Oncologists' and Haematologists' Views of what Facilitates or Hinders Referral of a Child with Advanced Cancer to Palliative Care in India.

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

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This thesis was my trial by fire. The successful survival does not prove my mastery, but HIS grace was sufficient to strengthen me in my weakness.

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Abstract

Title: Oncologists' and haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.

Background and Aim: In India, there is a high incidence, low cure rates and increased cancer-associated deaths among children with cancer. Although a significant proportion need palliative care, few are referred or referred late. Oncologists and haematologists gatekeep the referral process. This study explored their views on facilitators and barriers to palliative care referral.

Methods: Twenty-two paediatric oncologists and haematologists from thirteen Indian cancer centres were recruited and interviewed. The critical realist paradigm was the philosophical foundation informing this study. Data were analysed using reflexive thematic analysis. Findings were discussed using social exchange theory and feedback intervention theory.

Results: Four themes were generated. 1) Presuppositions about palliative care where qualifications, experience and being an oncologist conferred power to refer. Oncologists had mixed views about their ability to address palliative care needs. Palliative care could symbolise therapeutic failure and abandonment, which hindered referral. Trustworthy palliative care providers had clinical competence, benevolence, knowledge of oncology and paediatrics. 2) Making a palliative care referral was associated with stigma, navigating illness-related factors, negative family attitudes and limited resources, impeding palliative care referral. 3) There were cost benefits to palliative care referral: Symptom management and psychosocial support benefitted the patients. Teamwork, stress reduction and personal growth helped the oncologists. Perceived interference and communication by the palliative care team incongruous with the oncologist's views hindered referral. 4) Suggested strategies for developing an integrated palliative care model include clear collaboration between oncology and palliative care, early referral, rebranding palliative care as symptom control and an accessible, knowledgeable, and proactive palliative care team.

Conclusion: Presuppositions, associated tasks and cost-benefits influenced referral behaviour. Association with the palliative care team and the experience of palliative care referrals prompted the oncologists to provide feedback to a palliative care provider as professional inputs directed at further development of the palliative care team. Continuous feedback between cancer and palliative care providers could foster integration and improve the palliative care management of children. This study contributes to the literature on integrated palliative care by proposing an infinite loop model where the oncologist's feedback could assist in bettering the palliative care team's services, which might positively impact the oncologist's experience of working with the palliative care team. A positive experience might also influence the presuppositions of oncologists and haematologists, impacting future referrals.

Keywords:
views
oncologist, haematologist
consultation, referral
neonate, infant, child, adolescent
neoplasms, cancer, haematology
palliative care, palliative medicine

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Abbreviations and Terms

ACT: Association for Children's Palliative Care

APA: American Psychological Association

ASCO: American Society of Clinical Oncology

BMC: BioMed Central

CINAHL: Cumulative Index of Nursing and Allied Health Literature

Cochrane: Database on health-related systematic reviews

COVID-19: Corona Virus Disease of 2019

CTRI: Clinical Trials Registry of India

EMBASE: Excerpta Medica database (biomedical and pharmacological bibliography)

EORTC: European Organisation for Research and Treatment of Cancer

ESMO: European Society of Medical Oncology

FHMREC: Faculty of Health and Medicine Research Ethics Committee

GDP: Gross Domestic Product

Google Scholar: Search engine accessing full-text or metadata of scholarly articles

IAHPC: International Association of Hospice and Palliative Care

ICU: Intensive Care Unit

ICF: Informed Consent Form

IEC: Institutional Ethics Committee

MEDLINE: Medical Literature Analysis and Retrieval System Online

NCI: National Cancer Institute

NVivo: Qualitative Data Analysis computer software package produced by QSR international

PACT: Paediatric Advanced Care Team

PC: Palliative Care

PICo: Population, Phenomenon of Interest and Context

PIS: Participant Information Sheet

PhD: Doctor of Philosophy

PROSPERO: International Prospective Register of Systematic Reviews

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PsycINFO: A database of literature in the field of Psychology by the APA

PubMed: A search engine accessing MEDLINE database

RCPCH: The Royal College of Paediatrics and Child Health

SCOPUS: Multidisciplinary abstract and citation database of Elsevier

SEAR: South-East Asian Region

SET: Social Exchange Theory

UK: The United Kingdom

UNICEF: United Nations International Children's Emergency Fund

USA: The United States of America

Web of Science: Multidisciplinary abstract and citation database of Clairvate Analytics

WHO: World Health Organisation

Chapter 1: Introduction

In this chapter, I explain what the research was about, my background and what drove me to conduct this research. I lay out the context and my voice in this research. Furthermore, I have provided a glossary of key terms used in this study. I have concluded this chapter by giving an overview of the thesis and a brief outline of each thesis chapter.

1.1. Introduction to the Research

The palliative care referral phenomenon in a cancer setting involves cancer care and palliative care providers, children and their families as stakeholders (Snaman et al., 2020). Multiple factors and mechanisms underpin the phenomenon of referral. This research focused exclusively on oncologists and haematologists in a paediatric oncology setting in India, exploring their views on facilitators and barriers for palliative care referral.

The research question was

What are the views of oncologists and haematologists of what facilitates or hinders referral of a child with advanced cancer to palliative care in India?

The objectives were

a. To explore oncologists' and haematologists' views about the scope of palliative care in a child with advanced cancer in India.

b. To explore oncologists' and haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.

Note: In this thesis, the term oncologist encompasses oncologists and haematologists. When I have used the term haematologist(s), I refer specifically to haematologist(s) only.

1.2. My Background

I am a physician and professor of palliative care in a cancer centre affiliated with a university teaching hospital in India. I am a dual board-certified internal medicine and palliative medicine doctor with twelve years of consultant-level clinical experience. Although I trained as an adult palliative care physician, I am interested in paediatric palliative care. I conduct paediatric palliative care outpatient's clinics twice a week and provide consultation-liaison support to children with cancer referred to palliative care. I work with the hospital paediatric oncology disease management group, and I participate in joint clinics and tumour board meetings.

1.3. My Motivation to Conduct this Research

As a palliative care physician, I work closely at the intersection of paediatric oncology and palliative care. My constant observation has been that the children with advanced cancer are less often referred to palliative care when compared to adults or are referred late. They stayed with the palliative care team for a very short time before they died. A retrospective audit of five-year data from India validated my observations, where 78.2% of the children had completed all disease-directed therapy before referral to palliative care (Ghoshal et al., 2016).

Moreover, my hospital saw a significant number of out-of-town children accessing treatment. Most of them were referred just before discharge. We often saw them only once, and we hardly had any time to work with these children and their families. Most of these children referred to palliative care had unresolved symptoms, emotional issues, and families had very little information about the illness.

During the joint clinics and tumour board meetings, oncologists often expressed displeasure while making a palliative care referral. The paediatric oncology tumour board meetings had a power imbalance with many oncologists outnumbering a single palliative care physician, and my role in the clinical decision-making process was limited. Oncologists used to decide if and when the child has to be referred to palliative care. In my opinion, the dominant cure-oriented culture and gatekeeping denied many children and their families from receiving palliative care. Vulnerable children suffered needlessly, and families remained ill-informed and were not part of the decision-making process. Their voices were rarely heard. My research had a social agenda towards mitigating children's suffering with advanced cancer and the empowerment of families. I feel timely palliative care referral might overcome this health inequity. In my socio-cultural context, oncologists are the gatekeepers of referral. Knowing their perspectives about what helps or hinders palliative care referral could influence policies and practices that might have a transformative impact.

1.4. Research Context

The research was conducted in India, a low-middle-income country where a small proportion of its gross domestic product (GDP) is spent on health (World Bank, 2018; World Health Organization Global Health Expenditure database, 2016a). More than a million new cancer cases are detected every year (Chandramohan & Thomas, 2018), and cancer in children account for less than five per cent of total cancer diagnoses (Ganguly et al., 2020). Childhood cancers in India have significantly lower cure rates with a higher incidence of deaths when compared to high-income countries like the UK (Children with Cancer UK, 2020; Gupta et al., 2016). Although many children with cancer need palliative care, a tiny percentage of them have access to it (Clark et al., 2020; Downing et al., 2018). Diminished access is primarily due

to a lack of awareness of palliative care among healthcare providers and the public (Arias-Casais et al., 2020). Moreover, the capacity to provide paediatric palliative care in India is restricted to a few sporadic pockets (Downing et al., 2014). In both adult and paediatric oncology settings in India, patients were referred late, had significant symptoms and received disease-directed therapy until the last weeks of their lives (Adusumilli et al., 2018; Atreya, 2017; Chatterjee et al., 2019; Ghoshal et al., 2016; Sharma et al., 2009; Sinha et al., 2018). The research context is discussed further in chapter two.

1.5. Researcher's Voice

During this study, my voice as a clinician in the field of paediatric palliative care and as a researcher is heard and acknowledged. Reflexive thematic analysis (Braun et al., 2019), the method used for data analysis in this research, allows using the researcher's subjectivity and acknowledges the researcher's active role in knowledge production. These aspects are further explored in chapters four and six.

1.6. Glossary of Key Terms

A glossary of key terms used in this study is described in **Table 1.1**.

Table 1.1. Glossary of Key Terms

Oncologists and Haematologists	The medical oncologist is *"a doctor with special training in diagnosing and treating cancer in adults using chemotherapy, hormonal therapy, biological therapy and targeted therapy"*. The paediatric oncologist is *"a doctor who has special training in diagnosing and treating children with cancer"*. A haematologist is *"a doctor who has special training in diagnosing and treating blood disorders"* (National Cancer Institute, 2021). For this research, the term oncologists and haematologists refer to paediatric oncologists and paediatric haematologists. Moreover, in this research, the term was expanded to include adult medical oncologists and adult haematologists if 25% of their clinical practice involved managing children with solid or haematological malignancies, as the majority of children with cancer in India are still managed by medical oncologists.
Referral	A physician referral is *"the act of sending a patient for opinion or a therapy to a specialist or subspecialist because the patient has a disease or condition that the primary or referring physician cannot, or does not wish to, treat"* (National Guideline Centre, 2019). For this research, referral refers to oncologists and haematologists managing children with cancer making a referral to palliative care services.
Child	According to the United Nations Convention on the rights of the child, it defines a child as *"an individual who has not attained 18 years of age"* (UNICEF, 1989). When India became the signatory of the United Nations Convention on the rights of the child, it adopted the United Nations definition of a child (UNICEF, 1989). For this research, child is defined as an individual between 0 to 18 years of age.
Advanced cancer	Advanced cancer is *"cancer that is unlikely to be cured or controlled with treatment. Cancer may have spread from where it started to the nearby tissues, lymph nodes or distant parts of the body. Treatment may be given to help shrink the tumour, slow the growth of cancer cells, or relieve symptoms"* (National Cancer Institute, 2021). For this research, in solid tumours, advanced cancer in children corresponds to either recurrent or metastatic conditions where the intent of cancer treatment is palliative. In haematological malignancies, advanced cancer in children corresponds to relapse or the refractory nature of illness where the intent of cancer treatment is palliative. Palliative intent of treatment refers to therapy with an intent to slow the progression of the disease.
Palliative care	In 2018, the International Association for Hospice and Palliative Care (IAHPC) defined palliative care as "*the active, holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers"* (Radbruch et al., 2020). In the WHO definition, the scope of palliative care was limited to life-limiting illness (WHO, 1998). In comparison, the 2018 IAHPC definition extended the scope of palliative care to all severe illnesses. Moreover, the IAHPC definition introduced the concept of serious health-related suffering (Radbruch et al., 2020). For this research, palliative care corresponds to referral to either a hospital-based palliative care team offering outpatient, consultation-liaison or inpatient care, hospice or palliative home care (Radbruch et al., 2020). Paediatric palliative care is defined and discussed in chapter two.

1.7. Overview of the Thesis

Including the current chapter, the thesis has six chapters, references, and appendices. Each chapter focuses on the part of the research process, which cumulatively forms the whole dissertation. Tables and figures are represented along with the main body of the text. References and appendices are provided at the end of the thesis.

1.7.1. Chapter 2: Background

In this chapter, the concept of paediatric palliative care and its development is discussed. Research in the field of referral to palliative care in paediatric oncology is contextualised by discussing the needs of children and their families facing cancer, palliative care referral practices and their outcomes, and palliative care models in paediatric oncology. Palliative care and paediatric palliative care in the Indian context conclude this chapter.

1.7.2. Chapter 3: Review of the Literature

In chapter three, the views of oncologists and haematologists on palliative care referral were established through a narrative synthesis review (Popay et al., 2006). The review was conducted to identify gaps in knowledge and inform the PhD research. It enabled the formulation of the research question, development of the interview topic guide and discussion of the research findings.

1.7.3. Chapter 4: Methodology and Methods

In this chapter, methodology, methods, and ethical considerations for conducting this research are discussed. Critical realism was the philosophical approach underpinning this

research (Bhaskar et al., 1998), and the study findings are interpreted through the lens of social exchange theory (Ekeh, 1974). A qualitative approach was chosen to explore the phenomenon, and the research data were analysed using reflexive thematic analysis (Braun et al., 2019).

