.'*
>
> (Anton, Acute lymphoblastic leukaemia)

Other children born with life-limiting illnesses, were aware that *'this is what is normal for me'*, as Paula claimed. Nevertheless, they strive for what most people would consider normal. Paula's comment revealed how seriously ill children try to accept what normal is for them while they still strive for a more conventional view of 'normal'. Not being able to keep up with her peers was distressing for her.

These results show that children longing for 'normality' related not only to day-to-day aspects of life like going to school, meeting with their friends but also about their aspirations. Although Victoria expressed several times her desire to '*walk, to be like others, to be normal'*, she recognised that *'there is no such thing as being normal ... I came to a point where I realised that I could not change the way I am. Now I enjoy life as it is … I try not to compare myself to others and to accept myself as I am.*' Victoria said that normality is not defined by what her peers or society considered 'normal', but by being herself even though that meant she could not do as many things as most of her peers.

A deep pain was shown when seriously ill children talked about peers and friends, as they felt they are not seen and treated as 'normal' children in their peer group. They would like to be integrated into their groups of friends and to be invited to parties but tend to be overlooked and excluded. At this age, peers are important for psychological support and social development. When this need is not met, children feel excluded, lonely and their self-esteem is affected. Melissa, spoke several times about the difficulties of not being treated as a 'normal' child at school:

> *'I wish my classmates would behave normally with me … To talk with me and to make friends. I would like so much to have a friend … Simply, my classmates don't*

> *talk to me; they don't pay attention to me … I don't know why they behave like that. I am the only one in the class they treat this way.'*
>
> (Melissa, Epidermolysis bullosa)

When Melissa was around children who had a similar condition, she felt loved and accepted. However, she saw these children only once a year when she attended a camp with them. She used to spend most of the time with her peers at school or in the neighbourhood although she felt they did not accept her. In contrast, children at the camp treated Melissa as she longed to be treated; they interacted with her, invited her in their groups and talked with her. This positive interaction with her peers made her feel less isolated than she felt at school.

At this stage of development teenagers are acutely aware of body appearance and imperfections. Most of the children commented that they do not look 'normal'. Alisia, who was 15 years old and diagnosed with a life-limiting illness, explained that she was planning to have a complicated surgery so that her hands would look more normal. Even if she had the surgery, she would not be able to use her fingers, but the desire to look like a 'normal' person appeared to be more important than the pain and complications of the surgery. Her attitude exemplifies how far a child with a life-limiting condition can go to appear more 'acceptable'.

For children diagnosed with cancer, their body appearance was affected by losing their hair during chemotherapy which made them feel different from their peers. Even if they were not able to see their friends while in the hospital for the treatment, losing their hair 'in a moment', as Flaviu referred to it, made them feel embarrassed about their appearance. For Flaviu, losing his hair was the hardest thing about his illness, and he confessed that for him it was still difficult to talk about. When an illness affects one's physical appearance, the illness becomes visible.

The desire to live a 'normal' life was accompanied by the children's striving for independence which is particularly important for this age group. While they observe that their peers become more independent, they, in contrast, are becoming more dependent as the illness progresses or during treatment when they need to stay in hospital for a long period.

> *'I would like to be independent. I would like it so much! To not depend on mummy, to let her have her own life and to have my own life … we are like that instant coffee, two in one. I would like, at least, to manage to do things for myself … to be independent … it is hard to need someone constantly staying with me, somebody who must do everything for me … to not be able to do anything by myself.'*
>
> (Victoria, Muscular dystrophy)

Victoria clearly illustrated the experience of living with a life-limiting condition. The increased dependence was frustrating for her as it was for other children who expressed the difficulties of not being able to fend for themselves, their need for privacy, as well as not being able to go on dates and to parties as their peers.

Another factor that affected children's lack of independence was the inability to attend school, or if they were able to attend school to be dependent on somebody to accompany them, or to assist them in the classroom. Nevertheless, children who attended school had an increased sense of independence, even if they were accompanied, than did the children who were spending most of their time in the hospital or at home because of their condition. Despite this, being accompanied by their parents at school or different activities such as parties would mean that sometimes seriously ill children would still feel excluded from their peer group.

The findings suggest a tension between the desire to be independent and the need for dependency created by the illness. As underlined in the previous section, Victoria wished to be independent, *'all by myself'* and resented her mother's continuous presence. However, she also expressed her fear of being left alone. Even a moment alone resulted in distress and the fear of imminent danger. She even said that she '*didn't want to be alone at all*' because she was scared by any sound in the house or by what might happen to her while her mother was away.

Issues related to independence are part of the children's desire for normality. As Patrick, diagnosed with a rare skin condition, explained; *'it would be normal for me at this age to be independent, but I have to rely on my mum for common things, like getting my socks on.'* There was a wide range of dependencies, varying from putting on socks to going to university. It is evident that many aspects of children's lives were impacted.

5.1.6.2 Parents' perspective in comparison to their children's accounts

Parents of the children interviewed brought a different perspective on how they thought their children experienced their illness in relationship to normality and independence. Some of the parents' insights overlapped with their children's views while other parental insights contrasted with their children's perspective on their illness.

While Paula tried to consider herself a normal child, her mother explained that Paula was trying hard to prove to the other children she was like them:

> *'She was trying to redress the balance because she had to go to the hospital so often and in a way, she was trying to retrieve the lost time in the hospital. So, she would try to do what other normal children would do … she would try to demonstrate to her classmates that she can do everything that they were doing.'*
>
> (Paula's mother, Autoimmune thrombocytopenia)

For Paula, it was difficult to prove to her peers that she was like them, because, as her mother explained, *'even walking to school was difficult for her as it made her feel extremely fatigued'.* In contrast with what her mother said, Paula claimed that she was happy the way she was and the only problems for her would be that she could not keep up with the others and the frequent periods in hospital. There is a clear discrepancy in Paula's mother's comment compared to what Paula claimed.

From her perspective, Paula presented herself as being fine the way she was because she saw herself better than children diagnosed with cancer. However, her mother being by her side most of the time believed she knew what disturbed Paula, as she said: *‘It bothers her that her peers don’t want to keep in touch with her seeing that she is so short.’*

Similarly, Patrick’s mother explained how her son often told her when he was younger, *‘Mummy, I am healthy, I'm fine; if I did not have had these bumps, I would have no problem’*. Patrick was not the only child who was fighting with this contradiction, seeing themselves as ‘normal’ while recognising the difficulties brought by their illness. Patrick’s mother confessed that *‘as he grew up and the illness progressed, he realised what the real situation was about his condition’.* She explained how Patrick would long to be like other children and when her son would say he was fine that would mean he wanted a confirmation from her that he was fine because deep down in his heart he knew he was not all right.

Alisia was seeking normality through the difficult surgery she wanted on one of her hands, even if the normality she craved would never be achievable for her. Moreover, she also wanted to make an independent decision regarding this challenging medical procedure, despite knowing that her mother struggled with that. Her mother explained:

> *‘It’s hard in the sense that Alisia is becoming more aware that she is different; no matter how much I’ve tried to make her think she’s a normal child, she already realises she is different. Probably later it will be even harder; maybe she would want to have a boyfriend.’*
>
> (Alisia’s mother, Dystrophic Epidermolysis Bullosa)

Alisia’s mother focused on normalising her daughter’s life as much as possible. During the interview, she explained how her daughter would never be independent and have her own family however much she wished for that. She was protecting her daughter by minimising her illness, but as Alisia grew up, her mother understood that she had the same aspirations as a healthy child but that she would never achieve these accomplishments.

Victoria’s mother confirmed her daughter’s deep desire to live independently. Even as Victoria longed for that, it bothered her that her mother always had to be around. Having said that, she was afraid when her mother was not there. She explained how her daughter was possessive of her and was not happy at all when she had to be away even for short periods of time. Her mother was concerned that Victoria had become too dependent not only physically, but also emotionally by being possessive and not allowing anyone else to care for her.

5.1.7 Theme 6. Coping strategies

5.1.7.1 Children’s perspective

The analysis showed that the range of coping strategies used by children, besides their faith in God, included family, social support, distraction, talking with somebody about their worries, optimism and hopefulness.

In their attempts to cope with their illness, all participants described that they sought comfort from family members or their peers. For all the participants their mother was the main source of support. For example, Patrick reported that he felt comforted having his mother beside him:

> *‘Mum is always there for me … for whatever I need, she's there to help. And I'm so grateful for this. I mean, if I could have a long life to thank her every day for what she does for me, it wouldn’t be enough. She has a significant role in my life. I would be nothing without her. I don’t know if I could go through this if anything ever happened to her.’*
>
> (Patrick, Mixed Connective Tissue Disease)

Many participants also described social interactions with their friends which made a significant difference in their lives. For instance, Alisia stated that she has *‘many friends who treat me like a normal child and they go out with me which makes me feel accepted and loved.’*

Patrick was the only one among the children interviewed who had a girlfriend. This made a huge difference in coping with his illness. His girlfriend, whose mother died of cancer, seemed to be the one who cheered him up in the darkest moments of his life. He stated:

> *'… before I had a girlfriend, I was very apathetic ... whatever happened to me, I didn't care. Every day was the same … I had a crummy life with no colour, monotone … When I am upset, I talk to her and when I hear her happy voice, it changes everything inside me. In those moments I only need my girlfriend. Nobody could help me more than she does. When she tells me that I am the happiness of her life, it's more than you can imagine.'*
>
> (Patrick, Mixed Connective Tissue Disease)

Having somebody beside them was a real comfort for children. Paula also acknowledged that '*it is very sad to be alone. I can't deal with all my troubles alone'*. In addition to her mother's constant help when Paula got tired or went to the hospital, she also had her oldest brother who had the same life-limiting illness. Because they had similar issues related to their illness, they could support each other. He failed at university because of his illness but nevertheless, he was an encouragement to her.

Other coping strategies described by many children were different activities which would distract them**,** and which were not too physically demanding, like painting, listening to music, playing an instrument. For those who were able, video games and crafts were popular. Many of these activities were organised by the hospice, but they were also able to pursue them at home. Paula noted that painting helped her enter into a different world and helped her to forget about reality. She said, '*the colours are therapy for me.'*

Most children said that optimism and positive thinking are significant ways of coping with their illness. Alisia claimed that because nobody knows what tomorrow may bring, '*I must enjoy everything I can today because there is no point in always being afraid what's going to happen.'*

Similarly, Victoria highlighted how her positive attitude was her main way of dealing with her illness. Ever since she was a little child she has always been optimist.

> *'When I am very sick, I know that it's going be OK … there is always something which helps me to choose a good way … Optimism is helping me a lot. If I had been pessimistic, I wouldn't be able to do everything that I am doing right now.'*
>
> (Victoria, Muscular dystrophy)

Alongside her optimism, she accepted her illness and chose to see it as being '*a good thing for me'.* She explained:

> *'… It is not worth it to regret and think about how I would have been if I hadn't got this disease. Instead, I choose to be happy the way I am. Because we just have one life to live, we need to live it as it is … and to persevere. Any disappointment is a step forward for me. What depends on me I want to do it the best I can.'*
>
> (Victoria, Muscular dystrophy)

Like most of the participants, Victoria had moments when she was fearful about her future, but she and the others felt motivated when they looked at their future with a positive perspective. This attitude was a way of dealing with the hardships brought by their illness. Victoria confessed that she would feel depressed at the thought of not being able to succeed. She was able to make the decision to not let those thoughts overwhelm her. She realised through counselling sessions, that there was no point in allowing herself to get depressed. She had an exceptional approach to disappointment. She would try to motivate herself by making a difference in others' lives. She stated:

> *'The thought that I will be able to do something with my life … that I will succeed and become somebody and that I will manage to make a difference, make a change … to do something for society and especially for those around me … this helps me the most … And I don't like to stay at home too much, to be alone … I like to have people*

> *around me … I like to be involved in different things … that helps me … I feel good when I do something …'*
>
> (Victoria, Muscular dystrophy)

Another example is Anton who was diagnosed with leukaemia. Anton had two relapses and his oncologist communicated to him his limited prognosis. Despite this he said that what helped him cope with his illness was *'the thought that I will be all right and that I will be able to again do the things I like to do.'* Optimism, accompanied with hope, was mentioned by several children as a way of giving them the strength to deal with their illness.