1.7.4. Chapter 5: Research Findings

The study's key findings identified during data analysis as themes and subthemes are presented in this chapter.

1.7.5. Chapter 6: Discussion of Research Findings

In chapter six, the research findings are discussed in relation to research objectives and compared with literature identified in the systematic review and wider literature. They are interpreted using philosophical and theoretical lenses. Furthermore, the strengths and limitations of the research and its implications on policy, practice and future research are discussed. The implications of research and review findings on theory modification and new theory development and contribution to knowledge conclude this chapter.

1.8. Summary

In this chapter, the aim of conducting this research, my motivation and my background are discussed. The research context and my voice in this research are elucidated. A snapshot of the whole thesis with a summary of individual parts ends the chapter.

Chapter 2: Background

2.1. Introduction

The chapter begins with an introduction to the concept of paediatric palliative care and its evolution. Furthermore, palliative care in paediatric oncology is discussed in terms of the children and their families' needs, referral practices, outcomes of referral and palliative care models in paediatric oncology. Palliative care and paediatric palliative care in the Indian context conclude the chapter.

2.2. Paediatric Palliative Care

2.2.1. Introduction to Paediatric Palliative Care

Children's palliative care is an active, holistic care for children and young people with life-limiting illnesses (Together for Short Lives, 2013). It is provided from the point of child's diagnosis, throughout the child's life, death and beyond. It encompasses all elements of quality of life; physical, emotional, social, and spiritual. It focuses on enhancing a child's quality of life and providing support to the family. The scope of palliative care provision is not limited to symptom management but includes respite services, end of life care and bereavement support (Together for Short Lives, 2013). Palliative care is provided regardless of whether or not a child receives treatment directed at the disease and should be incorporated alongside active disease-directed therapies (WHO, 1998). Multidisciplinary palliative care support is individualised according to the child's needs. The extent of support from the palliative care team might vary depending upon child's illness and response to therapy (Together for Short Lives, 2013). It is essential to provide children's palliative care in

the tertiary, secondary hospitals and the community to ensure adequate and uninterrupted care (WHO, 1998).

Compared to the 1998 World Health Organisation (WHO) definition of paediatric palliative care (WHO, 1998), the 2013 definition provided an augmented scope (Together for Short Lives, 2013). It included aspects relating to spiritual elements of care and enhancing the quality of life (Bergstraesser, 2013). Furthermore, it also incorporated respite care, bereavement support and personalising the care approach (Bergstraesser, 2013). Some oncologists felt that the paediatric palliative care definition is unclear and without distinct boundaries due to overlap in care components between two disciplines (Laronne et al., 2021). Although most oncologists comprehended the modern definition of palliative care, integrating palliative care into paediatric oncology practice was often less well understood (Cuviello et al., 2020).

Globally cancer constitutes only 5.2 % of the palliative care needs in children (Knaul. et al., 2020). The lower percentage is attributed to the uncommonness of childhood cancers and the success of currently available treatment (Siden, 2018). Excellent outcomes in childhood cancer have diminished palliative care's relevance in paediatric oncology (Cheng et al., 2019; O'Leary et al., 2008). Generally, palliative care continues to be identified with cancer due to its traditional origins with cancer and inequitable referral of non-cancer conditions to palliative care services (Chen, 2019). In the Indian setting, paediatric palliative care is almost always associated with paediatric oncology. This narrow focus is probably contextual to India and other similar low and low-middle income countries (Singh & Harding, 2015). Therefore, my PhD research focus was limited to palliative care referral in children in a cancer setting.

2.2.2. Evolution of Paediatric Palliative Care in Paediatric Oncology

In 1997, The Association for Children's Palliative Care (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) jointly categorised chronic and life-limiting conditions (Baum, 1997; Wood et al., 2010). The categorisation of conditions is provided in **Table 2.1**. Childhood cancers were categorised as ACT 1 (Baum, 1997). All these conditions were suitable for palliative care, but the nature and level of palliative care involvement varied significantly from one category to another (Wood et al., 2010).

Table 2.1. Categorisation of Chronic and Life-limiting conditions in Paediatrics

ACT Category	Description	Key Characteristics	Examples
1	Curative treatment may be feasible but can fail. Palliative care may be necessary during phases of prognostic uncertainty and when treatment fails.	Possibility of cure	Cancer Certain cardiac conditions
2	A long duration of intensive treatment needed to prolong life, but premature death is still possible.	Prolonged course with predominantly normal phase, waxing and waning of health conditions	Cystic Fibrosis, Muscular Dystrophy, HIV/AIDS with antiretroviral treatment
3	Progressive conditions without curative treatment options, in which treatment is exclusively palliative	Prolonged course with progressive worsening	Batten's disease, Mucopolysaccharidosis, HIV/AIDS without antiretroviral treatment
4	Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications and may deteriorate unpredictably but are not considered progressive.	Non-progressive condition with an unpredictable course	Cerebral Palsy

The first guidelines on integrated palliative care in paediatric oncology were published in 2013 (Section on Hospice Palliative Medicine and Committee on Hospital Care, 2013). Guidelines mandated creating a specialist interdisciplinary team that can provide collaborative multi-modal care across all settings. The purpose was to provide support to children and their

families while ensuring the child's quality of life and safety. It advocated for child and family participation during communication and decision making. Moreover, guidelines emphasised the understanding of ethical aspects of care during child's end of life (Section on Hospice Palliative Medicine and Committee on Hospital Care, 2013). Another integrated palliative care model in paediatric oncology highlighted the provision of palliative care concurrently regardless of the disease status and improving palliative care familiarity by building relationships between palliative care specialists and paediatric oncologists (Waldman & Wolfe, 2013). Furthermore, palliative care was proposed as a standard of care in paediatric oncology (Weaver et al., 2015), and the American Society of Clinical Oncology (ASCO) in one of its publications recommended the integration of palliative care in the routine care of children, adolescents and young adults with cancer (Snaman et al., 2020).

2.3. Role of Palliative Care in Paediatric Oncology

In this section, the burden of childhood cancers, the needs of children and their families in a paediatric oncology setting, palliative care referral practices, outcomes of palliative care referral and palliative care delivery models in paediatric oncology is discussed.

2.3.1. Burden of Cancer in Children and Young Adults

Worldwide, every year around 300,000 children are detected with cancer with an incidence of 140.6 per million person-years in 0-14 years and 185.3 per million person-years in 15-19 years (Steliarova-Foucher et al., 2017). Over the last two decades, there has been a steady rise in the incidence of paediatric cancers (Autier, 2018). The reported incidence of childhood cancers, especially in haematological malignancies, were significantly more in high-income countries than low-income countries (Gupta et al., 2015; Howard et al., 2008). One of the

likely explanations is that children with haematological malignancies present with vague symptoms like fever and anaemia (Gupta et al., 2015). In a resource-constrained healthcare setting, clinical signs and symptoms of haematological malignancies may not be easily identified and referred to a cancer centre (Gupta et al., 2015). Incomplete population registries also contribute to underreporting childhood cancers in low and middle-income countries (Ferlay et al., 2010; Gupta et al., 2015). Moreover, interstate variations in the incidence of cancers were observed in India due to inconsistencies in cancer reporting in the regional population-based registries (Satyanarayana et al., 2014). The regions with better health care systems reported a higher incidence of childhood cancers over underserved regions, highlighting the gap between the reported incidence and actual cancer burden (Satyanarayana et al., 2014).

It is estimated that 90% of children with cancer live in low and middle-income countries, constituting 84% of the global burden of childhood cancers (Magrath et al., 2013). Children in high-income countries like the UK have a cure rate of 80% compared to low-income countries with a cure rate of 20-30% (Ellison et al., 2007; Gupta et al., 2015). The Lancet, in its editorial, termed this disparity as "unequal progress" (The Lancet p 980, 2019). Lower cure rates in childhood cancers in India were attributed to delays in diagnosis, poor treatment adherence, treatment abandonment, high risk of infections during treatment, relapses due to poor follow up, and lack of supportive cancer networks (Sinha et al., 2019; Yadav et al., 2014). Limited access to anti-cancer medications and non-affordability also contributed to low cure rates (Faruqui et al., 2019). In India, two-thirds of the population spend out of pocket for health-related expenses, which was the leading cause of treatment abandonment in cancer (Quintussi et al., 2015; Sengupta & Nundy, 2005). Over the last four decades, there has been

a drastic reduction in childhood cancer-associated mortality and improvement in five-year survival in high-income countries like the UK (Centre for Disease Control, 2017; Children with Cancer UK, 2020; National Institute of Cancer Prevention and Research, 2018; Smith et al., 2010). However, low- and middle-income countries do not mirror these trends (Gupta et al., 2015). Although the incidence of childhood cancers in India is similar to high-income countries (Arora et al., 2009; Das et al., 2017), the cure rates are low and cancer-associated deaths are high (Arora & Arora, 2016; Gupta et al., 2016). In 2010, 13,700 children died in India due to cancer (Gupta et al., 2016). However, these numbers may not represent the real burden of cancer in children, as only 4% of paediatric cancers are captured in the Asian cancer registries (Ferlay et al., 2010).

Although mortality rates associated with cancer in children has decreased in high-income countries, it is still the leading cause of non-accidental death in children (Cunningham et al., 2018; Kyu et al., 2018; Office for National Statistics UK, 2019). Improvements in sanitation, health awareness and health policies have resulted in a steep decrease in deaths due to communicable diseases in high-income countries (Liu et al., 2012; Lozano et al., 2011). Although mortality associated with childhood cancer remains high in India, it figures ninth in the top ten non-accidental causes of death in children (Bashar & Thakur, 2017). National policies are predominantly directed at cancer control in adults, and children dying of cancer in India have seldom been the focus of discussion (Sullivan et al., 2014). Therefore, this research on palliative care referral in a paediatric oncology setting has significance in the Indian context.

2.3.2. Needs of Children and their Families in a Paediatric Oncology Setting

Pain is one of the common symptoms experienced by a child with cancer (Contro et al., 2002). Pain is not just limited to the palliative phase (Drake et al., 2003; Hendricks-Ferguson, 2008; Hongo et al., 2003); children receiving active treatment also experience procedural pain while establishing a diagnosis and during cancer treatment (Darcy et al., 2014; Wise, 2002). Pain is more often seen in children with solid tumours than haematological malignancies (Goldman et al., 2006; Macartney et al., 2014). Both children and their families have voiced inadequate pain management as a concern (Ljungman et al., 1999; Pöder et al., 2010), and felt that this gap needs to be addressed (Oberholzer et al., 2011).

Breathlessness, nausea, fatigue, and loss of appetite are common non-pain symptoms seen in children with cancer during treatment and palliative phases (Jalmsell et al., 2006; Theunissen et al., 2007). Children also had symptoms like fever, mouth ulcers, diarrhoea, headache and neuropathy due to acute and long-term chemotherapy adverse effects (Anthony et al., 2012). They experienced low mood, worry, anxiety, fear, irritability, and anger (Montoya-Juárez et al., 2013; Olagunju et al., 2016). They also had difficulties conveying their feelings and often reported poor concentration, low energy, and lack of motivation (Hongo et al., 2003; Theunissen et al., 2007). They felt less resilient, experienced low self-worth and had challenges coping with illness (Woodgate, 2008). They also reported body image issues that caught their peers' attention, and they experienced peer isolation and bullying (Fan & Eiser, 2009). Prolonged hospitalisation meant disruption from school and play and a transformation of the home-school-play cycle to the home-hospital cycle, which children found very distressing (Abrams et al., 2007).

Children with cancer were often not informed about their diagnosis by their health care providers, and the older children, who were able to comprehend, felt a need to know (Hsiao et al., 2007; Stegenga & Ward-Smith, 2009). Adolescents with cancer felt that the illness destroyed the hope of a promising future (Jacobs et al., 2015). Moreover, fear of death among children was seldom addressed (Latha et al., 2016). Although some could reconcile and find meaning in life situations, others were not at peace and had a sense of loss (Kamper et al., 2010).

The parents of children with cancer found it challenging to manage emotional issues like feelings of isolation and behavioural changes of their children (Enskär et al., 1997). The families led very stressful lives, navigating the hospital environment, and dealing with uncertainties of the future while ensuring timely treatment of their child (Price et al., 2011; Stevenson et al., 2013; Woodgate, 2008). The families also needed financial help, practical tips on managing the child at home, and supporting other children (Monterosso et al., 2007; Monterosso et al., 2009).

Families felt that continuous communication between parents, family caregivers and health care providers is crucial during a child's end of life care to facilitate decision-making (Hechler et al., 2008; Heinze & Nolan, 2012; Wiener et al., 2020) and integrated palliative care (Saad et al., 2020). Learning about a child's diagnosis was highly distressing for parents (Hurley et al., 2021). Commonly they did not receive clear and honest communication about their child's illness, and they emphasised the need to know about their child's prognosis and what to expect (Heinze & Nolan, 2012; Price et al., 2013). Families often appreciated sensitive communication that preserved hope than blunt truth-telling (Sailian et al., 2021). There was

often a gap between the child's understanding and experience of illness and parental perception of what the child knows (Ciobanu & Preston, 2021). This gap led to barriers in communication within families.

In a terminal care setting, families often felt unprepared to deal with their child's death (Johnston et al., 2020; Wiener et al., 2020). They were either surprised by the child dying quickly or anxious about the long wait for the child's death (Pritchard et al., 2009). They found it difficult to let go of the child's cancer treatment, and transition to palliative care and adaptation to the new care provider was challenging (Kars et al., 2011; Wang et al., 2019). Families perceived involving palliative care as letting go of their child's treatment and experienced feelings of abandonment (Johnston et al., 2020; Kenny et al., 2020; Wang et al., 2019).

In hindsight, some families regretted providing acute hospital-based care for their child during the terminal phase of illness and regretted their child receiving cancer-directed therapy at the end of life (Das et al., 2020; Hechler et al., 2008). The majority of parents experienced anticipatory grief and guilt, and poorly controlled symptoms at the child's end of life was a common trigger for complex bereavement among the parents (Hechler et al., 2008; McCarthy et al., 2010; Surkan et al., 2006; Wikman et al., 2018). Furthermore, parents found grief isolating due to a lack of societal understanding of their grief (Price & Jones, 2015). Although all studies supporting the views on society and grief in the narrative review were from North America (Price & Jones, 2015), similar observations were made in an Indian study where grief associated with perinatal loss and child's death was inadequately recognised by the families, healthcare providers and the society (Das et al., 2021).

2.3.3. Palliative Care Referral Practices in Paediatric Oncology

Worldwide, approximately 21.6 million children need palliative care, and 8.2 million children need specialised palliative care (Downing et al., 2018). It is estimated that 4.2 million children need palliative care in India, and 1.6 million need specialised palliative care (Connor et al., 2017). However, the true level of cancer-associated paediatric palliative care needs in India is unknown due to poor reporting of cancer incidence and cancer mortality (Satyanarayana et al., 2014).

Globally children with cancer were infrequently referred to palliative care and referred late in the illness trajectory (Fraser et al., 2011; Johnston & Vadeboncoeur, 2012; Levine et al., 2016; Menon et al., 2008; Tzuh Tang et al., 2011; Ullrich et al., 2016). The median time gap from cancer diagnosis to palliative care referral was eighteen months (Vern-Gross et al., 2015). Only 16% were referred at the initial diagnosis, and 58% of the referrals happened after a cancer relapse (Johnston & Vadeboncoeur, 2012). Moreover, in most studies, palliative care referral occurred only in the last days of their lives (Feudtner et al., 2011; Jalmsell et al., 2006; Johnston & Vadeboncoeur, 2012; Menon et al., 2008). In a recent systematic review, internationally, the median duration between specialist palliative care referral and death was 19 days (Jordan et al., 2020). However, this was not a paediatric specific review.

Children with haematological malignancies were referred to palliative care less often than children with solid tumours (Bradshaw et al., 2005; Howell et al., 2011; Jalmsell et al., 2006; Rost et al., 2018; Vallero et al., 2014). Children referred to palliative care received some form of chemotherapy in their last days (Jalmsell et al., 2006; Menon et al., 2008; Rost et al., 2018; Tzuh Tang et al., 2011). Among the children referred, reasons underpinning the referral, goals

of care discussions and the decision-making process for referral was seldom documented (Bradshaw et al., 2005; De Graves & Aranda, 2002; Levine et al., 2016). Non-referral and delayed referral often led to invasive medical interventions at the end of life (Howell et al., 2011; Tzuh Tang et al., 2011) and increased in-hospital deaths (Fowler et al., 2006; Howell et al., 2011; Menon et al., 2008; Tzuh Tang et al., 2011). There was a mixed view of trial participation and palliative care referral. In one study, enrolment in a clinical trial deferred palliative care referral (Ananth et al., 2018). However, another study in a clinical trial setting did not support this finding (Levine et al., 2015).

Children in low and low-middle income countries are less likely to access palliative care due to a lack of awareness among paediatric oncologists about palliative care and the reduced number of services providing palliative care (Arias-Casais et al., 2020). Two Indian studies showed that 86% of children with cancer received chemotherapy during the last month of their life, and 78% were referred after cancer-directed therapy was completed, which hindered palliative care access (Ghoshal et al., 2016; Jacob et al., 2018). Non-referral and late referral to palliative care in paediatric oncology in Malaysia, Nigeria and Morocco led to poorly controlled symptoms, caregiver distress, and a majority of the children dying within a few weeks of palliative care referral (Chong & Khalid, 2014; Eke & Akani, 2016; Olagunju et al., 2016; Ziani et al., 2015). Moreover, availability and access to paediatric palliative care in these settings were proportional to the country's health spending (Delgado et al., 2010). Low and low-middle income countries had limited access to opioids, lack of interdisciplinary care and the families were less empowered to participate in decision-making (Delgado et al., 2010). Lack of palliative care funding, advocacy and leadership were the other factors hindering capacity to provide paediatric palliative care (Chong et al., 2017; Downing et al.,

2014; Ghoshal et al., 2018). Similar observations were made in a narrative review that identified lack of opioids and fear of opioids, lack of specialist paediatric palliative care education, lack of a national and institutional palliative care policy, lack of awareness about palliative care needs and lack of integration of palliative care in health systems as the key barriers hindering palliative care development in low and low-middle income countries (Downing et al., 2016).

2.3.4. Outcomes of Palliative Care Referral in Paediatric Oncology

Although improvement in children and their families' quality of life is the desired outcome, there are no ideal measures that accurately reflect these outcomes of palliative care referral in paediatric oncology (Coombes et al., 2016). Improvements in the domains of quality of life have to be contextualised to a specific illness and patient population (Coombes et al., 2016). Betterment of the child's quality of life is an essential factor motivating families to access palliative care (Tomlinson et al., 2011). Empirical studies have shown improvements in quality of life from palliative care referral in paediatric oncology (Gans et al., 2012; Mitchell et al., 2017; Weaver et al., 2018; Zernikow et al., 2019). However, these benefits were limited to physical and emotional domains of quality of life (Weaver et al., 2018).

Symptom management is a critical component of the physical domain of quality of life. Studies have shown symptom assessment (Osenga et al., 2016; Zhukovsky et al., 2009), and symptom management benefit from paediatric palliative care referral (Balkin et al., 2016; Doherty et al., 2020; Kuhlen et al., 2014; Lindley & Keim-Malpass, 2017; Mitchell et al., 2017; Osenga et al., 2016; Schmidt et al., 2013; Ullrich et al., 2016; Vern-Gross et al., 2015; Zhukovsky et al., 2009). However, pain management benefit was better appreciated by

children and families than managing other symptoms (Doherty et al., 2020; Schmidt et al., 2013; Ullrich et al., 2016; Vern-Gross et al., 2015). Furthermore, some oncologists felt that palliative care could enable treatment completion by managing pain and symptoms while the child is receiving cancer-directed therapy (Laronne et al., 2021). Two systematic reviews substantiated the above findings (Kaye et al., 2020; Marcus et al., 2020).

Referral to palliative care facilitated emotional support to children and their families (Doherty et al., 2020; Friedrichsdorf et al., 2015; Hendricks-Ferguson & Haase, 2019; Niswander et al., 2014; Plaza Fornieles et al., 2020; Ullrich et al., 2016). Emotional support to families extended beyond the child's death into the bereavement phase (Niswander et al., 2014; Plaza Fornieles et al., 2020). Support from palliative care enabled families to have realistic hope. Moreover, children and families engaged in fun activities and experienced events that added meaning to their lives (Friedrichsdorf et al., 2015; Hendricks-Ferguson & Haase, 2019).

Referral to palliative care in paediatric cancer settings improved communication between families and health care providers (Ekberg et al., 2020; Ekberg et al., 2019; Hendricks-Ferguson & Haase, 2019; Kassam et al., 2015; Kuhlen et al., 2014; Mesukko et al., 2020; Niswander et al., 2014; Plaza Fornieles et al., 2020; Seddighzadeh et al., 2018; Ullrich et al., 2016; Vern-Gross et al., 2015). Involvement of the palliative care team enabled early assessment (Greenfield et al., 2020); facilitated initiation of family meetings during the child's clinical deterioration (Ekberg et al., 2020) and assisted oncologists in prognostic discussions (Ullrich et al., 2016). Palliative care teams participated in family communications during the discussion of end-of-life care (Ekberg et al., 2019; Kassam et al., 2015; Vern-Gross et al., 2015), and helped the paediatric oncologists to navigate critical communications surrounding the

child's end of life (Kassam et al., 2015). Palliative care referral enabled goals of care discussion

and supported the process of shared decision-making (Atout et al., 2017; Dreesens et al.,

2019; Hendricks-Ferguson & Haase, 2019; Mesukko et al., 2020; Seddighzadeh et al., 2018;

Ullrich et al., 2016; Vern-Gross et al., 2015). Paediatric oncologists acknowledged the

complexities of shared decision-making and appreciated the support they received from the

palliative care team (Dreesens et al., 2019). Referral facilitated documentation of the

resuscitation preferences (Brock et al., 2016; Ullrich et al., 2016) and the preferred place of

care and death (Charlebois & Cyr, 2015; Mitchell & Dale, 2015; Niswander et al., 2014; Vern-

Gross et al., 2015). Palliative care involvement also facilitated advance care planning and

documentation of advanced directives (Chong et al., 2018; Taylor et al., 2020).

Palliative care input bettered end-of-life care support to children and their families in a

paediatric cancer setting (Charlebois & Cyr, 2015; Chong et al., 2018; Fraser et al., 2013;

Friedrichsdorf et al., 2015; Gans et al., 2012; Keele et al., 2013; Kim et al., 2020; Lindley &

Keim-Malpass, 2017; Niswander et al., 2014; Osenga et al., 2016; Schmidt et al., 2013;

Seddighzadeh et al., 2018; Taylor et al., 2020; Ullrich et al., 2016; Vern-Gross et al., 2015). It

facilitated less invasive diagnostic and therapeutic interventions at the end of life (Charlebois

& Cyr, 2015; Keele et al., 2013; Osenga et al., 2016; Seddighzadeh et al., 2018), and children

receiving palliative care input were less often resuscitated (Ullrich et al., 2016; Vern-Gross et

al., 2015). Children had fewer elective and emergency hospital admissions (Chong et al., 2018;

Fraser et al., 2013), and they had shorter hospital stay (Gans et al., 2012; Keele et al., 2013).

There were fewer intensive care admissions (Schmidt et al., 2013; Taylor et al., 2020; Ullrich

et al., 2016), and more home deaths (Friedrichsdorf et al., 2015; Johnston & Vadeboncoeur,

2012; Levine et al., 2016; Schmidt et al., 2013). Referral to palliative care reduced overall

health care resource utilisation, maintained care continuity at the end of life (Kim et al., 2020; Lindley & Keim-Malpass, 2017), and facilitated access to integrative therapies during the end of life (Osenga et al., 2016). However, a systematic review reported conflicting evidence on palliative care collaboration benefits on hospital admissions at the end of life and resuscitation at the time of death (Lin et al., 2021).

The families of children with cancer appreciated the healthcare system's support beyond usual clinical management (Monterosso et al., 2007; Monterosso et al., 2009). They valued the support they got in terms of managing finances and assistance to manage the child's needs at home (Monterosso et al., 2009). Palliative care referral improved family satisfaction of care (Kuhlen et al., 2014; Plaza Fornieles et al., 2020; Zernikow et al., 2019). Involving a palliative care team facilitated discharge planning, hospice utilisation and home-based care (Price et al., 2018; Vern-Gross et al., 2015). Children receiving home-based care received uninterrupted care (Inglin et al., 2011; Verberne et al., 2017). The families valued the palliative care team as a reliable and cost-effective source of support (Cheng & Wangmo, 2020; Verberne et al., 2017). Most of the studies alluded to in this section on palliative care referral outcomes in paediatric oncology were limited to Europe and North America. These study findings are understood through western lenses. However, there is limited empirical evidence from India on palliative care in paediatric oncology. In light of this, there is little choice but to refer to these studies until more evidence is generated from India.

2.3.5. Models of Palliative Care in Paediatric Oncology

A three-tier model is proposed to provide palliative care in paediatric oncology (Kaye et al., 2016), as represented in **Table 2.2**. It was developed from the earlier proposed integrative paediatric palliative oncology models (Baker et al., 2008; Duncan et al., 2007; Golan et al., 2008; Harper et al., 2007; Toce & Collins, 2003). In this approach, a vast majority of children with palliative care needs are seen by tier 1 services. A smaller number with complex physical and psychosocial needs are seen by tier 3 services (Kaye et al., 2016).