5.1.7.2 Parents' perspectives in comparison to their children's accounts

Some of the parents reiterated the accounts of their children's coping strategies. For instance, Patrick's mother reinforced his perspective regarding the importance of not being alone in his most difficult periods of time:

> *"To be with him, you know, helps him … once, when he was unwell, and I stayed beside him he was saying, 'Wow, mum, when you're here, it is like you are taking away all my pain.' Just sitting next to him, makes him feel better and calms him down.'"*
>
> (Patrick's mother, Mixed Connective Tissue Disease)

Parents also suggested that their children's hobbies like painting and listening to music were not only a way of coping with their illness but also of spending their time, as the long hours in the hospital or at home were so hard. Melissa's mother claimed that she *'keeps herself busy, as she likes to draw and paint … and time passes more easily for her that way.'*

The positive attitude was also mentioned by the parents, confirming that it played a significant role in their children's way of dealing with the difficulties brought by their illness. For instance, Anton's mother said that '*he's very optimistic. And he sees himself as part of the future'*. There were many occasions when Anton had to stay in an isolation room at the hospital because of his low immunity. Even if sometimes he was discouraged, his mother suggested that when he envisioned himself in the future this would give him the strength to get through the loneliness and other issues brought about by his illness, such as not being able to take his driving test or go to school.

Some parents described other things that helped their children cope which were not mentioned by their children. Melissa's mother indicated that her dog brought real comfort to her daughter because of the unconditional love she felt she received from her pet. Melissa suffered a lot because she often felt like she was being left out by her peers, but her dog was always beside her. Alisia's mother thought that communication between them and with hospice staff helped her daughter to deal with her illness.

Some of the parents' comments demonstrated a different interpretation of their children's coping strategies. Paula's mother said the way of dealing with her illness was that '*she would try to ignore her illness*'. She claimed that Paula was aware of what her illness meant and about her life expectancy, but she would ignore it altogether. Her mother explained that ignoring it would mean that she would refuse to talk about it and to deny her fears of the future.

Moreover, Denis's mother's account contrasted with his statements regarding his coping strategies. While he had said it helped that he had friends who came to visit him, his mother confessed that *'it had been more than six months since any friends have visited'*. She and another mother stated that they were not sure what helped their children cope. Denis's mother claimed that *'it is only Denis who knows what it is in his heart and soul.'* Denis's insights alongside those of his mother suggest that some of the children's self-presentation to me was designed to make them appear heroic or less lonely than they really were.

5.2 Summary of main findings

This chapter has presented an analysis of the data based on the interviews with children diagnosed with life-threatening or life-limiting illnesses as well as with their parents. Each of the six themes was presented in two sections. The first one explored the experiences of children from their perspective and the second section explored what their parents thought their child experienced. Together the interviews from both children and their parents provide a more global view of how it is for children to live with a serious illness which underlines the benefit of including both children and their parents in the study. Having the parents' accounts to match against those of their children, showed not only areas of misunderstanding but also acted as a measure against which false positivity could be observed. If the parents had not been interviewed the children's accounts would have been taken at face value.

The next chapter moves on to discuss these results and interpretations in the light of the research question: 'What are the experiences of children diagnosed with life-threatening or life-limiting conditions and how do their parents interpret their child's perspective?'

Chapter 6. Discussion

This chapter discusses how my findings contribute to knowledge through the in-depth understanding of the experiences of children diagnosed with a life-threatening or life-limiting illness from both their perspective and that of their parents.

The findings make several contributions to knowledge. This chapter begins by explaining the theory of awareness contexts, developed by Glaser and Strauss (1965), which was a great help in analysing the findings. This theory was applied to children in Bluebond-Langner's (1978) study, which showed that children learn gradually about their illness and move from one context to another. One of the most significant findings from my study is that children do not only evolve in one direction from closed to open awareness context, but they might move back and forth from one awareness context to another.

Moreover, this study contributes to the existing knowledge that even though there are some drawbacks of conducting research as an insider, there are also some advantages. It also shows that the stories children shared were unique and constructed in the context of collecting data as an insider researcher who had a prior relationship with the participants. This is a unique study and offers insight into a group of young people and their parents receiving palliative care.

This chapter also outlines the differences between the children's perspective and their parents' assumptions. These are discussed in relation to awareness contexts and developmental theory.

Because my study was conducted in a Romanian setting, differences can be seen between it and those conducted in the UK or the USA. An example is legislative issues such as the age at which a young person is deemed competent to make legal decisions for themselves, including the right of open dialogue with the doctor about their illness and prognosis. In addition, some themes may be related to cultural factors such as spirituality, which plays a significant role for many Romanian people. However, despite any culturally-specific issues, the findings have wider cross-cultural significance as they give a voice to the children as well as their parents. My study addresses issues and concerns relating to children between 14 to 17 years of age that transcend national boundaries. Moreover, it brings together the perspectives of both children diagnosed with life-threatening or life-limiting illnesses and those of their parents in a palliative care setting.

6.1. Awareness contexts

The experiences of children diagnosed with life-threatening or life-limiting illnesses can be understood in the context of awareness theory. As we have seen in the Background and Context chapter, there are four types of awareness contexts. Each of them is explained below in relation to the results of my findings. This section shows that at times children can move through different awareness contexts. They do not always stay in the same awareness context. Also, they do not only evolve from the closed awareness context to the open awareness context, but can move back and forth.

6.1.1. Closed awareness context

Glaser and Strauss (1965) comment that there are several factors which contribute to the closed awareness context, where no communication is shared by children and parents or healthcare professionals. One of the factors that contribute to closed awareness is that some patients do not want to know more about their illness, because they might be too afraid to face reality. Another factor which contributes to a closed awareness context is that family members try to guard the secret and the hospital staff hide medical information from the patient. Closed awareness context also includes those who might know the diagnosis, but they are not aware of the implications of the illness. Moreover, a closed awareness context happens when patients do not have anybody willing to share issues related to their illness and prognosis with them. This context can change if the doctor decides to tell the patient the truth, or children would talk with other children with similar conditions, which would lead to an open awareness context. Alternatively, it can change when the patient begins to suspect something about the illness which leads to a suspected awareness context.

In Romania, patients are told about their diagnosis and prognosis when they turn 18 years of age. Before then, the clinical details are shared with the parents, but sometimes the doctor, in agreement with the parents, can decide to tell the child from 16 years of age.

In my study, the children diagnosed with life-limiting illnesses had been at the level of the closed awareness context when they were very young. As they grew up they found out more about their illness either from their parents, other patients, healthcare professionals or the internet. In contrast, the group of children with cancer were all at the level of closed awareness context when they were diagnosed. As time passed they could evolve to mutual pretence, suspected awareness or open awareness while some remained or moved back at a closed awareness context. One example of closed awareness context from my study was the lack of information the patient received from the medical team. For instance, it was not common for the oncologists to explain to the patient the side effects of the chemotherapy, such as infertility. Moreover, none of the children reported that they had read about the long-term effects. This lack of information in Romania on possible infertility due to chemotherapy and radiotherapy reinforces the closed awareness context. Some parents said that their children with life-limiting illnesses never learned their diagnosis from their doctor but learned it from their parents or hearing their parents’ conversations with other adults. More concerning is that these children never had an honest discussion with their doctors about their prognosis and that they might not reach adulthood. These results may be related to the cultural norms in Romania where there seems to be a reluctance from the doctor to reveal some issues related to the illness, such as limited prognosis or secondary or long-term effects of chemotherapy.

6.1.2 Suspected awareness

Another type of awareness context which was evident during the interviews is suspected awareness where the participants tried to verify their suspicions about issues related to their illness (Glaser and Strauss, 1965). When children suspected that their parents or healthcare professionals knew more than they were telling them about their illness, they tried to obtain information about their condition in other ways in order to confirm their suspicions.

In accordance with the results of my findings, Bluebond-Langner's (1978) classic study demonstrated that children were able to recognise taboos when adults talked about their child's illness and prognosis. The children in my study also tried to take clues from their parents. They were aware that adults told one another things that they did not tell children. Therefore, they would try to listen to their parents' conversations. Children confessed that they would eavesdrop on their parents' conversations with other adults to grasp what they were saying about their illness. There were things, such as the name of the illness, that they learned from overhearing their parents' conversations. This kind of information allowed them to find out more through other means. However, because they were unable to share their new-found knowledge, they were left alone with an emotional burden.

Bluebond-Langner (1978) also explains that when children realised their illness was an inappropriate subject to discuss with their parents, they then pursued those conversations with their sick peers in treatment settings. Here they found a willingness to offer information and to answer questions about their illness while hiding from their parents that they wanted to talk about it. Some of the children from my study explained that because they realised it was not easy to talk with their parents about difficult issues related to their illness, such as their prognosis, they tried to talk with other sick children instead.

However, not all the participants in my study who suspected they had a particular illness or who suspected their parents had hidden information from them attempted to discover their real diagnosis or search for more information about their disease. Grinyer (2002) suggests that not all children or young people are open to talking about their illness and prognosis, even when they have cues from their parents that they want to share information with them. Alasdair's parents, from Grinyer's (2002) study, initially decided not to tell him about the seriousness of his condition. However, when his mother made attempts to explain more to him, he did not want to talk about it. It is possible that it would have been too difficult and painful for him to acknowledge his prognosis. Timmermans (1994) explains that a subject becomes taboo depending on the patient, parent or healthcare professional's reaction when it comes to discussing death, illness or prognosis. Children from my study did not give a clear explanation as to why they did not seek to learn more about their disease. It could be because they were taught by their parents not to ask about their illness and they wanted to please their parents by not doing so.

Another issue related to the suspected awareness context was children's reluctance to talk about their possible early demise. The interviews from my study revealed that some participants avoided thinking or talking about death as they believed it would not help them to feel better to think about what the future might bring. A previous study, Bearison (1991), argued that children who deny their fears, or who refuse to talk about them are afraid to admit it to others but also to themselves. Thus, not talking about fears, including the fear of death, does not imply that they do not have fears. Some of the children from my study would not openly admit their fears; their comments indicated that they were fearful but that they would try to ignore their fears. Some of them explained that the reason for doing so was that it was better to enjoy the moment without thinking the worst. This is in accordance with Timmermans' (1994) study which explains that some patients would rather suffer from uncertainty than knowing the truth. If this was the case with adult patients in Timmermans' study, it could be even more complicated with children. Research such as Bearison (1991) and Bluebond-Langner and Nordquest-Schwallie (2008), all show that children feel alone, excluded and alienated from their families when their concerns are not addressed. Being able to talk about it can help them cope.

In my study, some children commented that they were not encouraged by their parents or healthcare professionals to talk about their illness and prognosis which is why they were reluctant to express their fears and thoughts. They wanted to protect their parents, or they did not want to upset them with questions or to tell them their fears about their prognosis. In this way, they would operate in the suspected awareness context, by, for example, searching on the internet for information about their illness, so that they could confirm their suspicions. This explains how some children obtained knowledge about their illness and subsequently pretended not to have it, which led them into the mutual pretence context.

6.1.3 Mutual pretence

The most common awareness context reported by both children and their parents in my research was mutual pretence (Glaser and Strauss, 1965). It is clear from the interviews that some children concealed what they knew from their parents, and some parents were hiding information from their children; in a number of cases, both parent and child knew the reality, but they did not acknowledge it or discuss it.

In accordance with Glaser and Strauss' (1965) theory, results from my study demonstrated that in some of the interactions between the child and the parent, both sides avoided talking about 'dangerous' subjects regarding the child's condition and their prognosis. In many cases, the parent was the one to avoid what was perceived as dangerous topics, such as the worsening of their children's symptoms. Many parents confirmed that they avoided telling their children about their prognosis because they thought their children would give up fighting if they knew how bleak it was. However, some of these children had a strong suspicion that their illness was more serious than their parents would admit but they did not talk about it. Children would read about their diagnosis on the internet or talk with other children with similar conditions which allowed them to gain a clearer understanding of their illness. Seeing that their parents were not open to talking about it, they would behave as if they did not know their prognosis. Glaser and Strauss (1965) explain that mutual pretence is initiated when children note that parents and healthcare professionals are not willing to talk about their condition with them.