Table 2.2. Three-tier Model of Palliative Care in Paediatric Oncology

Tier	Description
Tier 1 Specialist Palliative Care	A team of specialist paediatric palliative care providers available for managing complex symptoms and psychosocial needs.
Tier 2 Consultation-Liaison	Presence of a consultation-liaison service, and there are triggers for palliative care referral. When the child satisfies the referral criteria, a consultation is triggered.
Tier 3 Palliative Approach	A palliative approach where all the oncologists, oncology trainees and oncology nurses have basic training in palliative care.

There are five palliative care models in paediatric oncology practised in various hospitals of the United States (Brock et al., 2019). **(Table 2.3)**. Any one model was not considered better or superior, and the choice of model depended on the need, preferences identified, and available resources. A centre with minimal resources may choose a trigger-based or a consultative model, whereas a centre with better resources may prefer a disease-specific embedded mode (Brock et al., 2019). Embedded paediatric palliative oncology models demonstrated a higher number of children accessing palliative care, longer stay with the palliative care service before death, and fewer days in the hospital during the last three months of their lives (Brock et al., 2021; Farooki et al., 2021). Furthermore, these models may be contextual to the United States setting, and their transferability to other country settings,

with scarce palliative care resources like India, might be challenging. Apart from these models, an Italian study showed that a virtual paediatric palliative care support network situated outside the hospital could partially substitute the lack of in-hospital palliative care services (Podda et al., 2021).

Table 2.3. Models of Palliative Care Clinics in Paediatric Oncology

Model	Description	Site Practiced
The Floating Clinic	A paediatric advanced care team (PACT) comprised of paediatric palliative care physician, paediatric palliative care nurse practitioners and social workers called as a "floating unit" moves along with the child in the hospital and consults them during outpatient oncology visits, hospital admission, day-care chemotherapy and transplantation.	Boston's Children's Hospital, Boston
The Disease-Specific Embedded Clinic	A team of paediatric palliative care physicians and paediatric palliative care nurse practitioners are situated in a disease-specific clinic like leukaemia clinic, neuro-oncology clinic or solid tumour clinic and they closely work with these disease-specific units and provide palliative care across all settings.	St Jude's Children Research Hospital, Memphis
Trigger-Based Clinic Embedded in the Oncology Space	The team is comprised of paediatric palliative care physician, paediatric palliative care nurse and social workers. A disease-specific criterion is created for palliative care referral. When the child meets the referral criteria, the oncology team initiates the referral process and seen by the paediatric palliative care team in the oncology clinic.	Randy Children's Hospital, San Diego.
Consultation based Clinic in the Oncology Space	It is a need-based referral initiated by oncologists to paediatric palliative care. There are no set referral criteria in this model, and the palliative care specialist is usually a dual board-certified clinician in both palliative care and oncology. The oncology team and the palliative care team sees the child concurrently in the same clinic, and the child receives joint advice.	Alfac Cancer and Blood Disorders centre, Atlanta
Telehealth Clinic	Providing access to children and their families in a remote or rural setting beyond the geographic catchment of the regular palliative care services. The clinic is operated by a team of palliative care providers, who provide telephonic, and video-calling based consultations.	Children's Hospital and Medical Centre, Omaha

2.4. Palliative Care and Paediatric Palliative Care in the Indian Context.

India belongs to the South-East Asian Region (SEAR), and the palliative care need in the adult population is estimated to be approximately 723 per 100,000 population compared to 1337 per 100,000 population in Europe (Knaul. et al., 2020). Cancer constitutes 20.4% of the palliative care needs in adults in SEAR compared to 40.6% in Europe, and likewise dementia constitutes 11.1% of the palliative care needs in SEAR compared to 18% in Europe (Knaul. et al., 2020). Decreased incidence, challenges in establishing the diagnosis and under reporting might have contributed to this disparity Moreover, lower number of adults needing palliative care in SEAR and India could be because of diminished identification of palliative care needs due to a lack of palliative care awareness among the public and health care providers (The Economist Intelligence Unit, 2015). Approximately 103 children per 100,000 in SEAR need palliative care compared to 50 per 100,000 in Europe. Similar percentages of children with cancer need palliative care in SEAR and Europe. However, increased incidence of paediatric palliative care needs in SEAR is attributed to deaths associated with prematurity, meningitis and malnutrition (Knaul. et al., 2020).

Although there is no published empirical literature on India's capacity to provide palliative care, a 2015 report showed that only 0.4% of the population could access palliative care in India compared to 44.2% in the UK (The Economist Intelligence Unit, 2015). However, this information was based upon a range of evidence including publications in peer-reviewed journals, conference presentations, grey literature, and opinion of key persons in the field of palliative care. Limited access to palliative care in India was attributed to a low demand and low supply situation. Low demand was due to limited awareness of palliative care among public and health care providers, and low supply was because of limited palliative care

resources (The Economist Intelligence Unit, 2015). No data on access to paediatric palliative care in India is presently available.

In India, approximately 1.1 million new cancer cases are diagnosed annually (Chandramohan & Thomas, 2018), and among them, 37-88% of patients have advanced stages of cancer on initial presentation (Mathew et al., 2019). Although more than two-thirds of patients with advanced cancer experience severe pain needing strong opioids (van den Beuken-van Everdingen et al., 2007), only 4% of the population in India have access to these analgesics (Vallath et al., 2017). India has 27 tertiary cancer care centres, and more than 300 hospitals provide cancer care (Munshi et al., 2019). Although there are 140 listed palliative care centres in India in the global directory of palliative care services, the details about the providers, expertise, scope of clinical services and opioid availability is not known.(International Association for Hospice and Palliative Care, 2020). Moreover, most of these palliative care services are standalone centres or clinics situated outside the cancer centres (International Association for Hospice and Palliative Care, 2020). Therefore, there is minimal integration of oncology and palliative care service in India.

India is a low-middle income country (World Bank, 2018). The country spends 3.6% of Gross Domestic Product (GDP) on health compared to 9.9% by the UK, and 64.5% of the population spend out of pocket for health-related expenses (World Health Organization Global Health Expenditure database, 2016a, 2016b). Approximately 63 million Indians, almost 7% of the population, become poorer every year due to rising health-related expenses, and the majority of health spending is for the last days of their lives (Berman et al., 2010). Moreover, low socio-economic status was associated with greater suffering at the end of life in Indian patients with

advanced cancer. (Malhotra et al., 2020). A survey conducted in a metropolitan city of India showed that 83% of the adult population preferred to die at home (Kulkarni et al., 2014). However, a significant percentage of adult patients had intensive care unit (ICU) admission in the terminal phase, resulting in high costs of care at the end of life and terminal discharges from ICU against medical advice due to lack of funds to sustain ICU treatment (Divatia et al., 2016; Jayaram & Ramakrishnan, 2008; Mani, 2003). A pilot project conducted in India has demonstrated a significant cost-saving benefit of palliative care intervention in these patients (Ratcliff et al., 2017).

The Medical Council of India recognised palliative care as a medical speciality in 2010, and the first specialist palliative care training program in palliative medicine commenced in 2012 (Salins, 2015). There are only three accredited sites in India offering specialist palliative care training, and there is a significant shortage of palliative care specialists in India. Moreover, palliative care knowledge among oncologists and oncology trainees is minimal as palliative care rotations are seldom part of oncology training (Patel et al., 2019). Nursing studies from India showed that nurses had limited awareness of palliative and end of life care practices (Gielen, Bhatnagar, et al., 2011; Gielen, Gupta, et al., 2011; Sadhu et al., 2010) and lacked opportunities for palliative care training (Lebaron et al., 2017).

There is no clarity in the legal framework or governmental policies that enable the clinicians to provide end of life care, which is a significant barrier for palliative care provision in India (Gursahani et al., 2020). Until recently, palliative and end of life care was not part of the national standards for hospital accreditation (Iyer, 2014). Moreover, palliative care has

minimal representation in the national health policies as the government's focus is still on communicable diseases (Maurya et al., 2017).

Paediatric palliative care in India is at the capacity building stage (Clark et al., 2020; Knapp et al., 2012). Although it began two decades ago, its growth is restricted to less than ten cancer centres with minimal community paediatric palliative care activity (Mathews, 2012). There are only a few paediatricians in India who are palliative care specialists. The majority of children needing palliative care in India are seen by adult palliative care physicians (Muckaden, 2013). Furthermore, in India, a significant percentage of children are still treated by adult medical oncologists and other cancer specialists (Arora & Banavali, 2009). -The lack of specialist providers highlights the need for the development of more paediatric oncology and paediatric palliative care services in India. Moreover, most paediatricians and paediatric oncologists in India have no formal training in palliative care (Latha et al., 2014). There is only one paediatric palliative care fellowship program offered at one of the cancer centres in South India. Others are mostly offered as short paediatric palliative care certificate courses and continued medical education programs (Downing et al., 2014; Ghoshal et al., 2018). During the corona virus pandemic, teleteaching and virtual mentoring were extensively used to improve paediatric palliative care capacity building in India (Doherty et al., 2021). Web-based learning was an adaptation to minimise direct contact sessions, and its impact is yet to be ascertained. Finally, there are no policy guidelines informing palliative care referral practices in paediatric oncology in India (Muckaden et al., 2011).

2.5. Conclusion

In summary, paediatric palliative care is the multidisciplinary holistic care of the child and the family throughout the illness continuum. Children with cancer experience physical symptoms and reduced quality of life. Families are often unprepared to deal with the loss and find it challenging to cope with emotional issues. Palliative care referral improves the quality of life, confers symptom management benefit, provides emotional support, enhances end of life care experience and supports children and their families' needs. Children with cancer were sparingly referred to palliative care and referred late. Oncologists and haematologists gatekeep the referral process, and their views about palliative care facilitate or hinder a referral. As there is no published research from India, conducting a study on paediatric palliative care referral in oncology is relevant due to high incidence, low cure rates and increased mortality among children with cancer in India. Moreover, research findings on paediatric oncologists' and haematologists' views might inform policy and practice development, facilitating augmented and early referral. In the next chapter, the literature on oncologists' and haematologists' views on palliative care referral is systematically reviewed.

Chapter 3: Review of the Literature

3.1. Introduction

Worldwide, most patients with cancer present in the late stages of illness and need palliative care (Ferlay et al., 2015). However, they are infrequently referred to palliative care or are referred late (Fraser et al., 2011; Smith et al., 2012). Early palliative care referral is associated with improved quality of life, symptom control, treatment decision making, advance care planning, end of life care and reduced costs (Brumley et al., 2007; Greer et al., 2012; Temel et al., 2010). In a cancer care setting, oncologists and haematologists may act as gatekeepers, and their views about palliative care referral may facilitate or hinder referral to palliative care (Dalberg et al., 2018; Kars et al., 2016).

A systematic review of the literature was conducted to establish oncologists' and haematologists' views on palliative care referral internationally. The purpose of the review was to inform my ongoing PhD research. The PhD research question was "What are the views of oncologists and haematologists of what facilitates or hinders referral of a child with advanced cancer to palliative care in India?". The scoping search showed a small number of studies when the search was limited to a paediatric population. Therefore, the scope of the review was expanded to include both adult and paediatric populations. A study that compared specialist palliative care referral of adult and paediatric oncologists showed similar referral practices (Wentlandt et al., 2014). Therefore, knowing what helps or hinders palliative care referral in an adult population might be useful while conducting a study in a paediatric setting. The review was limited to cancer as the PhD research explored palliative care referral in a paediatric cancer setting. Palliative care is more developed in cancer (Chen, 2019), and

cancer has a different illness trajectory when compared to non-cancer conditions (Murray et al., 2005). Moreover, palliative care referral in non-cancer is different from cancer as the majority of non-cancer patients were hospitalised during initial referral (Bostwick et al., 2017), died in the hospital (Cantin et al., 2009) and were less likely to be discharged into a community palliative care program (Stiel et al., 2015).

A scope of the multidisciplinary database SCOPUS (Burnham, 2006), identified previous systematic reviews on palliative care referral. These systematic reviews looked at barriers to accessing palliative care (Ahmed et al., 2004), referral criteria (Hui, Meng, et al., 2016), and appropriateness of referral (Howell et al., 2011). Other related systematic reviews looked at interventions to improve palliative care referral (Kirolos et al., 2014), integration of oncology and palliative care (Hui & Bruera, 2015), the effect of age of the patient on palliative care referral (Burt & Raine, 2006), and collaboration between generalist and specialist palliative care teams (Firn et al., 2016). However, no systematic reviews looked at the views of oncologists and haematologists on palliative care referral. Although there are studies about oncologists' and haematologists' views on palliative care referral, these studies have not been systematically reviewed. Moreover, in 2018 when this systematic review was conducted, a search for the protocol of ongoing systematic reviews in the international prospective register of systematic reviews website (PROSPERO) showed no ongoing systematic review on the views of oncologists and haematologists on palliative care referral.