Children from my study asked their parents questions about their illness, such as when they would be able to walk again. The way their parents responded indicated their reluctance to talk to their children about their illness. Sometimes children would not ask any questions because they knew how upset their parents were and they did not want to upset them even more with their questions. Bluebond-Langner and Nordquest-Schwallie (2008) showed how children react when they ask questions that their families or healthcare professionals are reluctant to answer because the answer could reveal unpleasant things about the child's illness. Children stopped asking questions because of the adults' reactions and their family members or healthcare professionals would avoid answering by ignoring the question or reprimanding the children.

Another side of mutual pretence explained by Glasser and Strauss (1965) is where all the parties would focus on topics which were safe. Some of the parents from my study encouraged open discussions with their children, but only to the point where the parent felt safe. This means that parents avoided talking about issues such as that their child's illness would get worse or that they could die because of the illness. As Bluebond-Langner's (1978) classic study found, safe topics were those that did not remind the child about the implications of their illness. Both the child and the parent would talk about areas which they enjoyed such as movies, TV programmes or daily routines. Similarly, parents in my study would try to focus on discussions which were positive and devoid of references to disease. Sometimes, parents discussed their child's illness with them in terms of day-to-day issues rather than long-term plans or prognosis. Thus, parents protected their children, without realising that in some cases their children were well aware of the prognosis.

In a mirror image, the children from my study protected their parents by not sharing their worries, if they saw their parents were not open to talking about ‘dangerous’ subjects. The children adjusted their behaviour depending on how their parents reacted in front of them. How each of them reacted was crucial, as this determined the interaction between the parent and the child. Therefore, not only did the parents want to protect their children, the children wanted to protect their parents. Although children did not use the word ‘protect’ it appeared that this is what they attempted to do by not engaging their parents in discussions about their prognosis or other sensitive information related to their illness. In this way, mutual pretence was maintained by protecting both children and parents from ‘dangerous’ topics.

These findings support the classic work of Bluebond-Langner (1978) who explains that children and parents engage in activities and discussions which do not remind them about their incapacities. Children from my study would distract their attention from the hardship of their illness by listening to music or engaging in crafts. Their parents would often encourage them to find different activities they enjoyed which would take their minds of their illness thus allowing the mutual pretence to continue without the threat of challenge.

6.1.4 Open awareness

Glaser and Strauss (1965) explain that open awareness is a process. Patients go through closed, suspected or mutual pretence contexts to come to the point of an open awareness context. Some researchers, including Bluebond-Langner (1978) think that open awareness happens only when there is a mutual acknowledgement of the prognosis between the child and the parents or healthcare professionals. Using this definition, none of the participants in my study had come to the point of open awareness in their interactions.

Timmermans (1994) explains that if the patient gets the information about the illness or prognosis, even if they do not act on that information, they are still in the open awareness context continuum. In my study, there was only one mother who openly communicated with her son. He had been diagnosed with leukaemia and his mother shared all the details given to her by the medical staff about his diagnosis and prognosis. He received the information calmly, even though his mother had told him that his prognosis was limited. However, he continued to behave as if the disclosure had never happened, which would imply he was in denial. Timmermans (1994) explains that when a patient does not acknowledge the disclosure in their behaviour or conversations, this can be perceived as the patient disregarding the explanations about the disease. Weisman (1972) argues that this attitude is regarded as being in total denial. Timmermans (1994) places this attitude in the open awareness context and categorises it as *suspended awareness context*. Not only did the participant from my study disregard the negative information about his illness, he still claimed that he hoped for a good outcome. Given that this participant was given full information about his illness and prognosis, he was on the open awareness context continuum, even if he did not openly acknowledge what he knew about his illness and prognosis. The results from my study are in agreement with Timmermans' (1994) findings which showed that adult patients do not exclude that things can evolve unfavourably but prefer to have hope rather than to have the certainty of death. My study shows that children may act in the same way as adults, preferring to have hope in the midst of bad news.

6.1.5 Awareness contexts – final remarks

Even though my study was conducted in Romania, the awareness contexts were similar to those identified by Bluebond-Langner (1978). The dominant mode of interaction between the children and the parents in my study was mutual pretence. These results reflect those of Bluebond-Langner and Nordquest-Schwallie (2008) who explain that this practice is the most frequent one because death is a taboo and therefore must not be discussed. Maintaining mutual pretence allowed both children and their parents to act as if children had a future. However, not all participants were stable in the mutual pretence awareness context. One day the patient and their family can act as if they suspect or know more about the prognosis and another day they can relapse back into mutual pretence. Protecting one another usually informed the participants' decision to talk or not about their illnesses, to acknowledge them or not. As Timmermans (1994) explains there is no appropriate emotional response to a terminal condition and no awareness context should be imposed upon patients and their families.

The conversations I had with the participants as a researcher could have had an important role in changing their awareness contexts even during the interviews. Discussing their illness in-depth could have brought questions to children's minds which they wanted to address either with their families or healthcare professionals involved in their care or may have resulted in them articulating that which had not previously been unacknowledged.

The awareness context framework was extremely useful in understanding the experiences of children diagnosed with life-threatening or life-limiting conditions. Unlike Glaser and Strauss (1965) study which was conducted with adults, and which places patients in a specific awareness context, my study shows that in children, awareness contexts are more complex and nuanced. Bluebond-Langner (1978) showed that children progressively move from closed awareness contexts. Whilst I also found this, my study shows that children might move back and forth from one context to another depending on the circumstances. This could also apply to adults.

6.2 Parents and children: differences between their perceptions of the illness

Previous studies have focused on either children's experiences or the parents' perspective of the children's experiences, but none of the studies has compared children's and their parents' beliefs in the way that my research has in dyads in a palliative care setting. Bluebond-Langner's (1978) study was the first to give voice to children regarding their illness. Since then, there has been no study which has gone into such depth. Other studies which explored the experiences of children (Bearison, 1991, Cohen-Gogo et al., 2011) did not include the perspectives of their young participants' parents. Grinyer (2009) studied the difference in perspectives between teenagers with cancer and those of parents who have a child with cancer. Nevertheless, the parents in Grinyer's work were not related to the young patients who were interviewed as the data had been taken from two different datasets from separate studies. In my study, I also included children with other life-threatening or life-limiting illnesses besides those diagnosed with cancer.

An important finding of my study was the dichotomy between some of the children's experiences and their parents' beliefs about their child's experiences. Although parents thought they knew almost everything about their children, results suggest that many of them did not know as much as they believed. For example, many parents assumed that their children did not know very much about their prognosis. However, children understood more about their illness and prognoses than their parents realised. It also showed that parents made assumptions about what they thought their children experienced but did not know as much as they assumed they did about their children's feelings, thoughts and experiences. These findings provide evidence that there is a great need to support the parents as well as the professionals involved in the care of the children and their families to communicate better with the patients.

6.3 Developmental impact on illness

Researchers have different opinions regarding children's perceptions of their illness. Some believe that it is linked to their developmental stage (Perrin and Gerrity, 1984, Murray, 2000) or that children's perceptions are related more to their personal experiences (Eiser, 2007). Deatrick and Faux (1991) explain that there tends to be a dichotomy between the basic assumptions held by researchers. Either they believe that children are not able to understand and describe their experiences because of their developmental immaturity; or they hold the view that children can understand and describe their experiences. My study shows a more nuanced continuum which suggests both their development and experiences contribute to the perception of their illness. For example, one participant explained that when she was young she could not understand much about her illness, but as she grew up she could understand better what it meant to be diagnosed with her illness. She explained that her experiences related to her illness contributed to her understanding. Alderson (2007) and Sartain et al. (2000) believe that children's perceptions regarding their illness are more linked to their experiences than to their developmental stage.

In my study, children's understanding could be discerned by how they were able to express and explain significant issues related to their illness although frequently not being given the information related to their illness and prognosis. For example, children with life-threatening illnesses were able to articulate their awareness regarding their prognosis even though no-one had communicated directly with them about it. Moreover, children with life-limiting illnesses could explain how they were aware that their condition had worsened as they grew up and that they wished someone would explain the situation to them. The differences between children with life-threatening and life-limiting illnesses are discussed in the next section of this chapter.

My study shows that children's behaviour can alternate between accelerated maturity and infantile regression according to changing circumstances. A significant case reported by Grinyer (2002) supports this evidence. George was a young man who was a university student when he was diagnosed with osteosarcoma at the age of 19. When his doctor told him that his osteosarcoma had metastasised to his lungs and there was little that could be done, he threw all the x-rays out of the hospital window. He acted in a childlike manner even though he was relatively mature at that time, aged 23. This example is a graphic demonstration of the fragile hold on maturity at this life stage when regression into childlike behaviours can result from fear, shock and anger at the unfairness of their situation. The children with life-limiting conditions displayed similar behaviour. From the discussion that I had with parents and children, I came to the conclusion that sometimes these children also behaved like much younger children when it came to their wishes and desires. For example, they could understand the implications of their illness, but they would sometimes behave in an infantile way when going to the hospital for treatment.

While there may be regression to infantile behaviour, some of the children and young people can appear to be more mature than their age because of what they have had to deal with. They have life experiences that their peers never have to cope with. Children from my study, diagnosed with life-threatening illnesses tended to be more mature than some of the children diagnosed with life-limiting illnesses, as the former had reached a higher level of maturity when they first become ill. However, some of the children diagnosed with life-limiting illnesses have also shown great maturity for their age. Understanding their level of maturity can help parents and healthcare professionals relate to these children and explain relevant issues regarding their illness.

The age range that my study includes is the adolescent developmental stage which covers the ages 14 to 19 years old (Larcher, 2017). Christenson et al. (2010) claim that the development of self-confidence would be normal in this age group. Their self-confidence can be shattered when facing a life-threatening illness because of the many difficulties they have to face (Wu et al., 2009). Moreover, becoming independent and establishing their identity is distinct for this age group, as set out below.

Children struggled because their desire to be independent and ‘normal’ was often threatened. Grinyer (2002) explains that for young people diagnosed with cancer, their default identity may be that of a dependent child after diagnosis, while other identities which were formed through a series of life events and relationships are lost. However, the findings of my research show how difficult it was for the children to lose their independence when they became ill. Regarding children’s identity, Rollins (2005) says that the effects that serious illness has on a child, like losing their hair, can lead to them losing their identity and perceiving themselves as different. For children with life-threatening illnesses, as their illness progresses, they are compelled to become more and more dependent on their parents at a life stage when they would normally be expecting to gain more independence (Flavelle, 2011). The other group of children from my study, diagnosed with life-limiting illnesses, were struggling with similar issues as it was difficult for them to start developing independence while being ill, or lose the limited independence they had when their illness progressed.

6.3.1 Life-threatening in comparison to life-limiting illnesses in children

It was not the purpose of the study to look for differences between children diagnosed with life-limiting illnesses with those diagnosed with cancer. However, the results showed that they did not always have the same trajectories. Some of the differences have been already mentioned in previous sections. Although they experienced similar thoughts and concerns, such as their striving for independence and their fear of death, my results showed that there were some significant differences between these two groups. A noteworthy finding was that the children diagnosed with life-limiting conditions, were more aware of the likelihood they would be unable to have children of their own, than the participants diagnosed with life-threatening conditions such as cancer. The understanding of children with life-limiting illnesses regarding their future was related directly to their level of maturity. Some of them were mature enough to understand that because of their conditions they would not be able to have children. Being realistic about their condition, they had learned to accept their limitations which they had experienced since infancy. Some of the children expressed the longing to experience the freedom that healthy children have. Even children who had been diagnosed with cancer later in their life had previously enjoyed this freedom whereas children with life-limiting illnesses had never experienced the joys of childhood such as running or jumping.

Regarding the group of children with life-threatening illnesses, there was no evidence to show that they had concerns regarding having a family and children in the future. This could be because they had not been informed that chemotherapy could affect their fertility, as explained in the closed awareness context section. Because they had not been given this information, they were not worried about it. Both children diagnosed with life-threatening and life-limiting illnesses acknowledged death, however, there were no significant differences between these two groups of children regarding death and dying.