3.2. Literature Review Methods

3.2.1. Aim of the Review

This systematic review aimed to systematically identify, explore, and synthesise oncologists' and haematologists' views on palliative care referral.

3.2.2. Review Question

The review question was

"What are the views of oncologists and haematologists on palliative care referral"?

The review question was formulated using the **P**opulation, Phenomenon of **I**nterest and **Co**ntext (PICo) framework (Stern et al., 2014). The population studied was oncologists and haematologists; the phenomenon of interest was views on palliative care referral, and the context was the cancer care setting.

3.2.3. Philosophical Underpinnings and Theoretical Framework

The literature was reviewed using a critical realist lens (Okoli, 2012), and the findings were interpreted using social exchange theory (Ekeh, 1974). The critical realist approach involves documenting the empirically known phenomenon of referral and going beyond the empiric observations to explain the actual events and generative mechanisms (Collier, 1994). Social exchange theory theorises the social behaviour of exchange where people are motivated to engage in an exchange where they may gain or forfeit something of value (Ekeh, 1974). The critical realist approach (Collier, 1994) underpins my PhD research process, and social exchange theory (Ekeh, 1974) is used to discuss my PhD research findings. The critical realist

paradigm and social exchange theory are discussed in detail in chapter four, sections 4.3.1 and 4.3.2.

3.2.4. Review Design

The scoping search results showed that the typology of evidence informing this review is a heterogeneous mixture of surveys, qualitative studies, and mixed-method studies. Popay's narrative synthesis method was chosen as the review approach as it is appropriate for synthesising textual data from surveys and qualitative studies into themes (Popay et al., 2006) and facilitates using a theoretical framework for interpreting study findings. Moreover, it provides flexibility in choosing the steps and approaches within the synthesis method relevant to the review (Popay et al., 2006).

3.2.5. Review Protocol Registration

The systematic review protocol was registered with the Centre for Reviews and Dissemination, University of York. The PROSPERO registration number was CRD42018091481.

3.2.6. Search Strategy

The review question was divided into search concepts, and a scoping search helped identify the key search terms relevant to each concept of the review question. The scoping search also helped identify three index papers to test the search's sensitivity (Dalberg et al., 2013; Johnson et al., 2011; Twamley et al., 2014). The index papers facilitated the expansion of the search terms to find free-text and thesaurus terms related to the review's scope (Ramer, 2005). Four subject-specific databases (PubMed, CINAHL, PsycINFO and EMBASE) were searched by combining free-text and the thesaurus terms specific to the database using

Boolean operators (Chang et al., 2006). Three multidisciplinary databases (SCOPUS, Web of Science and Cochrane database) were searched using free-text terms. **Appendix 3.1** provides information about the thesaurus and free text terms used in this review. The initial systematic review accessed literature up to 31/08/2018 and informed the design of my study. The review was updated again in January 2020 for publication (Salins et al 2020), and this updated review is presented here.

Studies published in English involving human subjects from 01/01/1990 to 31/12/2019 were accessed. The article search was limited from 1990 onwards as the first published literature on palliative care in MEDLINE dated back to 1993 (Bradshaw, 1993). **Appendix 3.2** provides the list of eleven journals hand searched for additional citations. They were chosen based on the scoping review. The bibliographies of the full-text articles included in the review were checked to ensure no relevant studies were missing (Eyers, 1998). The citations of the included publications were searched using Google Scholar and Web of Science to identify more articles pertaining to the review. The included articles identified through citation searching were checked for their citations until the search led to no additional relevant articles (Hinde & Spackman, 2015).

3.2.7. Study Eligibility and Scoring for Methodological Rigour

The selection criteria of the studies included in the review are listed in **Table 3.1**. All studies were scored for their methodological rigour using Hawker's tool (Hawker et al., 2002). Hawker's tool **(Appendix 3.3)** allows methodological scoring of a mixed typology of studies, and a growing number of palliative care systematic reviews have used this tool (Ahmed et al., 2004; Firn et al., 2016; Oishi & Murtagh, 2014). Scoring is based on the nine criteria set by

Hawker provided in **Appendix 3.3**. Each criterion is assigned a score between 1 to 4 (1= very poor and 4=good), where 9 is the minimum score, and 36 the maximum (Hawker et al., 2002). Only those studies scoring 19 and above were included in the review. Although the tool does not provide a cut-off score for inclusion, previous palliative care systematic reviews have used a score of 19 for inclusion (Firn et al., 2016; Flemming, 2010). Three studies were excluded from the review as they scored less than 19 in Hawker's score (Hawker et al., 2002). The minimum score of the studies included in this review was 25, and the mean score was 30.

Table 3.1. Selection Criteria of the Studies Included in the Review

Inclusion Criteria	Exclusion Criteria
1. Empiric research on human subjects published in English in a peer-reviewed journal after 1990. 2. Studies exploring views of the oncologists, haematologists and cancer specialists about palliative care referral. 3. Studies with Hawker's methodological quality score of 19 or above.	1. Empiric research on the effectiveness of palliative care referral or mechanisms underpinning the effectiveness of the referral. 2. Studies conducted in a non-cancer setting and not involving oncologists and haematologists.

3.2.8. Data Extraction

Screening, quality appraisal and data extraction were conducted independently by two reviewers. The data extraction sheet provided in **Appendix 3.4** has five sections. The initial section had information regarding the country and year of publication. The second section focused on the type of study, that is, survey, qualitative or mixed-method. In this section, study objectives, population and study setting were also described. The study sample, participants, inclusion and exclusion criteria, research design and methods were elucidated in the third section. The fourth section provided information on study findings and conclusions. The last section discussed the strengths and limitations of the study and biases.

3.2.9. Data Synthesis

During narrative synthesis, the first step was to identify a theoretical framework for the review that can contribute to the interpretation of review findings (Popay et al., 2006). The theoretical lens of social exchange theory was used to interpret the themes discovered during the synthesis (Ekeh, 1974). The second step was to develop a preliminary synthesis. A preliminary synthesis was generated by providing a brief textual description of the studies informing the review. The studies informing this review were grouped according to the country, type of population studied and the factors influencing referral. A textual description helped the reviewers to be familiar with the data before analysis. The third step was to explore relationships within and between studies. The relationships were explored by representing the review findings as meaningful categories and themes **(Appendix 3.5)**. During this step, the reviewers also explored the heterogeneity of the included studies in terms of population, setting and typology. The fourth step was to assess the robustness of the synthesis. This was done by critically reflecting the synthesis process and providing information about the limitation of the synthesis and possible sources of biases (Popay et al., 2006).

3.3. Review Findings

3.3.1. Overview of the Studies

Out of 9336 initial database citations, 23 studies were included for synthesis. The PRISMA flow diagram for this review is provided in **Figure 3.1**. Ten studies were qualitative, ten were surveys, and three were mixed-method studies. Twelve studies were from North America (nine USA and three Canada), seven from Europe (three from France, one each from Belgium, United Kingdom, Hungary and Cyprus), two from Australia and two from Asia (one each from

Japan and Israel). The majority of the surveys and mixed-method studies were multi-centre studies spanning several centres within the country and across countries. Moreover, they were often linked to professional cancer societies. The qualitative studies were mostly limited to one or more centres within a region. A detailed overview of the studies can be found in **Table 3.2**. There were only two studies on paediatric referrals (Nyirő et al., 2018; Wentlandt et al., 2014). One had a mixed adult and paediatric population (Wentlandt et al., 2014), and the other a qualitative study of paediatric oncologists (Nyirő et al., 2018). The data from the paediatric studies were separately examined during subgroup analysis.

Figure 3.1. PRISMA Flow Diagram

Identification

Records identified through database searching
(n = 9336)

Additional records identified through other sources
(n=868)

Screening

Records after duplicates removed
Titles screened (n=8289)

Titles excluded
(n = 7697)

Abstracts screened
(n = 592)

Abstracts excluded
(n = 379)

Eligibility

Full-text articles assessed for eligibility
(n = 213)

Full-text articles excluded, with reasons
(n =190)
Conference reports - 13
Non-empiric research - 32
Non-cancer - 7
Studies involving mixed population of physician and non-physician providers - 26
Effectiveness/outcomes, mechanisms underpinning outcomes of referral - 82
Process and patterns of referral - 27
Hawker's score <19 - 3

Included

Studies included for the review synthesis
(n =23)

Table 3.2. Overview of the Studies Included in the Review

Author, Year Country	Research question	Participants Setting	Method	Key findings	Hawker Score
(Horlait et al., 2016) Belgium	What are the barriers to introduce palliative care into a discussion with patients with advanced cancer?	15 medical oncologists from academic and non-academic hospitals	Grounded theory	Following were the barriers identified by the oncologists. Physician related barriers were emotional bonding with the patients, feeling of professional failure, discomfort with death and dying and lack of experience and training in managing patients with advanced illness. Patient-related barriers were language and culture, denial, and unrealistic expectations. Family-related barriers were the protection of patients and family disputes. Disease-related barriers were lack of clear guidelines for palliative care referral, the unpredictable trajectory of illness and unexpected progression. Organisation related barriers were lack of availability of palliative care services, excessive focus on cure, lack of space and time to discuss palliative care, and excessive workload. The societal barrier was the stigma associated with palliative care and palliative care referral.	34
(Charalambous et al., 2014) Cyprus	What are the attitudes and referral patterns of lung cancer specialists to palliative care?	50 cancer specialists from the EORTC Lung Cancer Group representing 14 countries.	Survey	Oncologists like to refer to palliative care when they have difficulty controlling symptoms or when no treatment is available. Some refer during the diagnosis of metastatic disease or cancer treatment. The non-availability of palliative care physicians is a significant barrier. Oncologists felt that patients do not like to be referred to palliative care and referral meant abandoning their patients. Moreover, oncologists had concerns about the expertise of palliative care physicians and felt that they may discourage or interfere with oncological treatment.	29
(Cherny & Catane, 2003) Israel	What is the practice and attitudes of ESMO oncologists in relation to the supportive and palliative management of patients with	895 ESMO member oncologists representing 64 countries.	Survey	All advanced cancer patients should receive concurrent palliative care. Oncologists should coordinate the care at all stages of disease, including end of life care. They preferred to manage advanced cancer and dying patients themselves. They felt they have acquired some knowledge of palliative care during their training and felt confident about managing symptoms. Palliative	33

	advanced and incurable cancer, and what are the oncologist-related barriers to the provision of optimal supportive and palliative care?			care physicians do not have enough understanding of oncology to counsel patients with advanced cancer regarding treatment options.	
(Morikawa et al., 2016) Japan	What are the barriers to collaboration between haematologists and palliative care teams in a relapse or refractory leukaemia and malignant lymphoma patients' care?	11 Haematologists from University Hospital	Content Analysis	Barriers for referral were a. treatment provided by palliative care providers were not as preferred by the haematologists b. treatment of primary disease prioritised over palliative care c. lack of aggressive approach by the palliative care team d. negative image of palliative care, the patients equate palliative care to imminent death e. palliative care team may not be able to support the haematology patients and they have a different perspective on assessment f. lack of interdisciplinary communication and g. lack of palliative care human resources.	25
(Johnson et al., 2008) Australia	What are the triggers that initiate a referral to palliative care, and what are the reasons for non-referral?	699 cancer specialists practising at various hospitals in Australia	Survey	Patients with advanced cancer should be referred early. Early referral is beneficial, and patients will benefit from palliative care while receiving anti-cancer treatment. Patients are often referred when they have a terminal illness, uncontrolled physical symptoms, complex patient needs, and not coping with the physical care. They prefer integrated care and would like to be involved in the care even after palliative care referral. They are confident about managing symptoms and unlikely to refer if the patient's symptoms are well controlled and the prognosis is good.	34
(Ward et al., 2009) Australia	What are the attitudes of Australian medical oncologists towards palliative care and collaboration with palliative care services?	115 Medical Oncologists who are members of Medical Oncology Group of Australia.	Mixed Method (Survey and thematic analysis)	Provision of palliative care is central, rewarding and adds value. Have adequate palliative care training and confidence in managing symptoms and communication. Palliative care rotation should be part of medical oncology and vice-versa. The major reason for referral is symptom management, community support, hospice and terminal care. They preferred the concurrent model over the sequential model. Barriers for referral: a. inadequate palliative care resources b. refusal by palliative care to take patients	33

				receiving anti-cancer therapy c. lack of clear guidelines regarding the timing of referral	
(Hay et al., 2017) USA	What are the Gynaec-oncologist's views that influence the utilisation of outpatient specialist palliative care?	34 Gynaec-oncologists working at NCI designated cancer centres	Grounded theory	Long term relationship with the patients helps in convincing the patients to access palliative care. They value the communication skills of the palliative care provider, emotional support, help in navigating challenging circumstances, goals of care discussion and prognostic awareness. They preferred embedded clinics and better inter-disciplinary communication. They expressed concerns about losing control and awareness of patients while receiving palliative care.	27
(Wright & Forbes, 2017) UK	What are the views and perceptions of haematologists towards palliative care, and the factors that helped or hindered referral to palliative care?	8 Haematologists working in a tertiary referral cancer centre	Grounded theory	Equated palliative care with worsening prognosis, death and dying. Hospice has a negative connotation, and hospice referral requires sensitive and proactive explanation. Symptom control was the most common reason to refer. Barriers for referral were a. insufficient number of palliative care beds b. palliative care lack resources to provide blood products c. stringent referral criteria d. prejudice by the palliative care providers against haematology patients d. difficult timing and transition due to complex and unpredictable nature of illness e. uncomfortable to refer curative patients f. mixed messages g. loss of control g. sense of professional failure h. feelings of abandoning patients. They preferred joint care approach.	32
(Smith et al., 2012) USA	What influences lung cancer physician's decision to refer their patients to experts in palliative care?	155 Lung Cancer Physicians practising at various teaching hospitals in USA	Survey	Patients and families would be alarmed by the mention of palliative care. Patients prefer to focus on curative therapies than palliative care. Patients do not want to discuss prognosis. Palliative care providers are good in discussing complex issues and goals of care. They help in reducing symptoms, provide spiritual support and decrease the length of stay.	32
(Rhondali et al., 2013) USA	What are medical oncologists' perceptions of the supportive care	17 medical oncologists working in a	Grounded Theory	Symptom control is the primary function of palliative care. Palliative care communication helps in transitioning patients to end of life care. Psychological support provided by palliative care	33

	service and whether changing the name "palliative care" to "supportive care" influenced communication with patients and their families about palliative care and the referral?	tertiary referral cancer centre		decreased caregiver anxiety and facilitated communication. Palliative care involvement has time saving benefit and helps patients to complete treatment due to better symptom control. The earlier referral is better as it will enable better therapeutic relationship. Triggers for referral are the terminal nature of the illness, metastatic disease and exhaustion of treatment. Barriers for referral are no clear-cut point to stop treatment, communication involved in referral is challenging, conflicts in goals of care and physician ownership. They preferred the name to be changed as supportive care as patients perceive it better and will be more receptive for referral.	
(Schenker et al., 2014) USA	What are the oncologist factors that influence referral decisions?	74 Oncologists practising at various hospitals in the USA	Qualitative data analysis	Palliative care is an alternative to chemotherapy and cannot have both. Palliative care referral decision based on disease stage and treatment option. Palliative care has a different philosophy of care not compatible with active disease-modifying care. PC providers create conflict and provide a dismal prognosis. Referral to palliative care means abandoning, giving up. They are territorial and would like to provide treatment till the end and do not like others interfering with the care. They have palliative care skills and refer patients for symptom control. Having a positive referral experience might facilitate future referral.	25
(LeBlanc et al., 2015) USA	What are the differences in referral practice and views of palliative care among haematologists and solid tumour oncologists?	23 Haematologists 43 Solid tumour oncologists practising at academic cancer centres	Mixed Method Study (Survey + Qualitative Data Analysis)	Haematologists view palliative care as end-of-life care and as antithetical to cancer care. Solid tumour oncologists feel palliative care expertise is valuable and believe in the co-management of patients. Haematologists expressed distrust, need to maintain control, avoiding involvement of other consultants, mixed messages, and prognostic uncertainty. Palliative care is inconsistent with treatment goals and a significant barrier for a referral. Solid tumour oncologists felt lack of palliative care resources, logistics of accessing, insurance as barriers for referral	28
(Wentlandt et al., 2012) Canada	What are the referral practices of Canadian oncologists to palliative	603 medical, radiation and surgical	Survey	Diagnosis of incurable cancer, uncontrolled physical symptoms and a prognosis of less than one year was the likely reason for referral. Referrals are also made for discharge planning and	32

		oncologists from the Canadian oncology societies		psychosocial support. The term palliative care has a negative perception and would refer if the name is changed to supportive care. They will refer the patients early if there are more palliative care services and palliative care providers accept patients receiving chemotherapy.	
(Wentlandt et al., 2014) Canada	What are the attitudes and referral practices of paediatric oncologists to specialised palliative care services and to compare their practices and opinions with those of adult oncologists?	48 Paediatric Oncologists & 595 Adult Oncologists practising at various hospitals in Canada	Survey	Paediatric oncologists refer terminally ill children, metastatic disease, prognosis of less than 6 months, and with uncontrolled symptoms to palliative care. Paediatric oncologists feel palliative care has a negative perception and prefer name change to supportive care. They are comfortable treating advanced patients at the end of life. Adult oncologists refer earlier, when the prognosis is less than one year, for discharge planning, psychosocial and spiritual support.	30
(Suwanabol et al., 2018) USA	How surgeons who care for patients with colorectal cancers approach end-of-life care and engage palliative care specialists?	131 Cancer Surgeons belonging to the American Society of Colon & Rectal Surgeons	Mixed Method Study (Survey + Qualitative Data Analysis)	Oncologists have a lack of knowledge, training and opportunities for the delivery of palliative care. Barriers are inadequate communication between teams, unrealistic expectation in a poor prognosis situation and effectiveness of treatment, uncertainty in decision making, legal liability, opioid phobia, family conflict, lack of time, lack of palliative care services and a culture of continuing life-sustaining treatment in the hospital.	28
(Gidwani et al., 2017) USA	What are the oncologist's views and attitudes towards palliative care referral?	31 Medical Oncologists practising at academic cancer centres and Veteran Affairs hospitals in the USA	Thematic Analysis	Palliative care is an essential layer of support, should be provided early, and the unavailability of the palliative care provider is the barrier. Excessive focus on inpatient palliative care and absence of outpatient and community palliative care is the barrier. The palliative care provider is perceived as an outsider, unable to understand oncology patients, oncology treatment and unable to recognise a recoverable sick oncology patient from a dying patient. Issues with care coordination and oncologists being left out of crucial discussions and lack of interdisciplinary communication are barriers for a referral. Palliative care has a	25

				narrow focus, and palliative care providers excessively rely on sedation and analgesics.	
(Cripe et al., 2019) USA	What are the perceived barriers to integrating speciality palliative care into gynecologic cancer care?	174 Gynaec-oncologists who are members of the Society of Gynaecologic-Oncology in the USA	Survey	Barriers to speciality palliative care in gynecologic oncology practice were unrealistic expectations of families and patients, limited access to speciality palliative care, inadequate insurance reimbursement, time constraints, and concern of reducing hope or trust.	34
(Nyirő et al., 2018) Hungary	What is the timing and circumstances of implementing paediatric palliative care in the Hungarian paediatric oncology practice?	22 physicians from the Hungarian Paediatric Oncology Group	Survey	Barriers to early palliative care implementation were an increase in parental anxiety, detrimental effects on the doctor-family-patient relationship and equating palliation with end-of-life care. Oncologists preferred discussing with the parent's first before referral, gradual information disclosure, and waiting till the end of the child's life for making a referral. They chose to have a psychologist in the earlier discussions. Avoided using the term palliative care and used euphemisms to communicate death/dying.	33
(Ethier et al., 2018) Canada	What are the various perceived barriers for having goals of care (GOC) discussions and palliative care referral?	127 oncologists from 12 cancer centres in Ontario, Canada	Survey	According to oncologists, patients have difficulty accepting prognosis and desire for aggressive treatment due to inflated expectation of treatment benefit. Other barriers were lack of time to have conversations, prognostic uncertainty, desire to maintain hope, the uncertainty of the benefits of further active cancer therapy, difficulty in recommending discontinuation of treatment in the younger population and patient and family refusals	34
(Feld et al., 2019) USA	What are the practices and attitudes regarding the role of early palliative care referral among oncologists and patients with metastatic	279 Oncologists from the International Association for the Study of Lung Cancer	Survey	Common factors influencing participants to refer patients to palliative care were inadequately managed pain, no further or dwindling treatment options, other cancer-related symptoms, depression/anxiety. The common reasons for not referring patients to palliative care include lack of time to address palliative care needs, lack of patient symptoms, belief that oncologists can manage palliative care needs independently, not wanting to	33

	non-small cell lung cancer?				burden patients with additional appointments, concern that referral may not be well-received by patients, and long wait times.	
(Prod'homme et al., 2018) France	What are the perceptions of haematologists on end-of-life discussion in patients and families with relapsed haematological malignancies?	10 haematologists from haematology centres of northern France and Belgium	Grounded Theory	Reluctance to discuss death and dying. Talking about death and dying is stressful, complicated and a taboo. The primary role is to cure and save from death. Responsibility is to reassure, motivate and infuse confidence. End of life discussion is not compatible with the physician's role. Treatment effectiveness is proof of a physician's performance, and death is a professional failure. End of life discussion causes loss of physician credibility and jeopardises patient compliance. Will initiate conversation only when there is an explicit request and would like to protect patients from violent discussions on end of life. Initiating palliative care and end of life care is incompatible with hope. Palliative care can be activated when all the treatment is discontinued.	32
(Tricou et al., 2019) France	What are the barriers to referring to specialist palliative care from the perspectives of the haematologists?	14 haematologists from two haematology centres at Lyon, France	Grounded Theory	Referral only when there are difficult to control symptoms like severe pain, complex situations and therapeutic decision making. Early referral is beneficial in an asymptomatic patient for facilitating a smooth transition. The term palliative care has a negative connotation, and patients/families react negatively to palliative care. Preferred to use the term supportive care instead of palliative care. The short time frame from the appearance of symptoms and end of life hinders referral	28
(Sarradon-Eck et al., 2019) France	What are the perceptions and attitudes of oncologists on early referral to palliative care and working with the palliative care services?	13 Oncologists working at 10 cancer treatment sites across France	Grounded Theory	The term palliative care has a negative connotation. The term is unsuitable, scares people, harms them. Term palliative care elicits feelings of abandonment, stopping treatment and euthanasia. They preferred to use euphemisms like supportive care, comfort care instead of palliative care. More likely to refer if it is called supportive care. Referral to palliative care causes loss of patient compliance, loss of hope, elicits distress and equivalent to announcing poor prognosis. Palliative care is the last recourse and restricted for patients with less than three months life expectancy. Palliative care assessment is vague, not evidence-based, and oncologists are experienced in symptom management.	28

3.3.2. Literature Review Themes

Five themes were developed during synthesis. They were a) presuppositions of oncologists and haematologists, b) power relationships and trust issues, c) Making a palliative care referral: A daunting task, d) cost-benefit of a palliative care referral, and e) strategies to facilitate a palliative care referral. The themes, subthemes and the explanatory narrative for the subthemes and the citations, are displayed in **Table 3.3,** and the thematic map of the review is visually represented in **Figure 3.2.**

Table 3.3. Review Themes, Subthemes and Explanatory Narrative

Themes	Subthemes	Explanatory Narrative
1. Presuppositions of oncologists and haematologists about palliative care referral	Role conflict	Handing over patients to palliative care is a professional failure (Wright & Forbes, 2017) Amounts to letting down and failing the patients (Wright & Forbes, 2017) Treatment effectiveness is proof of physician's performance (Prod'homme et al., 2018) The primary role is to cure and save from death (Prod'homme et al., 2018) Medical training geared towards cure or control of the disease (Horlait et al., 2016) End of life discussion is not compatible with the oncologist's role (Prod'homme et al., 2018) End of life discussion causes loss of physician credibility (Prod'homme et al., 2018)
	Abandonment	Will be viewed by families as abandonment (Charalambous et al., 2014; Schenker et al., 2014) Sense of abandonment when the focus of care was changed (Wright & Forbes, 2017) Announcing poor prognosis, signified abandonment (Sarradon-Eck et al., 2019)
	Rupture of the therapeutic alliance	Breakdown of a doctor-patient relationship (Nyirő et al., 2018) Jeopardises patient compliance (Prod'homme et al., 2018; Sarradon-Eck et al., 2019)
	Loss of hope	Desire to maintain hope is lost (Ethier et al., 2018; Sarradon-Eck et al., 2019) Initiating palliative care is incompatible with hope (Prod'homme et al., 2018) Responsibility to reassure, motivate and infuse confidence (Prod'homme et al., 2018) Protect patients from violent discussions on end of life (Prod'homme et al., 2018)
	Negative emotions	Emotional toll while making palliative care referral (Sarradon-Eck et al., 2019; Wright & Forbes, 2017) Emotional burden associated with delivering news of poor prognosis (Sarradon-Eck et al., 2019) Emotional bond associated with long-term knowledge of the patients (Horlait et al., 2016) Inability to handle emotional reactions associated with palliative care referral (Horlait et al., 2016)
	Self-efficacy	Symptom management, psychosocial support and communication is an integral part of oncology and can provide ourselves (Feld et al., 2019; LeBlanc et al., 2015; Sarradon-Eck et al., 2019; Schenker et al., 2014) Oncologists have training in managing physical and psychological symptoms and communicating with patients and families (Cherny & Catane, 2003; Johnson et al., 2008; Ward et al., 2009)
2. Power relationships and trust issues	Control and coordinate the care process	Be responsible for the care of the patient till the end (Hay et al., 2017; Horlait et al., 2016; Rhondali et al., 2013; Schenker et al., 2014) Coordinate the care of the patient at all stages of the illness (Cherny & Catane, 2003; Wright & Forbes, 2017) Referral leads to loss of control (Hay et al., 2017; LeBlanc et al., 2015)