6.4 Living with the illness

The research revealed how hard it is for the children included in my study, who were between the ages of 14 to 17, to live with such a difficult diagnosis. Jones and Weisenfluh (2003) confirm that for this age group, it is particularly difficult to be diagnosed with a serious condition or to be faced with the possibility of continuing adolescence with a long-term condition. The thoughts my participants shared about their experiences opened a door to their universe, allowing us to understand what it means for them to bear the burden of a life-threatening or life-limiting diagnosis. Jones and Weisenfluh (2003) show that at this age children can experience profound loneliness, making the disease even more unbearable. It is important to note that some of the children from my study said that they often felt lonely, even though paradoxically, they were never alone since they needed to have someone by their side most of the time.

Children whose parents hid information from them were more fearful than children whose parents openly communicated information about their diagnosis and prognosis. The fears that they had, such as that they did not know what to expect from their illness or their fear of death, affected their everyday lives. These results are in agreement with the findings of Holge-Hazelton et al. (2016) which showed that worries about disease and dying influenced children’s daily lives in different ways. In my study, children became fearful when changes occurred such as when they had a relapse or when a child with a similar condition got worse and eventually died.

Holge-Hazelton et al. (2016) explain that the fear of death was not predominant for all of the children in their study. This is also true for the children in my study. Some of them explained that they had decided not to let the fear of getting worse or the fear of death rob them of the joy found in the things that they could enjoy, like going to a camp or meeting with their friends.

Jones and Weisenfluh (2003) report that children find it helpful to see and talk to another child facing similar illness and issues. However, Jones and Weisenfluh (2003) explain that facilitating such interactions and conversations between children may cause much suffering from losing a close friend if one of them dies. For the children in my study, it was difficult to see that other children with similar illnesses or perhaps different conditions, got worse and eventually died. However, it was better for them to have someone to talk to and not feel alone in their illness, than not interacting with them at all, since most of the time they did not have friends other than those in the hospital.

Other strategies used by children to help them deal with the disease, were their friends, their faith in God and talking with someone about their illness. Other studies (Bearison, 1991, Cataudella and Zelcer, 2012) support these results and point out that children developed a variety of coping strategies.

Spirituality was not a key focus of my research. However, results show that children tried to find meaning and understanding in their situation. Most of the participants interviewed were religious so it is understandable that it was important for them to refer to their spirituality. Even healthy children ask themselves questions related to the meaning of life and spirituality especially after the age of 12 (Stillion and Papadatou, 2002). For those who are sick, these questions became even more profound. They would try to rationalise their situation which becomes a way of coping with their illness. Flavelle (2011) gives us a useful example of a 15-year-old boy diagnosed with osteosarcoma who found solace in spirituality and believing in the existence of God. My results also show that faith in God was important to some and helped them to cope with their illness. These results reflect those of Bearison (1991) which shows that some children diagnosed with life-threatening illnesses accept their disease as being the will of God and found comfort in having the support of their priest or pastor. However, not all of my participants found comfort in this way. Some of the children attributed their illness to a form of punishment, or they kept asking themselves why God would allow them to suffer. Others would attribute their suffering to God and as a result turned their anger towards Him.

6.5 My journey as a researcher

Conducting this research was emotionally demanding as participants shared with me some of their deepest emotional experiences and burdens they carried. At times I had to take a break to process the information I had collected from the participants to be able to continue with a fresh mind. However, at the same time, it was rewarding to be able to acquire a new level of understanding of the experiences of seriously ill children with whom I have been working for over ten years. It was always a privilege for me to be part of these children's lives. Discussing with them as a researcher allowed me to gain insight into their thoughts, feelings and experiences that I do not think I would have been able to access were it not for our previous relationship. The information provided by them helped me to get a fuller picture of what they were going through in their difficult journey. The trust and respect I had built with the participants in our prior relationship increased the likelihood of successful recruitment and openness to share their experiences with me. The interviews also had a positive impact on relationships with children and their families when I met with them in my clinical role. They were more open to sharing their thoughts and feelings and to getting support from me, a trusted person.

The process of undertaking this research was not without challenges and my academic supervision provided important support while collecting data and helped me to maintain my role as a researcher. As my social worker role was overlapping with that of a researcher, I had to learn to set boundaries and not act as a social worker during the interviews. This was difficult at times, especially when the participants asked direct questions or when they were very emotional while they were sharing their experiences. Some children and parents had questions, such as *‘Why is God allowing me to suffer this much?’* or *‘Do you think it is OK that I am not telling her more?'*. Because I was not able to answer those questions during the interview, I had to explain we could talk about it on another visit.

Another challenge for me was after the interviews when some parents asked me to disclose what their child had said. I explained that the interview with their child was confidential if they chose not to participate in their child’s interview, just as the interview with them as parents was also confidential. Beresford and Shakespeare (1998) explain that their information should be disclosed to others only if the child gives consent. In this context, I was able to encourage parents to have a better dialogue with their children and to support them in having the courage to let their children express their thoughts and fears.

This research has had a great impact in my professional role. It has helped me to be even more attentive to what children and their families want to share, to look for the best way to approach them through the most challenging periods of their lives and to facilitate good communication between children and their families.

Chapter 7. Conclusions and final remarks

7.1 Limitations and strengths

While the research contributes to knowledge about the experiences of children living with life-threatening and life-limiting conditions, these results are subject to certain limitations. Because the research was conducted in a single institutional setting, and a limited number of life-threatening and life-limiting illnesses were included, the results might be specific to certain illnesses. Even so, our discussion was not specific to their illnesses, but normally covered more general topics, such as self-esteem and independence.

Another limitation is that the interviews were conducted by a single interviewer which could lead to bias (Pannucci and Wilkins, 2010). Moreover, in some instances there was a discrepancy between factual elements of the data such as when a child claimed to have friends visit, when the parent confirmed this has not happened for months. This is one of the reasons why dyad interviews were conducted to contribute to the veracity of the findings. Also, only one interview took place with participants; serial interviews at different stages of their illness may have provided a broader picture of their experiences (Moody et al., 2006). The experiences of these children have been captured on a particular date; if I had spoken with these children and parents a second time, their answers may have been different.

However, because I talked with them in-depth, I have a broad perspective of their experiences even if children were vacillating in their thoughts, views, concerns and other issues related to their illness and prognoses. Parallel interviews with parents created a richer context of their experiences. Thus, this study offers meaningful insights into the experiences of seriously ill children and is strengthened by the inclusion of the perspectives of both the children and their parents.

As explained in the Methodology chapter, I was an insider researcher, which means that I was confronted with a dual role, struggling to balance between the insider role and the researcher role as Unluer (2012) explains. However, there were great advantages of being an insider researcher. I was already known by the palliative care team staff as well as by the children and their parents which allowed me to have access to sensitive information. This would have been difficult if I had not had a prior relationship, especially with the children (Kim, 2012). Knowing my participants before the research helped them to trust me with their information.

Another strength of this research is the qualitative method which allowed children to express their experiences and give voice to their most profound thoughts about what it was like for them to live with their illnesses. Qualitative interviews generated rich and detailed data about both child and parent experiences and perspectives.

7.2 The implications for practice

The findings of this study have significant implications. Firstly, they can be used to deepen healthcare professionals' understanding of the experiences of children diagnosed with life-threatening and life-limiting illnesses. Healthcare professionals need to be aware that children have worries and fears about their illness, as well as anxieties about death and dying, which may remain unvoiced if children are not enabled to express them. Being aware of that, they can alleviate the suffering of the children by acknowledging their experiences and walking with them through their difficult journey (Hinds et al., 2005). This would mean that being conscious of the complexity of the awareness contexts, healthcare professionals can be more open to talking with children about their fears and to answer their questions. With parental agreement, healthcare professionals can explain issues related to their illness. In this way, the children might not feel so alone in their physical, emotional, social, and spiritual pain. Across the disease trajectory, children should be invited by their healthcare professionals to talk about their concerns and offer them emotional and spiritual support.

Furthermore, healthcare professionals can advise parents about how to have conversations with their children which would enable the children to give voice to their thoughts, emotions and experiences. Healthcare professionals should be offered training in communicating with parents as well as with children. The professionals should be aware of the children's and parents’ knowledge related to the illness, what knowledge is shared between them and that sometimes children are unlikely to behave or react as their parents expect. Training professionals in communication skills with children and their parents would help them to understand this unique dynamic. When healthcare professionals understand that there is a discrepancy between a child’s awareness and what parents think their children know, they can better support parents by encouraging a more open dialogue between parents and children. These conversations could help them cope better with their illness. Professionals need to be trained and to understand the awareness contexts so they can assess the children and their family on any particular day/moment, on the illness trajectory. This is important because one day a child may seem to know its medical condition and the next day they may be in denial. Professionals need to be aware of this and to develop practical skills that enable them to support and help patients and their families in these situations. Moreover, healthcare workers should not assume that the parent knows what the child knows, they should be able to explain to the parents that their children could know more than they think.

In addition, parents should be supported in developing an awareness of their children’s understanding of their illness. Educating parents about children’s ability to read their parents’ behaviour and adjust their interactions with them to protect their parents or to please them, could help parents understand their children better and communicate with them more effectively. Children may otherwise feel more lonely and fearful. Parents also need to be encouraged to be open to allow their children to talk and explore issues related to their illness and to explain different things about their illness at their level of understanding. The process of implementing these practical implications is challenging and requires good leadership of the multi-disciplinary team.

Thus, the contrast between how the illness is experienced by the child and what the parent believes has the following practical implications:

- Organising support groups with parents who have children diagnosed with life-threating or life-limiting illnesses to support them regarding how to communicate and interact with their children at diagnosis and throughout the illness;
- Organising training with healthcare professionals from paediatric haemato-oncology ward as well as from the palliative care services. Training for professionals should include techniques for developing communication between parents and their children. In this way, parents can avoid the common experiences of alienation that children feel when their parents avoid discussing the issues related to their illness.

The research findings will also be disseminated through publications in journals such as Palliative Medicine, Children and Society, Qualitative Health Research, Paliația (Romanian Palliative Care Journal) as well as through presentations in national and international conferences.

7.3 Recommendations for future research

Although my study adds to the knowledge about the experiences of children diagnosed with a life-threatening or life-limiting condition, future research is warranted especially with younger children because most studies concentrate on adolescents or young people. Bluebond-Langner's (1978) study was with young children, but there is a need for more recent studies to support her findings because there is much to be learned from such children. I attempted to include younger children in my study but all three subjects got worse and died before I was able to interview them. In any future research with a younger age group, it would be important to include parents in their child’s condition. The importance of including both children and parents in the same study is that palliative care focuses on both the children and their families as a unit of care, providing physical, emotional, social and spiritual support (ACT Staff et al., 2009). Paediatric research has the potential to generate knowledge with broad application across the age spectrum of children diagnosed with a life-threatening or life-limiting condition.

Further studies could investigate the development of the children and their behaviour as it relates to the awareness contexts. This type of study could be used as the basis for developing interventions to help healthcare professionals and parents manage these situations more effectively.

For a greater understanding of children's experiences, longitudinal studies which look at various phases of children's illnesses from diagnosis and beyond, would add an additional perspective in understanding children's experiences. In cases where children were born with their disease, such a longitudinal study could cover their early childhood memories of their illness as well as their experiences throughout later years. Longitudinal studies offer the benefit of following change in participants over time and can provide valuable information in the future for comparison to the evolution of individual cases. Caruana et al. (2015) explain that by following the participants over prolonged periods of time, we can have a greater understanding of the fluidity of the awareness contexts.

7.4 Summary

The James Lind Alliance (January 2018) recommends that one of the top ten priorities in palliative care research about teenagers and young people with cancer is finding ways of supporting them psychosocially. My research extends this priority to include a wider group of children and type of illness. It has been designed to develop a deeper understanding of the experiences of children diagnosed with both life-threatening and life-limiting illnesses. Being one of the first studies that brings together the perspectives of both parents and ill children who receive palliative care, it makes a unique contribution to knowledge. Research in children with life-threatening or life-limiting illnesses has been identified as a priority as it can contribute to a better understanding of the experiences of ill children and may help to support them, ensuring a better quality of life for them (Woodgate, 2001).