		Dislikes interference in patient care (Rhondali et al., 2013; Schenker et al., 2014)
	Gatekeeping	Wait till the end of potentially curative treatment to make a referral (Nyirő et al., 2018)
		Referral only when all the treatment is discontinued (Prod'homme et al., 2018; Sarradon-Eck et al., 2019)
		Initiate palliative care discussion only when there is an explicit request (Prod'homme et al., 2018)
	Competency-based trust	Treatment provided by palliative care not as expected (Morikawa et al., 2016)
		Palliative care providers not skilled in managing side effects (Morikawa et al., 2016)
		Unable to differentiate a recoverable sick patient from a dying patient (Gidwani et al., 2017)
		Do not have adequate oncology knowledge to counsel patients (Cherny & Catane, 2003)
		Lack aggressive approach (Morikawa et al., 2016; Schenker et al., 2014)
		Excessive focus on pain medications and sedation (Gidwani et al., 2017)
		Palliative care providers have a different perspective on assessment (Morikawa et al., 2016)
		Palliative care assessment is vague and not evidence-based (Sarradon-Eck et al., 2019)
3. Making a palliative care referral: A daunting task	Stigma associated with palliative care	Palliative care referral equals death, end of life, terminal care (Cripe et al., 2019; Horlait et al., 2016; LeBlanc et al., 2015; Morikawa et al., 2016; Nyirő et al., 2018)
		Negative perception about palliative care precludes the use of the term (Horlait et al., 2016; Nyirő et al., 2018; Sarradon-Eck et al., 2019; Tricou et al., 2019; Wentlandt et al., 2014; Wentlandt et al., 2012)
		The term palliative care is unsuitable, scares people, harms them (Sarradon-Eck et al., 2019)
		Elicits feelings of abandonment, stopping treatment and euthanasia (Sarradon-Eck et al., 2019)
		Use supportive care and comfort care instead (Nyirő et al., 2018; Sarradon-Eck et al., 2019)
		Reluctance to discuss death and dying (Prod'homme et al., 2018)
		Discussing death is stressful and a taboo(Horlait et al., 2016; Nyirő et al., 2018; Prod'homme et al., 2018)
		Patients and families get alarmed by the mention of palliative care (Smith et al., 2012)
		Physicians have to address the negative connotation associated with palliative care (Hay et al., 2017)
		Palliative care referral requires careful explanation (Wright & Forbes, 2017)
		Referring to palliative care means patients are weak and unable to fight the disease (Rhondali et al., 2013)
	Illness and treatment-related factors	Advanced, recurrent or metastatic cancers are referred (Rhondali et al., 2013)
		Unpredictable course of illness hinders referral (Morikawa et al., 2016)
		Relapsing and remitting nature of haematological malignancies is a barrier for referral (Wright & Forbes, 2017)
		Rapid progression and complications hinder referral (Wright & Forbes, 2017)
		Short time frame from the onset of symptoms to end of life is a constraint for referral (Tricou et al., 2019)
		Prognostic uncertainty is a barrier (Ethier et al., 2018)
		Referred when prognosis is poor (Wentlandt et al., 2014; Wentlandt et al., 2012)

		Uncertainty in decision making hinders referral (Suwanabol et al., 2018)
		No referral if the general condition is good (Horlait et al., 2016)
		Uncontrolled symptoms facilitate referral (Feld et al., 2019; Rhondali et al., 2013; Wentlandt et al., 2014; Wentlandt et al., 2012)
		No referral in the absence of symptoms (Feld et al., 2019; Johnson et al., 2008; Wentlandt et al., 2014)
		No referral until treatment failure or late stage of the disease (LeBlanc et al., 2015)
		No referral if the possibility of cure exists (Ethier et al., 2018; Johnson et al., 2008; Wright & Forbes, 2017)
		Lack of treatment options is a trigger for referral (Feld et al., 2019)
		Priority on the treatment of the disease and cure until the end hinders referral (Morikawa et al., 2016)
		Difficulty in recommending discontinuation of treatment in the younger population (Ethier et al., 2018)
	Patient and family attitudes	Unrealistic expectation of cure and desire for aggressive treatment (Cripe et al., 2019; Ethier et al., 2018; Horlait et al., 2016; Suwanabol et al., 2018)
		Unwilling to discuss prognosis and non-curative approach (Ethier et al., 2018; Johnson et al., 2008; Smith et al., 2012)
		Unwilling to discuss referral to palliative care (Charalambous et al., 2014; Feld et al., 2019; Horlait et al., 2016; Ward et al., 2009)
		Family conflict (Suwanabol et al., 2018)
		Cultural barriers (Horlait et al., 2016; Suwanabol et al., 2018)
		Language barriers (Horlait et al., 2016)
		Negative public perception about death (Suwanabol et al., 2018)
	Organisational Challenges	Hospital culture directed towards a cure (Horlait et al., 2016; Suwanabol et al., 2018)
		Lack of time to discuss about palliative care (Cripe et al., 2019; Ethier et al., 2018; Horlait et al., 2016; Suwanabol et al., 2018)
		Lack of space to discuss about palliative care (Horlait et al., 2016)
		Documentation deficiencies in oncology case notes (Horlait et al., 2016)
		Legal liability of palliative care referral (Suwanabol et al., 2018)
		Fear of opioids and their side effects (Suwanabol et al., 2018)
		Lack of knowledge among the oncologist's about palliative care (Suwanabol et al., 2018)
	Lack of referral criteria	Not sure when to refer (Charalambous et al., 2014; Morikawa et al., 2016; Wentlandt et al., 2012)
		Lack of consensus among the oncologists about when to refer (Horlait et al., 2016)
		Lack of clear guidelines for palliative care referral (Rhondali et al., 2013; Ward et al., 2009; Wright & Forbes, 2017)

	Limited palliative care resources	Inadequate access to palliative care services (Cripe et al., 2019; Johnson et al., 2008; Suwanabol et al., 2018) Inadequate number of palliative care providers (Charalambous et al., 2014; Morikawa et al., 2016) Inadequate palliative care resources (Gidwani et al., 2017; Ward et al., 2009; Wright & Forbes, 2017) Long waiting times for palliative care appointments (Feld et al., 2019; LeBlanc et al., 2015) Palliative care with excessive inpatient focus, lack of outpatient clinics (LeBlanc et al., 2015)
4. Cost-benefit of palliative care referral	Benefits of referral	Pain and symptom control (Charalambous et al., 2014; Feld et al., 2019; LeBlanc et al., 2015; Rhondali et al., 2013; Schenker et al., 2014; Smith et al., 2012; Tricou et al., 2019; Wright & Forbes, 2017) Psychosocial support, managing depression and anxiety (Feld et al., 2019; Hay et al., 2017; Johnson et al., 2008; Rhondali et al., 2013; Smith et al., 2012) Improvement in quality of life (Gidwani et al., 2017; Johnson et al., 2008) Navigating complex situations and therapeutic decision making (Hay et al., 2017; Tricou et al., 2019) Prognostication and Goals of care discussion (Hay et al., 2017; Smith et al., 2012) Conflict resolution (Hay et al., 2017) Saves oncologist's time (Rhondali et al., 2013) Facilitating treatment completion by better symptom control (Rhondali et al., 2013) Survival benefit (Rhondali et al., 2013) Discharge planning (Wentlandt et al., 2014; Wentlandt et al., 2012) Reducing the length of hospital stay (Smith et al., 2012) Community support (Ward et al., 2009)
	Incongruent communication	Confusing and overwhelming communication (LeBlanc et al., 2015; Morikawa et al., 2016; Schenker et al., 2014; Wright & Forbes, 2017) Incongruent perception of prognosis by the palliative care providers. Information provided to the patients and families is not consistent with oncologist's views (Gidwani et al., 2017; LeBlanc et al., 2015; Rhondali et al., 2013; Schenker et al., 2014) Not including oncologists in goals of care discussion and advance care planning (Gidwani et al., 2017)
	Curtailment of care	Reluctance of palliative care to consult haemato-oncology patients (Wright & Forbes, 2017) Patients unable to access blood products while receiving palliative care (Morikawa et al., 2016) Reluctance of palliative care to consult patients receiving active anti-cancer treatment (Suwanabol et al., 2018; Ward et al., 2009) Cost and burden of additional consultation (Feld et al., 2019)

5. Strategies to facilitate palliative care referral	Integrated model of care	Concurrent anti-cancer treatment and palliative care (Cherny & Catane, 2003; Ward et al., 2009; Wentlandt et al., 2012)
		Co-management of patients (Johnson et al., 2008; LeBlanc et al., 2015; Ward et al., 2009)
		Complementary role (Gidwani et al., 2017)
		Embedded into oncology clinics (Hay et al., 2017)
		Palliative care rotation should be part of oncology training and vice-versa (Charalambous et al., 2014; LeBlanc et al., 2015)
		Communication between the oncology and palliative care teams (Hay et al., 2017; Suwanabol et al., 2018; Ward et al., 2009)
		Clarification and assignment of roles and responsibilities (Ward et al., 2009)
		Rapport building and smooth transition (Johnson et al., 2008; Rhondali et al., 2013; Schenker et al., 2014; Tricou et al., 2019; Ward et al., 2009; Wentlandt et al., 2012)
	Changing the name	Changing the name to supportive care (Rhondali et al., 2013; Sarradon-Eck et al., 2019; Tricou et al., 2019)
		Referral likely if the name is changed to supportive care (Sarradon-Eck et al., 2019; Wentlandt et al., 2014; Wentlandt et al., 2012)
	Resource augmentation	Availability of services (Cherny & Catane, 2003; Schenker et al., 2014)
		Consistency and continuity of care (Ward et al., 2009)
		Presence of in-patient palliative care beds (Ward et al., 2009)

Figure 3.2. Thematic Map of the Review Findings

- Role conflict
- Abandonment
- Rupture of therapeutic alliance
- Loss of hope
- Negative emotions
- Self-efficacy

Presuppositions of oncologists and haematologists about palliative care referral

- Control and coordinate care process
- Gate-keeping
- Competency based trust

Power relationships and trust issues

- Integrated model of care
- Changing the name
- Resource augmentation

Strategies to facilitate palliative care referral

REVIEW THEMES

- Benefits of referral
- Incongruent communication
- Curtailment of care

Cost-benefit of palliative care referral

Making a palliative care referral: A daunting task

- Stigma associated with palliative care
- Illness and treatment related factors
- Patient and family attitudes
- Organisational challenges
- Lack of referral criteria
- Limited palliative care resources

3.3.2.1. Theme 1: Presuppositions of Oncologists and Haematologists about Palliative Care Referral

Presupposition refers to an implicit assumption or belief system about a phenomenon that fosters decision-making and a course of action (Danermark et al., 2019). From a critical realist perspective, structure, power and tendencies are the deeper dimensions of reality underpinning a phenomenon (Collier, 1994). Illness related factors form the structure, which is a necessary pre-requisite for making the referral. The virtue of being an oncologist or haematologist confers the power to refer. Presuppositions about the phenomenon are one of the features that form the tendencies (Collier, 1994). The tendencies have the potential to influence decision making and choice of action (Danermark et al., 2019).

Data from this review suggests that oncologists and haematologists perceived palliative care referral as role conflict, abandonment, rupture of therapeutic alliance and loss of hope. Making a palliative care referral triggered negative emotions, and they felt that they have the self-efficacy to manage palliative care needs. These perceptions informed some of the tendencies that might have hindered palliative care referral.

Some studies reported views on role conflict (Horlait et al., 2016; Prod'homme et al., 2018; Wright & Forbes, 2017). Role conflict occurred due to disagreement in expectations for a particular role (Prod'homme et al., 2018). Haematologists felt that their role was to cure and save their patients, and end of life discussions was not compatible with their role (Prod'homme et al., 2018). Role conflict also led to a sense of decreased performance and reduced job satisfaction (Prod'homme et al., 2018). Haematologists viewed palliative care referral as a therapeutic failure and letting down patients and their families (Wright & Forbes,

2017). Moreover, they also felt that engaging with palliative care reflected poorly on their performance and credibility (Prod'homme et al., 2018).

Oncologists and haematologists expressed views on abandonment (Charalambous et al., 2014; Sarradon-Eck et al., 2019; Schenker et al., 2014; Wright & Forbes, 2017). In a serious illness like cancer, patients and families often developed strong bonds with their health professionals due to an extended period of treatment, which created a sense of false security and expectations (Schenker et al., 2014). Abrupt referral to another service was perceived as not meeting expectations and constituted abandonment (Schenker et al., 2014). British haematologists and French oncologists felt that their patients and families experienced abandonment when there was a change in focus of care and during discussing poor prognosis (Sarradon-Eck et al., 2019; Wright & Forbes, 2017).