Children's development and the awareness contexts frameworks have proved to be useful ways of exploring the experiences of seriously ill children. Acknowledging that the awareness contexts are not always fixed and children can move back and forth from one context to another is an important finding. This could help healthcare professionals to provide support by communicating with families and their children on any given day in their illness trajectory. Understanding that there is a discrepancy in children's experience and view of their illness and what their parents believed they experience and know about their illness, may help healthcare professionals involved in their care to support parents in relating to their ill children. Moreover, understanding how children cope with their illness provides insights into how to develop interventions to help these children, such as facilitating good communication between them and their parents. Results from my study, especially about the awareness of children regarding their illness and prognosis, will be presented to healthcare professionals in my team as well as in support groups for parents who have children diagnosed with life-threatening and life-limiting illnesses. Presentations will also be made at national and international conferences.

The present study will provide a base for further research on the experiences of children with life-threatening and life-limiting conditions who receive hospice or palliative care services. Because there are universal experiences of children diagnosed with life-threatening and life-limiting illnesses, as well as culturally situated experiences in different contexts, this study will be helpful for future research in the Romanian context as well as in other cultural settings.

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Appendix 1 - Glossary of terms

Palliative care – seeks to offer a better quality of life for patients and their families addressing physical pain/disease symptoms, along with emotional, social, and spiritual pain. Palliative care can be employed for any patients with a chronic severe heath condition or life-limiting illness. This type of care can be received while the patient can also continue curative treatment (Casey, 2019).

Paediatric palliative care – is the active total care of the child's body, mind and spirit, and also involves giving support to the family; it begins when an illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease (IMPaCCT, 2007, p. 2).

Life-threatening illness – is one where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood such as with cancer (ACT Staff et al., 2009). Life-threatening illnesses continually and actively threaten children's lives. There may be effective treatment for these illnesses, but cure is not guaranteed. Children who followed successful curative treatment or who are in a long-term remission are not included in this category.

Life-limiting condition – is defined by the Standards of Paediatric Palliative Care in Europe (2007) as a condition where 'premature death is usual' and where there is no reasonable expectation of a cure. Some conditions, for example Duchenne Muscular Dystrophy, can cause progressive deterioration, making the child increasingly dependent on their parents (ACT Staff et al., 2009).

Children – The Association of Children's Palliative Care (2009) defines 'children' as those who have not yet reached their 19th birthday. For the purpose of this study children and young people were defined as being between 10 and 17 years old. This is consistent with the terms used most commonly in Romania where the word 'children' was used by my participants.

Appendix 2: The combination of search terms

Spider tool	Concepts	Search terms
S	**Child (up to age 18) & parent**	children OR adolescent* Or teenager* OR pediatric OR paediatric OR parent* OR mother OR father OR main carer*
P of I	**Life-threatening or life-limiting**	life-threatening OR life-limiting OR seriously ill OR end-of-life OR incurable OR advanced OR terminally ill OR terminal care OR hospice care OR last stage OR death OR hospice* OR palliative care OR hemato-oncology OR hospital OR home-based hospice* OR hospice and palliative care
D	**Design**	questionnaire* OR survey* OR interview* OR focus group* OR case stud* OR observ* OR grounded theory OR narrative OR thematic OR content analysis OR ethnolog* OR structured interview*
E	**The child patient's experience**	experienc* OR concern* OR distress OR voice* OR view* OR quality of life OR perspective* OR feel* OR understand* OR belief* OR believ* OR worrie*
R	**Research type**	qualitative OR quantitative OR mixed methods

1. End-of-life or palliative stage of any illness

life-threatening OR life-limiting OR seriously ill OR end-of-life OR incurable OR advanced OR terminally ill OR terminal care OR hospice care OR last stage OR incurable OR death OR hospice* OR palliative OR hospice OR hemato-oncology OR hospital OR home-based hospice*OR hospice and palliative care nursing

2. Child (up to age 17)

"children" OR "adolescent*" OR "teenager*" "pediatric" OR "paediatric

3. The child patient's experience

"experienc*" OR "concern*" OR "distress" OR "voice*" OR "view*" OR "quality of life" OR "perspective*" OR "feel*" OR "understand*" OR "belie*" OR "believ*" OR "worrie*"

4. Qualitative studies

questionnaire* OR survey* OR interview* OR focus group* OR case stud* OR observ* OR grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR Qualitative

Appendix 3: Data extraction – children/teenagers

Author, year, country Quality score	**Topic**	**Participants**	**Method**	**Key findings**	**Themes/Subthemes**
(1) Nicholas et al. (2011) **Canada** **33**	To examine how End-Stage-Renal-Disease was experienced and integrated into daily life, and how these young people participate in their End-Stage-Renal-Disease care.	25 children and adolescents who are undergoing End-Renal-Stage-Disease treatment.	Ethnographic approach. Semi-structured interviews. Qualitative research method. Content analysis.	Beginning to hear the experiences, challenges, and priorities of children with End-Stage-Renal-Disease constitutes a significant step in that important direction. This study echoes a growing body of literature that attests that children bring insightful and meaningful commentary to their experiences, capacities, needs, priorities, and quality of life. Most participants struggled to manage the routines and rigours of school, and to varying degrees, they bemoaned these disruptions in daily life. For some participants, this included determining accommodations in adapting their medical regimen to fit within other priorities of daily life.	**Independence & Normality** Not feeling "normal"; Absence from school; Revealing ESRD to peers; Relying on family, friends and healthcare providers; **Development** Developing knowledge about End-Stage-Renal-Disease and involvement in treatment; **Emotional/spiritual response to illness** Assuming responsibility for End-Stage-Renal-Disease care; Adjusting despite the challenge.
(2)Scheppingen et al. (2008) **Netherlands** **32**	To examine (1) What do children with epidermolysis bullosa experience as the most difficult problems: (2) What is the impact of these challenges on their daily life; and (3) Do these	11 children with epidermolysis bullosa recruited from EB dermatology database of the University Medical Center Groningen, Netherlands.	A series of semi-structured interviews with children. The interviews were analysed systematically with the help of the qualitative	Severely affected children suffered most from itch and treatment-related pain. Mildly affected children had more problems with activity-related pain. Mildly affected children also had more concerns about their appearance and the teasing and staring at others than did severely affected children. Both groups had difficulties with participation, the visibility	**Physical symptoms** Having an itchy skin; Being in pain; **Independence & Normality** Having difficulties with participation; The feeling of being different. **Emotional/spiritual response to illness** Lack of understanding from others.

	experiences differ between mildly and severely affected children?		software package Atlas-ti.	of their disease and the feeling of being different.	
(3) Carnevale and Gaudreault (2013) Canada 36	To examine what are a critically ill child's sources of discomfort and comfort.	12 children recruited from the paediatric intensive care unit (PICU)	Formal and informal interviews. Phenomenological integrative analysis.	Diverse types of discomforts were reported, including fears and worries, hurt and pain, invasive interventions, missing significant people, noise, food or eating problems, boredom, physical symptoms, as well as four additional discomforts reported by individual participants. Several sources of comfort were described, including parents, visitors, and friends, hospital staff (principally nurses), stuffed animal/favourite blanket, entertainment, and play, food, selected medical interventions, thinking of going home, being able to walk or run, sleep, waking up, gifts, along with two other comforts reported by individual participants. Embodiment and tension between aloneness and being with someone were identified as the key phenomena underlying these children's experiences.	**Emotional/ spiritual responses to illness** Fears and worries; Noise; Missing significant people; Boredom; **Physical symptoms** Hurt and Pain; Symptoms. Food or eating problems. **Treatment experience** Invasive interventions;
(4) Holge-Hazelton et al. (2016) Denmark 39	To reveal (1) to which extend Danish AYAs with cancer have experienced fears and worries about dying; (2) whether Danish AYAs with fears and worries about dying had talked to	822 participants (teenagers and young adults). The study population was identified through the Danish Cancer Registry which is a national registry containing	A 151-item questionnaire (plus open-ended items)	Most of the adolescents and young adults had experienced fears and worries about dying, but one-third of them had not talked to anybody about those thoughts. It is an important clinical point that young age does not preclude fears and worries about dying in AYAs with cancer.	**Emotional/spiritual responses to illness** Fear and worry can be triggered; Having responsibility for others; Experiencing an existential transition process; Mood and personality have changed substantially; Viewing the future and feeling hopeless The body feels alienated and deceitful.

	anybody about their concerns; and (3) how worries or thoughts about the disease and death influenced the everyday life of Danish adolescents and young adults with cancer.	data on cancer incidents.			
(5) Flavelle (2011) Canada 36	To provide a unified description of an adolescent's experience of living with and dying of cancer.	A 15-year-old boy named Ed, who was diagnosed as having osteosarcoma in 2003 and died of his disease one year later.	Analysis of his 90-page journal that spanned three months just before his death. Qualitative analysis using phenomenological methods.	Ed's journal, suggest that some of his experiences are parallel to those of other adolescents living with cancer. Ed's sharp and often sarcastic sense of humour enabled him to endure tremendous pain, compromised mobility, and constant fatigue. He also found solace in spirituality and his belief in the existence of God. Ed has given others the opportunity to understand his journey and to appreciate that many of his experiences are reflected in the lives of youth faced with similar challenges.	**Development** The negative impact on the trajectory of adolescent development; **Emotional/spiritual responses to illness** Escape from illness; Spirituality (finding meaning and purpose in life). Changing relationships; **Physical symptoms** Pain; Compromised mobility
(6) Moody, K. et al. (2006) New York 38	To identify important quality-of-life issues from the perspectives of children with cancer and to determine how they think their experience with cancer treatment	31 paediatric oncology patients age 5–21 were recruited from the outpatient paediatric haematology/oncology clinic and inpatient wards.	One to one interviews. Responses were analysed using standard qualitative techniques.	Children with cancer do not participate in many of the activities and socialisation processes that are integral to having a normal childhood, and this results in feelings of loneliness and isolation. Food and eating once considered pleasurable also become a significant source of distress. Nausea, pain, and disability are frequently encountered because of cancer and cancer therapy.	**Emotional/spiritual responses to illness** Loneliness and isolation: the loss of a normal childhood; Emotional responses to cancer, specifically anger and fear. **Physical symptoms** Physical discomfort and disability; Hurt; Decreased pleasure from food.

	could be improved.			Finally, all these changes as well as the life-threatening component of cancer brings about feelings of anger and fear.	
(7) Snethen, J.A. (2001) **USA** **38**	To explore the perception of adolescents living with End Stage Renal Disease.	35 adolescents living with End of Life Stage of Renal Disease.	Mixed method was chosen to implement in this research study.	The findings of most of the subjects in this study suggest that adolescents with End Stage of Renal Disease have different perceptions about living with the condition. Some of them are positive about living with the illness, and some of them are more negative.	**Independence and Normality** Normalization Illness intrusion; barrier to normality
(8) Woodgate, R.L. (1998) **Canada** **36**	To increase our understanding of adolescents' chronic illness experiences and identify how adolescents deal with their chronic illness.	23 adolescents diagnosed with a Chronic illness as, Crohn's disease	A qualitative research design based on grounded theory was used to elicit detailed descriptions of adolescents' chronic illness experiences Open-ended interviews. The constant comparative method was used to analyse all data from the interviews.	The findings revealed that having a chronic illness made life more difficult for the adolescents. Adolescents experienced extra effort, restrictions, pain, and additional worries because of having a chronic illness. What theory was generated?	**Emotional/spiritual responses to illness** "It's hard." "It's a whole bunch of worries." **Independence and Normality** "It takes extra effort." "It is restraining " **Physical symptoms** "It's painful."

(9) Wu et al. (2009) **Taiwan** **38**	To describe the essence of the coping experiences of Taiwanese adolescents with cancer	Ten adolescents aged 12–18 years who were receiving chemotherapy	Open-ended interviews were conducted. Interview data were analysed using Giorgi's four-step procedures	Interviewees vacillated between moving on and giving up, depending on the strength of their hope. A focus on rebuilding hope helped the adolescents to move on in the midst of many distressful events.	**Emotional/spiritual responses to illness** Losing confidence (psychological suffering) Rebuilding hope (thought restructuring, revaluing what I have, envisioning hopeful images of the future) **Physical symptoms** Losing confidence (physical suffering)
(10) Rollins (2005) **UK & USA** **39**	To (a) explore and compare the nature of stressors of everyday life and disease that child with cancer in the United Kingdom and the United States experience, (b) explore and compare the coping measures they use to manage these stressors.	22 children ages 7 to 18 years, 13 boys and nine girls receiving treatment for cancer in the United Kingdom and The United States.	Quantitative and qualitative methods were used within a grounded theory approach and included drawing to accompany the traditional grounded theory methods of interview and observation.	Findings indicate that children, regardless of their ethnicity and other cultural components, respond to the childhood cancer experience in a similar manner. The use of drawing enhanced communication through direct visual expression and through verbal expression.	**Treatment experiences** Surgical procedures Getting chemotherapy Hospitalisation in general Needles **Emotional/spiritual responses to illness** Significant event (out of body, near death, dream) Fear of death "What is going to happen to me?" Missing school **Independence and Normality** Hair loss Appearance

Appendix 4: Data extraction – parents

Author, year, country Quality score	**Topic**	**Participants**	**Method**	**Key findings**	**Themes/Subthemes**
(1) Juarez, R.M. et al. (2013) **Spain** **39**	To capture the parents' perspective about the suffering of their children with terminal illnesses.	13 parents of hospitalised children with a terminal illness	Semi-structured interview. Three item questions. Content Analysis	Parents described children's suffering as manifested through sadness, apathy, and anger towards their parents and the professionals. The isolation from their natural environment, the uncertainty towards the future, and the anticipation of pain, caused suffering in children. The pain is experienced as an assault that their parents allow to occur.	**Emotional/spiritual responses to illness** Concept of Suffering (Emotional state, Feeling,) Signs of suffering (State of mind) Causes of suffering (Isolation, Uncertainty) **Physical symptoms** Signs of suffering (Gestures, Behaviour or conduct, Verbalisation) Concept of suffering (Discomfort, pain) Causes of suffering (Other discomfort symptoms) **Independence and Normality** Causes of suffering (Dependency/Lack of autonomy). **Treatment experiences** Invasive procedure
(2)Cataudella and Zelcer (2012) **Canada** **36**	To explore the psychological experiences of children with brain tumours at the end of life from parental perspective	24 parents of children diagnosed at less than 18 years of age with a brain tumour	Focus groups of bereaved parents were used to retrospectively investigate the perceived experiences of children dying from brain tumours.	Key characteristics were exhibited by these children including showing maturity beyond their years, greater concern for others, appreciating the little things in life, and continuing to have hope. These children also developed a variety of adaptive coping strategies that demonstrated their resilience in the face of dying, including spirituality, humour, maintaining daily pleasurable activities, and setting specific, achievable short-term goals	Three main domains were identified that describe parents' perceptions of their child's psychological experiences: **Development** (1) Intrapsychic changes—those processes within oneself, and encompassing internal aspects of a person such as cognitive and emotional variables; (2) Post-traumatic growth—those positive personal changes that can occur

				Most parents felt that their child was aware they were dying. Children who die from brain tumours experience a distinct set of progressive neurologic deteriorations that invariably impact on psychological status both positively and negatively.	as the result of a significant struggle or hardship. **Independence and Normality** (3) Interpersonal interactions—those interactions between oneself and others, including being treated like their same aged healthy peers and maintaining relationships with others.
(3)Anderzén-Carlsson et al. (2007) Sweden 38	To highlight parents' lived experience and understanding of their child's fear	15 parents (nine mothers and six fathers) of children aged between 2 to 15 years old.	Focus group interviews were held with parents of children with cancer. The transcripts were analysed moreover, interpreted in accordance with a phenomenological hermeneutic method	Fear, in children with cancer, is, from a parental point of view, a multidimensional phenomenon, which is somehow integrated with other feelings of uneasiness. It is well recognised by the parents but still somehow difficult to identify. An overall description of how the parents experience their children's fear could be as a suffering and as an ethical demand.	**Emotional/spiritual responses to illness** The suffering child (The origin of fear; Feelings of uneasiness; The difficulty in recognising fear) The nonsuffering child (No fear; A feeling of security; The impact of knowledge; The parent's fear—another issue) **Development** Different ages—different fears.

Appendix 5: Data extraction – parents & children/teenagers

Author, year, country Quality score	**Topic**	**Participants**	**Method**	**Key findings**	**Themes/Subthemes**
(1) Sartain et al. (2000) **UK** **38**	To explore children's, parents' and health professionals' experience of chronic childhood illness	Seven hospitalised children aged between eight to fourteen. Their parents were also interviewed at home after children were discharged.	Semistructured interviews. The children's interviews were augmented with a `drawing' technique. Grounded theory approach facilitated data collection and analysis.	The findings have shown that research and data collection with children, has been efficient and has given them a voice. The importance of giving children a voice is reflected in the research data. The research findings in this study convey that children are not only capable of giving an opinion but that their views can lead to a significantly greater understanding of their illness.	Children **Emotional/spiritual responses to illness** Being in hospital (forgotten, insecure) Being at home (miss being at home, going to school) Parents **Independence and Normality** Living with chronic illness (Living as normally as possible) **Developmental** Biographical disruptions.
(2) Grinyer, A. (2009) **UK** **39**	To compare and contrast the issues raised by parents from parents of teenagers and young adults with cancer with interview data gathered from young adults being treated for cancer.	28 young adults: 12 young adults with cancer recruited through Teenage Cancer Trust. Twelve through a non-specialist Trust and four through informal introductions There were also interviews with parents of 28 young adults with cancer most of whom have died.	Narrative correspondence method to gather data from parents. An in-depth interview with the young adults.	The secondary analysis of the two datasets illuminates contrasting familial perspectives. While some of the topics raised by parents are also addressed by young people, their views differ, thus offering a 'mirror image' of the same issue. The contrast in priorities can contribute to stress within the family and can increase the danger of conflict over critical decisions that may impact upon the health of the young adult with cancer.	**Independence and Normality** Appearance Independence and normality Family tensions

(**3)** **Bluebond-Langner (1978)** **UK** **39**	To get as close as possible to children's thoughts, their interactional strategies, and their structuring of the situation. What children see, feel, and put together at each step of their finite journey. Attention is directed to the problems of how and why dying children choose to conceal their awareness from adults.	32 children diagnosed with advanced cancer were significant informants. Supplementary data about the terminally ill children came from informal interviews with the parents.	Primary data about the children came from observations and researcher's conversation with them. The parents and staff were informally interviewed.	Children can develop techniques and theories about their sickness and are fully aware of what is going on by adapting to their environment and reacting to others and the medication. Bluebond-Langner also proves that children can understand their condition from the way they protect their parents.	**Development** Changes in self-concepts **Treatment experience** Painful medical procedures **Emotional/spiritual responses to illness** Children will withdraw from their family

Appendix 6: Themes based on the type of the articles

	Parent’s accounts studies	Child’s account studies	Parent’s and child’s account studies
Life-limiting studies	• Emotional response to illness • Spiritual response to illness • Independence and Normality • Physical symptoms	• Emotional response to illness • Spiritual response to illness • Independence and Normality • Physical symptoms • Development	• Emotional response to illness • Spiritual response to illness • Independence and Normality • Development
Life-threatening studies	• Emotional response to illness • Spiritual response to illness • Independence and Normality • Development	• Emotional response to illness • Spiritual response to illness • Independence and Normality • Physical symptoms • Treatment experiences • Development	• Emotional response to illness • Spiritual response to illness • Independence and Normality • Treatment experience • Development

Appendix 7: Participant information sheet for parents

Participant Information Sheet

Title of Study: Experiences of children attending hospice or palliative care services in Romania

My name is Estera Ciobanu and I am conducting this research as a student in the Palliative care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The purpose of this study is to explore the experiences of children attending hospice or palliative care services.

Why have I been approached?
You have been approached because you are the parent of a child who is attending a hospice service. The study hopes to gain a greater understanding of the experiences of parents and children.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part in the study. Your decision, whether positive or negative, will not affect the services your child receives in any way.

What will I be asked to do if I take part?
If you decide you and your child would like to take part, you would be asked to sign a consent form to participate in the study. If the child doesn't want to take part in the study you will not be interviewed as well. If you don't want to participate in the study the child will not be interviewed as well.

Will my data be Identifiable?
The information you provide is confidential. Information from the interviews will be transferred in a computer protected by a password and only the researchers involved in the study will have access to the data. The researcher will transcribe and will anonymise the data.

If any quotes from the interviews are used in publications, no personal data about you will be used, and you will be allocated a pseudonym to ensure anonymity.
The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Hard copies of questionnaires will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. Audio

recordings will be deleted once the project has been examined. At the end of the study hard copies of the interviews will be kept in a locker and destroyed after ten years.

- At the end of the study, hard copies of questionnaires will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?
The results will be summarised and reported thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?
There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?
This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact my academic supervisors:

Dr Anne Grinyer
Email: a.grinyer@lancaster.ac.uk

Dr Nancy Preston
Email: n.j.preston@lancaster.ac.uk

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

Dr Bruce Hollingsworth Tel: +44 1524594154
Director of studies Palliative Care, Email: b.hollingsworth@lancaster.ac.uk
Division of health research

Lancaster University
Lancaster
LA1 4YG

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

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research
Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

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

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Daria Sass
Psychologist
Emanuel Hospice Organisation
Redutei 1A, Oradea, Romania
Email: dariasass@yahoo.com

Appendix 8: Participant Information sheet for children

Participant Information Sheet

Hello! I am writing a paper for a study and I would like to hear more about you, about your life, your illness.

What is the study about?

The study will explore the experiences of children using hospice services.

Do I have to take part?

It's completely up to you to decide whether or not you take part in the study. Your decision, whether positive or negative, will not affect the services you receive in any way.

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

If you decide you would like to take part in the study, you would be asked to sign that you assent to participate in the study along with the one of your parents.

You are free to choose not to answer any question if you don't want to.

Will my data be Identifiable?

The information you provide is confidential. I will chat with you for maybe an hour and everything we are talking is between us.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to my research supervisor. If possible, I will tell you if I have to do this.

Thank you for reading this information sheet!

Appendix 9: Consent form – parents

Consent Form

Study Title: Experiences of children diagnosed with life-threatening and life-limiting conditions in Romania

We are asking if you would like to take part in a research project which aims to explore the experiences of seriously ill children.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. The data from the interviews will be shared and discussed with my supervisor. If you have any questions or queries before signing the consent form please speak to the principal investigator, Estera Ciobanu.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until data is transferred and encrypted. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time before or during the interview and up to two weeks fallowing the interview without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with her research supervisor. ☐
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐

Name of Participant ___________________ **Signature**______________**Date** ____________

Name of Researcher ___________________**Signature** ______________**Date** ____________

Appendix 10: Assent form

Assent Form

Study Title: Experiences of children attending hospice services in Romania

We are asking if you would like to take part in a research project which aims to explore the experiences of adolescents using hospice services.

Before you assent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. The data from the interviews will be shared and discussed with my supervisor. If you have any questions or queries before signing feel comfortable to ask me.

PLEASE INITIAL EACH STATEMENT

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until data is transferred into a safe place. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time before or during the interview and up to two weeks fallowing the interview without giving any reason, without my care or rights being affected. ☐
6. I understand that once my data have been anonymised it might not be possible for it to be withdrawn. ☐
7. I understand the information from my interview will be pooled with other participants' responses, anonymised and may be published ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the interviewer may need to share this information with her research supervisor. ☐
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐

Name of Participant__________________**Signature**____________**Date** ____________

Name of Researcher __________________**Signature** ___________**Date** ____________

Appendix 11: Interview Guide

The Lived Experiences of Children diagnosed with Life-threatening and Life-limiting Conditions in Romania

Topics to discuss[1] – April 2016

1. Understanding of illness
2. Family relationships
3. Impact of living with a life limiting illness
4. Describing diagnosed in one word
5. Doubts about treatment
6. Thoughts/feelings when doubts that the treatment will work
7. Fears and concerns since the diagnoses

1. Worries regarding the illness
2. Things that helps at the moment
3. Worst things at the moment
4. Coping strategies
5. Important persons
6. Thoughts about the future
7. Things that can bother
8. Hopes for the future

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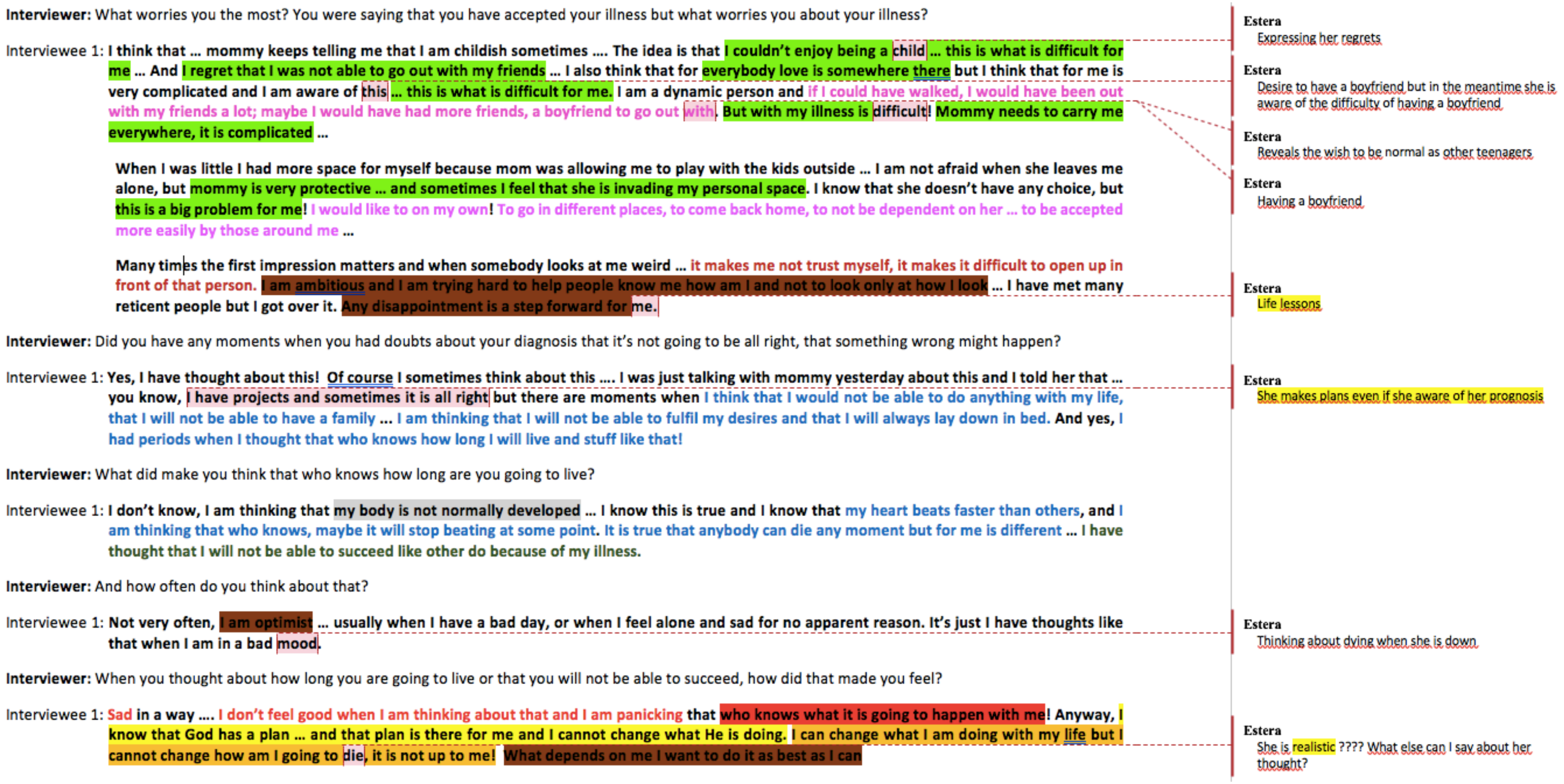
[1] Topics for children as well as for parents

Appendix 12: Coding excerpt



Interviewer: What worries you the most? You were saying that you have accepted your illness but what worries you about your illness?

Interviewee 1: **I think that … mommy keeps telling me that I am childish sometimes …. The idea is that I couldn't enjoy being a child … this is what is difficult for me … And I regret that I was not able to go out with my friends … I also think that for everybody love is somewhere there but I think that for me is very complicated and I am aware of this … this is what is difficult for me. I am a dynamic person and if I could have walked, I would have been out with my friends a lot; maybe I would have had more friends, a boyfriend to go out with. But with my illness is difficult! Mommy needs to carry me everywhere, it is complicated …**

When I was little I had more space for myself because mom was allowing me to play with the kids outside … I am not afraid when she leaves me alone, but mommy is very protective … and sometimes I feel that she is invading my personal space. I know that she doesn't have any choice, but this is a big problem for me! I would like to on my own! To go in different places, to come back home, to not be dependent on her … to be accepted more easily by those around me …

Many times the first impression matters and when somebody looks at me weird … it makes me not trust myself, it makes it difficult to open up in front of that person. I am ambitious and I am trying hard to help people know me how am I and not to look only at how I look … I have met many reticent people but I got over it. Any disappointment is a step forward for me.

Interviewer: Did you have any moments when you had doubts about your diagnosis that it's not going to be all right, that something wrong might happen?

Interviewee 1: **Yes, I have thought about this! Of course I sometimes think about this …. I was just talking with mommy yesterday about this and I told her that … you know, I have projects and sometimes it is all right but there are moments when I think that I would not be able to do anything with my life, that I will not be able to have a family … I am thinking that I will not be able to fulfil my desires and that I will always lay down in bed. And yes, I had periods when I thought that who knows how long I will live and stuff like that!**

Interviewer: What did make you think that who knows how long are you going to live?

Interviewee 1: **I don't know, I am thinking that my body is not normally developed … I know this is true and I know that my heart beats faster than others, and I am thinking that who knows, maybe it will stop beating at some point. It is true that anybody can die any moment but for me is different … I have thought that I will not be able to succeed like other do because of my illness.**

Interviewer: And how often do you think about that?

Interviewee 1: **Not very often, I am optimist … usually when I have a bad day, or when I feel alone and sad for no apparent reason. It's just I have thoughts like that when I am in a bad mood.**

Interviewer: When you thought about how long you are going to live or that you will not be able to succeed, how did that made you feel?

Interviewee 1: **Sad in a way …. I don't feel good when I am thinking about that and I am panicking that who knows what it is going to happen with me! Anyway, I know that God has a plan … and that plan is there for me and I cannot change what He is doing. I can change what I am doing with my life but I cannot change how am I going to die, it is not up to me! What depends on me I want to do it as best as I can**

Estera
Expressing her regrets

Estera
Desire to have a boyfriend but in the meantime she is aware of the difficulty of having a boyfriend

Estera
Reveals the wish to be normal as other teenagers

Estera
Having a boyfriend

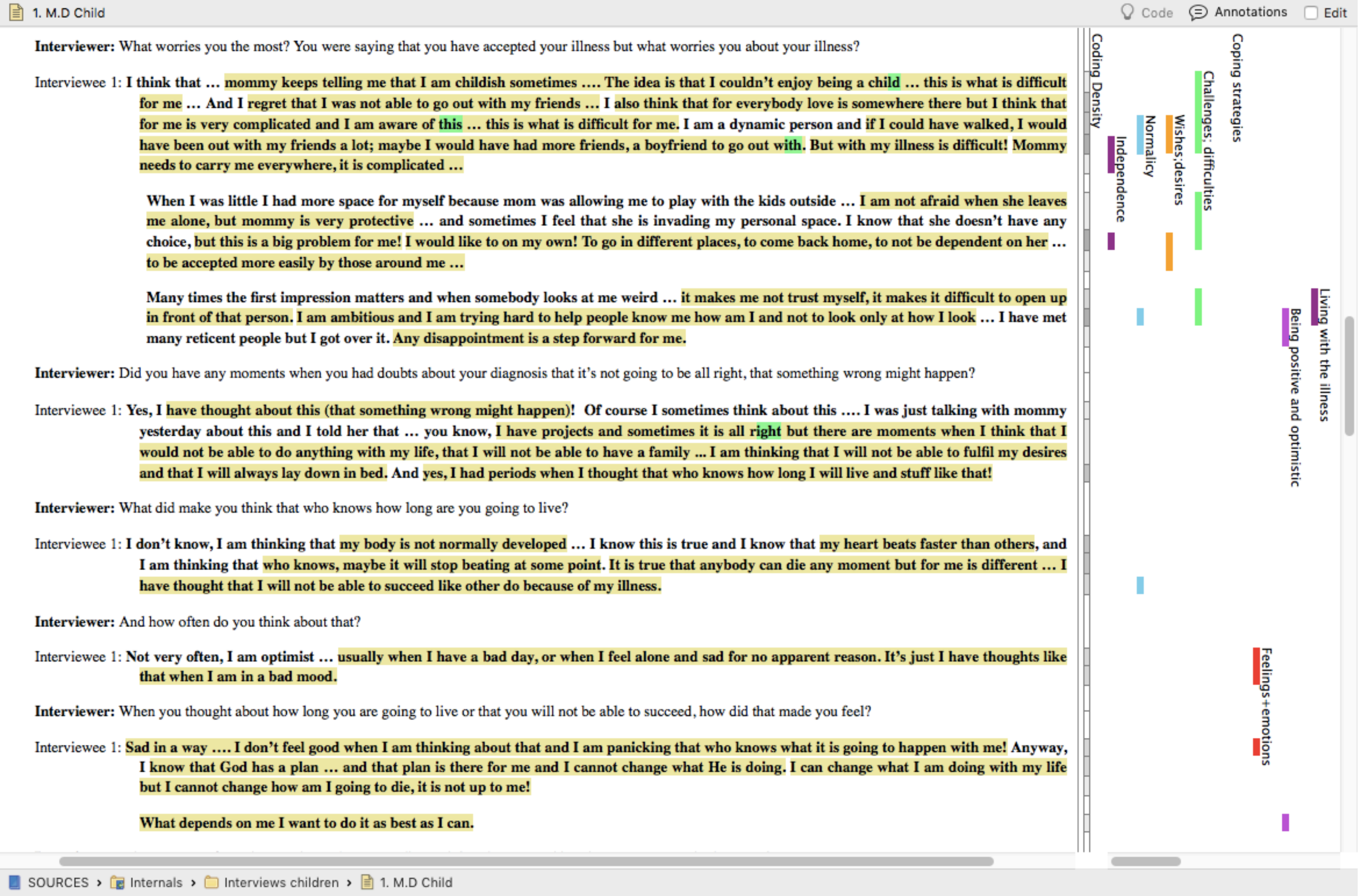
Estera
Life lessons

Estera
She makes plans even if she aware of her prognosis

Estera
Thinking about dying when she is down

Estera
She is realistic ???? What else can I say about her thought?

Colour	**Code**	**Examples**
Red	feelings, emotions	Scared
Grey	**Worries/fears**	**I have thought that over time I might not be able to use it even so … that's what scares me**
Blue	Awareness of the prognosis/illness	lives no more than a year or something like that
Dark green	Getting worse	each year that passed it was more difficult, and now I find it really hard even to write
Brown	Living with the illness	I've always wanted to walk, to be like the others, to be normal, but I come to realize that there is no such a thing *to be normal.* I always wished that I could do the things that others can do
Green	Physical condition/appearance	My body is not normally developed
Purple	Hope	At least I would like to be able use my hands again.
Turquoise	Describe illness in one word	it is hard to need someone staying constantly with me, somebody who needs to do everything for me … to not be able to do anything by myself
Green	Challenges/difficulties	mommy is very protective … and sometimes I feel that she is invading my personal space …. but this is a big problem for me
Grey	Symptoms	
Yellow	Spiritual response to illness	I know that God has a plan … and that plan is there for me and I cannot change what He is doing.
Pink	Coping	The thought that I will be able to do something with my life
Pink	Wishes/ desires	to study at the university and then to find a job and work.
Dark blue	Relations/friends	… they saw me as I was … not necessarily the exterior side of me, but me as a person.
Thick underline	Family Relationships/Significant persons	My illness brought them (parents) together Mommy without whom I would have not been able to do anything
Red	Uncertainty about the diagnosis	I don't think that in our country is any doctor who can tell me exactly what my diagnosis is.
Wave underline	Accepting illness/themselves	I come to a point when I realized that I cannot change that.
Italic	*Finding more about the illness*	*I searched via internet …. I searched on Google and I found the disease*
Brown	**Being positive and optimistic**	**Now I enjoy life as it is. I try not to compare myself with others and to accept me as I am.**
Orange	Desire to die/thoughts about dying	I can change what I am doing with my life but I cannot change how am I going to die, it is not up to me!



Interviewer: What worries you the most? You were saying that you have accepted your illness but what worries you about your illness?

Interviewee 1: **I think that … mommy keeps telling me that I am childish sometimes …. The idea is that I couldn't enjoy being a child … this is what is difficult for me … And I regret that I was not able to go out with my friends … I also think that for everybody love is somewhere there but I think that for me is very complicated and I am aware of this … this is what is difficult for me. I am a dynamic person and if I could have walked, I would have been out with my friends a lot; maybe I would have had more friends, a boyfriend to go out with. But with my illness is difficult! Mommy needs to carry me everywhere, it is complicated …**

When I was little I had more space for myself because mom was allowing me to play with the kids outside … I am not afraid when she leaves me alone, but mommy is very protective … and sometimes I feel that she is invading my personal space. I know that she doesn't have any choice, but this is a big problem for me! I would like to on my own! To go in different places, to come back home, to not be dependent on her … to be accepted more easily by those around me …

Many times the first impression matters and when somebody looks at me weird … it makes me not trust myself, it makes it difficult to open up in front of that person. I am ambitious and I am trying hard to help people know me how am I and not to look only at how I look … I have met many reticent people but I got over it. Any disappointment is a step forward for me.

Interviewer: Did you have any moments when you had doubts about your diagnosis that it's not going to be all right, that something wrong might happen?

Interviewee 1: **Yes, I have thought about this (that something wrong might happen)! Of course I sometimes think about this …. I was just talking with mommy yesterday about this and I told her that … you know, I have projects and sometimes it is all right but there are moments when I think that I would not be able to do anything with my life, that I will not be able to have a family ... I am thinking that I will not be able to fulfil my desires and that I will always lay down in bed. And yes, I had periods when I thought that who knows how long I will live and stuff like that!**

Interviewer: What did make you think that who knows how long are you going to live?

Interviewee 1: **I don't know, I am thinking that my body is not normally developed … I know this is true and I know that my heart beats faster than others, and I am thinking that who knows, maybe it will stop beating at some point. It is true that anybody can die any moment but for me is different … I have thought that I will not be able to succeed like other do because of my illness.**

Interviewer: And how often do you think about that?

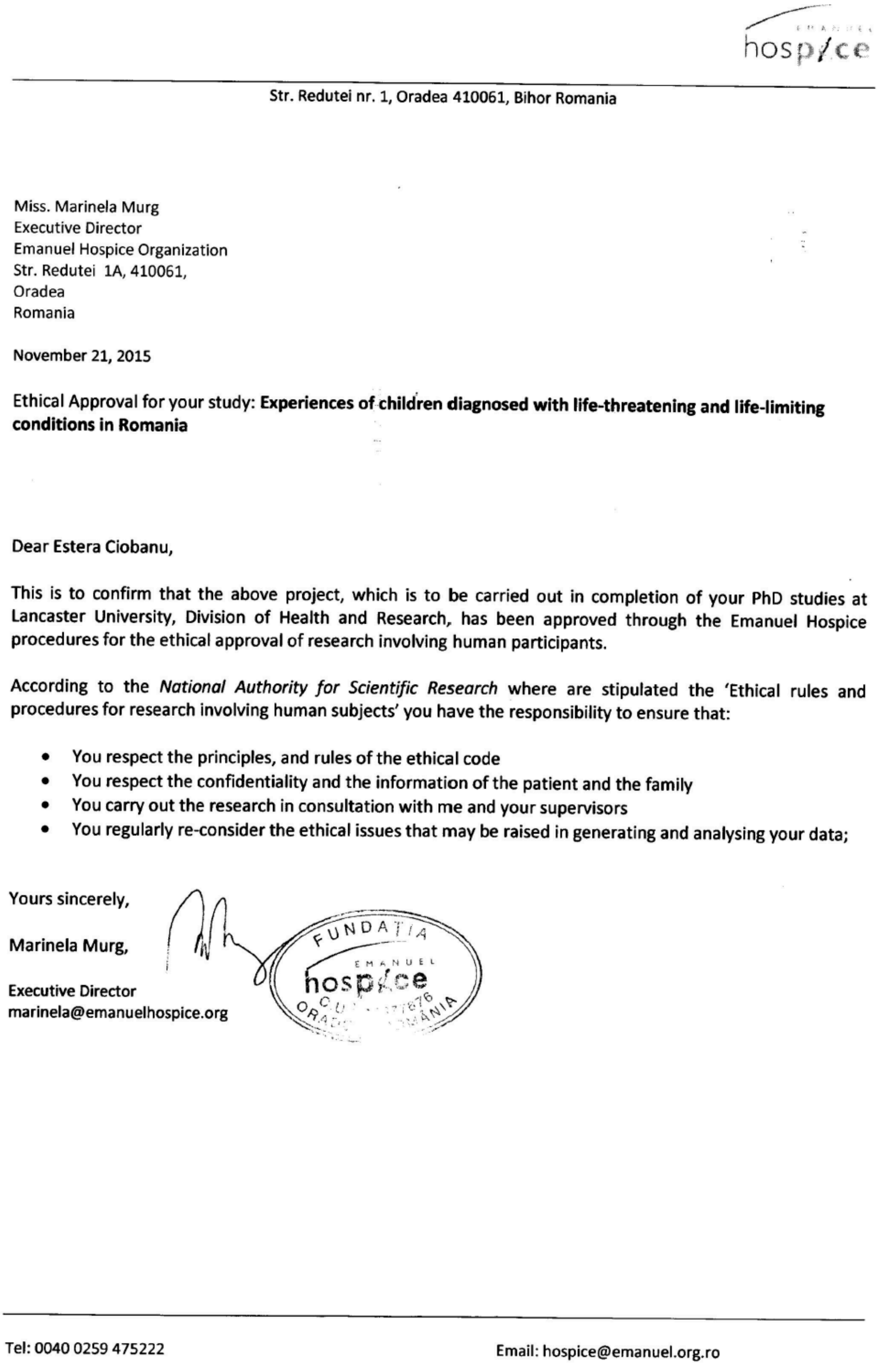
Interviewee 1: **Not very often, I am optimist … usually when I have a bad day, or when I feel alone and sad for no apparent reason. It's just I have thoughts like that when I am in a bad mood.**

Interviewer: When you thought about how long you are going to live or that you will not be able to succeed, how did that made you feel?

Interviewee 1: **Sad in a way …. I don't feel good when I am thinking about that and I am panicking that who knows what it is going to happen with me! Anyway, I know that God has a plan … and that plan is there for me and I cannot change what He is doing. I can change what I am doing with my life but I cannot change how am I going to die, it is not up to me!**

What depends on me I want to do it as best as I can.

Appendix 13: Ethical Approval



EMANUEL hospice

Str. Redutei nr. 1, Oradea 410061, Bihor Romania

Miss. Marinela Murg
Executive Director
Emanuel Hospice Organization
Str. Redutei 1A, 410061,
Oradea
Romania

November 21, 2015

Ethical Approval for your study: **Experiences of children diagnosed with life-threatening and life-limiting conditions in Romania**

Dear Estera Ciobanu,

This is to confirm that the above project, which is to be carried out in completion of your PhD studies at Lancaster University, Division of Health and Research, has been approved through the Emanuel Hospice procedures for the ethical approval of research involving human participants.

According to the *National Authority for Scientific Research* where are stipulated the 'Ethical rules and procedures for research involving human subjects' you have the responsibility to ensure that:

- You respect the principles, and rules of the ethical code
- You respect the confidentiality and the information of the patient and the family
- You carry out the research in consultation with me and your supervisors
- You regularly re-consider the ethical issues that may be raised in generating and analysing your data;

Yours sincerely,

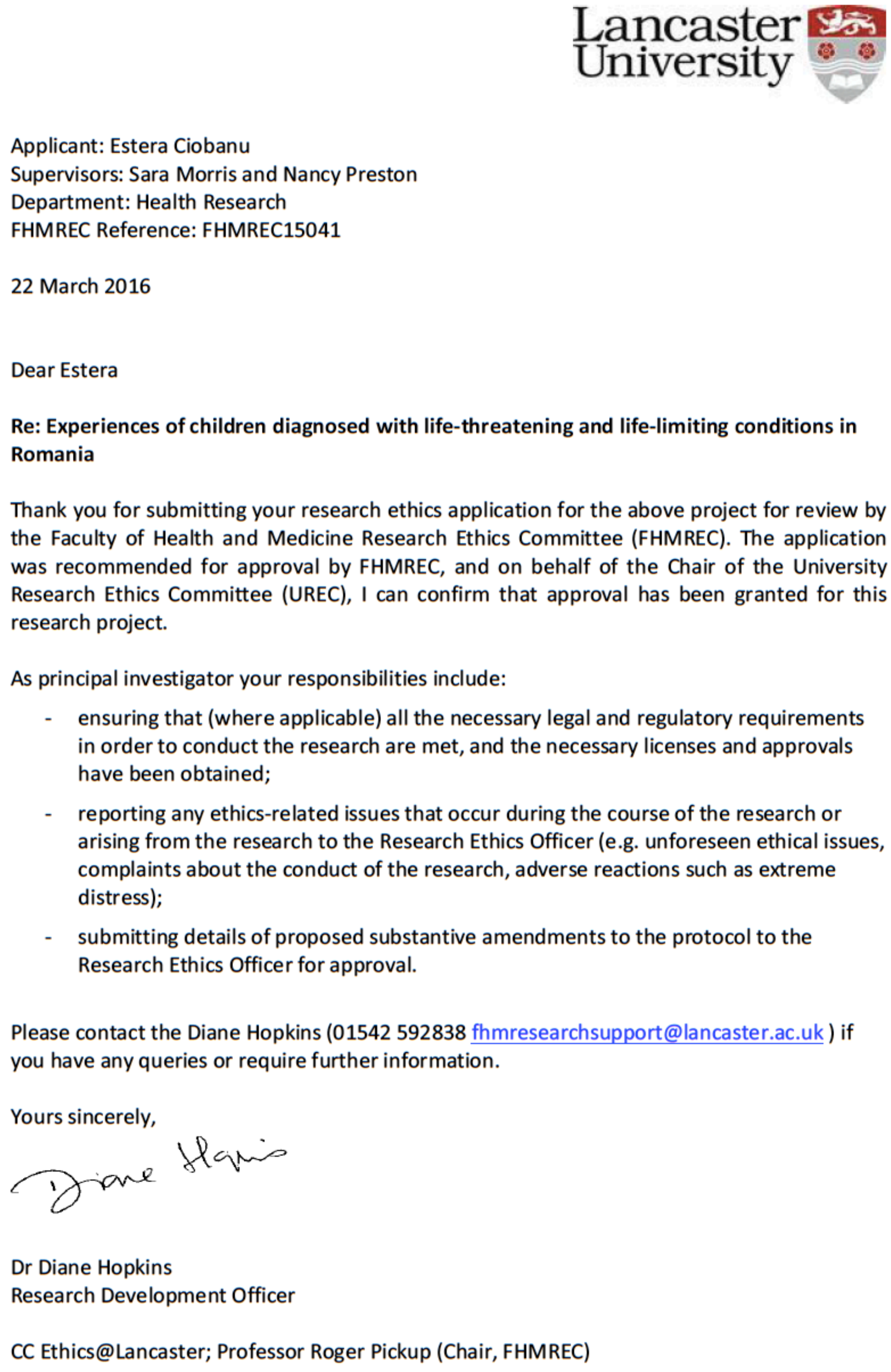
Marinela Murg,

Executive Director
marinela@emanuelhospice.org

Tel: 0040 0259 475222

Email: hospice@emanuel.org.ro

Appendix 14: Ethical Approval



Lancaster University

Applicant: Estera Ciobanu
Supervisors: Sara Morris and Nancy Preston
Department: Health Research
FHMREC Reference: FHMREC15041

22 March 2016

Dear Estera

Re: Experiences of children diagnosed with life-threatening and life-limiting conditions in Romania

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Diane Hopkins (01542 592838 fhmresearchsupport@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Development Officer

CC Ethics@Lancaster; Professor Roger Pickup (Chair, FHMREC)