Some studies reported views on therapeutic alliance rupture (Nyirő et al., 2018; Prod'homme et al., 2018; Sarradon-Eck et al., 2019). Hungarian paediatric oncologists felt that palliative care referral could cause strain on the therapeutic relationship, which could lead to loss of trust and treatment dropout (Nyirő et al., 2018). They also felt that parental anxiety associated with early palliative care referral contributed to the disruption of the therapeutic relationship (Nyirő et al., 2018). These views were corroborated by French oncologists and haematologists, who felt that palliative care referral could jeopardise both the doctor-patient relationship and compromise treatment compliance (Prod'homme et al., 2018; Sarradon-Eck et al., 2019).

Oncologists and haematologists equated palliative care referral to loss of hope (Ethier et al., 2018; Prod'homme et al., 2018; Sarradon-Eck et al., 2019). Patients with advanced stages of illness and poor prognosis experienced hopelessness, and the oncologists often felt a need to nurture hope in these patients (Ethier et al., 2018). A desire to maintain hope was a barrier for palliative care referral among Canadian and French oncologists (Ethier et al., 2018; Sarradon-Eck et al., 2019). The French haematologists felt the need to reassure and inspire confidence in their patients and protect them from any information that caused the loss of hope (Prod'homme et al., 2018).

Making a palliative care referral could trigger negative emotional reactions among some oncologists and haematologists (Horlait et al., 2016; Sarradon-Eck et al., 2019; Wright & Forbes, 2017). Negative emotions triggered by palliative care referrals influenced future referrals (Horlait et al., 2016). French oncologists felt emotionally burdened while delivering the news of poor prognosis (Sarradon-Eck et al., 2019). Belgian oncologists and British haematologists felt that close emotional bonds resulted from knowing patients over time (Horlait et al., 2016; Wright & Forbes, 2017). It made them emotional while making a referral. Moreover, some Belgian oncologists found it challenging to handle the emotional reactions of patients and families associated with palliative care referral (Horlait et al., 2016).

Many studies supported the view that oncologists and haematologists perceive they have the self-efficacy to manage palliative care needs (Cherny & Catane, 2003; Feld et al., 2019; Johnson et al., 2008; LeBlanc et al., 2015; Sarradon-Eck et al., 2019; Schenker et al., 2014; Ward et al., 2009). Oncologists and haematologists felt that managing symptoms, providing psychosocial support and communicating with the patients are integral aspects of oncology,

and believed that they had developed these skills in their oncology training (Cherny & Catane, 2003; Johnson et al., 2008; Ward et al., 2009).

3.3.2.2. Theme 2: Power Relationships and Trust Issues

From a social exchange perspective, power in an exchange relationship refers to the privilege of a social actor to regulate the exchange, and trust is the belief in another social actor's ability or trustworthiness (Homans, 1958). Data from this review suggests that oncologists had the power to gatekeep the referral process and had diminished trust in the palliative care team's competency. Power and trust have an interdependent relationship, and the reduced trustworthiness of one social actor gives another social actor more power to regulate the exchange (Blau, 1968).

Many studies supported the view that oncologists and haematologists preferred to gatekeep the referral process and liked to control and coordinate the care process of their patients at all stages of their illness trajectories (Cherny & Catane, 2003; Hay et al., 2017; Horlait et al., 2016; Rhondali et al., 2013; Schenker et al., 2014; Wright & Forbes, 2017). The American oncologists perceived palliative care referral as a loss of control (Hay et al., 2017; LeBlanc et al., 2015) and interference in the care process (Rhondali et al., 2013; Schenker et al., 2014).

In some studies, oncologists and haematologists liked to regulate the timing of the referral (Nyirő et al., 2018; Prod'homme et al., 2018; Sarradon-Eck et al., 2019). Hungarian paediatric oncologists preferred to wait until the end of cancer treatment to make a palliative care referral (Nyirő et al., 2018) just as French oncologists and haematologists made palliative care referral after all the treatment was discontinued (Prod'homme et al., 2018; Sarradon-Eck et al., 2019).

Synthesis of data from some studies shows that oncologists and haematologists have diminished trust in palliative care providers' competency (Cherny & Catane, 2003; Gidwani et al., 2017; Morikawa et al., 2016; Sarradon-Eck et al., 2019; Schenker et al., 2014). Japanese haematologists and French oncologists felt that palliative care providers have suboptimal assessment and management skills (Morikawa et al., 2016; Sarradon-Eck et al., 2019). Medical oncologists worldwide felt that palliative care providers' oncology training was inadequate (Cherny & Catane, 2003). American oncologists questioned the reliability of palliative care providers as they could not differentiate a recoverable sick patient from a dying patient (Gidwani et al., 2017).

3.3.2.3. Theme 3: Making a Palliative Care Referral: A daunting task

From a social exchange perspective, a task refers to the efforts needed to complete an activity (Cropanzano et al., 2017). If the effort needed is significant, the social actor may not choose to engage in the exchange activity (Cropanzano et al., 2017). Data from this review suggests that oncologists and haematologists perceive the task of making a palliative care referral as daunting. They had to deal with the stigma associated with palliative care, navigate illness and treatment associated factors, address patient and family attitudes, and overcome organisational challenges. Moreover, a lack of referral criteria and limited palliative care resources made the referral process even more challenging.

Most studies supported the view that oncologists and haematologists had to deal with the stigma associated with palliative care, including public stigma or negative public attitudes about palliative care, due to the stereotyped association of palliative care with death (Cripe et al., 2019; Horlait et al., 2016; LeBlanc et al., 2015; Morikawa et al., 2016; Nyirő et al., 2018).

European oncologists and haematologists felt that families were reluctant to discuss death and viewed discussing death as a taboo (Horlait et al., 2016; Nyirő et al., 2018; Prod'homme et al., 2018). Moreover, families felt stressed during end-of-life discussions and equated these conversations with abandonment and euthanasia (Prod'homme et al., 2018; Sarradon-Eck et al., 2019).

Oncologists and haematologists also had to deal with label avoidance stigma or the choice not to pursue a line of management due to stigma associated with the language used in relation to the illness or treatment (Horlait et al., 2016; Nyirő et al., 2018; Sarradon-Eck et al., 2019; Tricou et al., 2019; Wentlandt et al., 2014; Wentlandt et al., 2012). French oncologists felt that the term palliative care has a potential to induce fear (Sarradon-Eck et al., 2019), and American lung cancer specialists believed that patients and their families get alarmed on the mention of palliative care (Smith et al., 2012). British haematologists and American gynae-oncologists felt that the term palliative care required careful explanation, and they had to dispel negative connotations associated with it (Hay et al., 2017; Wright & Forbes, 2017). Hungarian paediatric oncologists and French oncologists suggested changing the term to comfort care or supportive care (Nyirő et al., 2018; Sarradon-Eck et al., 2019).

In most studies, oncologists and haematologists elucidated illness-related factors either facilitating or hindering palliative care referral. These were the predisposing factors that influenced the choice of utilising a specific healthcare service. In the presence of predisposing factors, social actor's tendencies either enabled or constrained them to access a health service (Homans, 1958). The stage of the illness (Rhondali et al., 2013), its course (Morikawa et al., 2016; Tricou et al., 2019; Wright & Forbes, 2017) and complications (Wright & Forbes,

2017) determined palliative care referral. Prognostication (Ethier et al., 2018; Wentlandt et al., 2014; Wentlandt et al., 2012), cure potential (Ethier et al., 2018; Johnson et al., 2008; Morikawa et al., 2016; Wright & Forbes, 2017), availability of treatment options (Feld et al., 2019; LeBlanc et al., 2015), and decision-making challenges (Suwanabol et al., 2018) also played an important role in palliative care referral. Presence of symptoms (Feld et al., 2019; Johnson et al., 2008; Rhondali et al., 2013; Wentlandt et al., 2014; Wentlandt et al., 2012) and performance status (Horlait et al., 2016) of the patient were the other factors determining referral to palliative care.

Data from this review suggests that patient and family expectations and health beliefs were not congruent with what is proposed by oncologists and haematologists, which acted as a barrier for palliative care referral. Unrealistic expectation of cure (Cripe et al., 2019; Ethier et al., 2018; Horlait et al., 2016; Suwanabol et al., 2018), unwillingness to discuss prognosis and non-curative approach (Ethier et al., 2018; Johnson et al., 2008; Smith et al., 2012), and reluctance to discuss palliative care referral (Charalambous et al., 2014; Feld et al., 2019; Ward et al., 2009) were the certain attitudes that hindered palliative care referral.

In this review, oncologists and haematologists had to overcome healthcare organisational challenges that hindered palliative care referral. A lack of space and time to discuss palliative care was a significant barrier (Cripe et al., 2019; Ethier et al., 2018; Horlait et al., 2016; Suwanabol et al., 2018). American surgical oncologists and Belgian oncologists felt that hospital culture directed towards cure hindered referral (Horlait et al., 2016; Suwanabol et al., 2018). American surgical oncologists feared the legal liability of palliative care referral and expressed reservations about opioid use (Suwanabol et al., 2018). Both American medical and

surgical oncologists believed that insufficient documentation about a patient's illness in the medical records constrained palliative care referral (Horlait et al., 2016; Suwanabol et al., 2018).

In this review, the lack of agreed-upon criteria for palliative care referral hindered referral as specialities like oncology and haematology rely on health care criteria for patient management. The lack of palliative care referral guidelines (Rhondali et al., 2013; Ward et al., 2009; Wright & Forbes, 2017), and uncertainty about when to refer (Charalambous et al., 2014; Morikawa et al., 2016; Wentlandt et al., 2012) constrained palliative care referral. Belgian oncologists felt that the lack of consensus among the oncologists about the timing of referral was also a limiting factor (Horlait et al., 2016).

Oncologists and haematologists perceived that palliative care resources are limited, and the perception of limited resources in this review led to a downward trend in referral. Inadequate palliative care resources (Gidwani et al., 2017; Ward et al., 2009; Wright & Forbes, 2017), fewer palliative care providers (Charalambous et al., 2014; Morikawa et al., 2016), and limited access to palliative care (Cripe et al., 2019; Johnson et al., 2008; Suwanabol et al., 2018) hindered palliative care referral. American oncologists felt that long waiting times for palliative care appointments and limited palliative care outpatient clinics were some of the other barriers for referral (Feld et al., 2019; LeBlanc et al., 2015).

3.3.2.4. Theme 4: Cost-Benefit of Palliative Care Referral

From a social exchange perspective, cost corresponds to the losses or negative effects, and benefit corresponds to immediate or long-term rewards of participating in the exchange process (Blau, 1968). The cost-benefit or the profit is the proportion of rewards gained to the losses incurred. It determines the social actor's future participation in the exchange. In this review, oncologists and haematologists have elucidated both the rewards and negative effects of making a palliative care referral.

Pain and symptom management and psychosocial support are the well-known benefits of palliative care. In many studies included in this review, oncologists and haematologists subscribed to the views on well-known benefits of palliative care referral. However, only a few studies elucidated the lesser-known benefits of palliative care, such as facilitating goals of care discussion and shared decision-making. Australian and American oncologists felt that palliative care improved their patients' quality of life (Gidwani et al., 2017; Johnson et al., 2008). According to some studies, palliative care referral helped in decision-making (Hay et al., 2017; Tricou et al., 2019) and enabled goals of care discussion (Hay et al., 2017; Smith et al., 2012). It also facilitated treatment completion (Rhondali et al., 2013), reduction in hospital stay (Smith et al., 2012), discharge planning (Wentlandt et al., 2014; Wentlandt et al., 2012) and support for the patients in the community (Ward et al., 2009). Oncologists and haematologists also experienced some direct benefits as involvement of the palliative care team enabled them to resolve family conflicts and saved oncologists' time (Hay et al., 2017; Rhondali et al., 2013).

Cost refers to unintended potential negative effects accompanying the rewards associated with the activity (Blau, 1968). In this review, oncologists and haematologists felt that they experienced some unintended negative outcomes of palliative care referral. In some studies, they felt that a lack of congruence in communication between them and palliative care providers led to patients and families receiving mixed messages suggesting that palliative care communication could make patients and their families confused and overwhelmed (LeBlanc et al., 2015; Morikawa et al., 2016; Schenker et al., 2014; Wright & Forbes, 2017). Moreover, they felt that palliative care providers have incorrect perceptions about the course of illness and treatment outcomes leading to inconsistencies in communication (Gidwani et al., 2017; LeBlanc et al., 2015; Rhondali et al., 2013; Schenker et al., 2014). The American oncologists emphasised an oncologist's presence during the initial family meeting after palliative care referral to avoid miscommunication of clinical information (Gidwani et al., 2017).

Oncologists and haematologists felt that palliative care referral could risk the curtailment of care of their patients. British and Japanese haematologists believed that palliative care providers are reluctant to consult haematology patients and patients cannot access blood products while receiving palliative care (Morikawa et al., 2016; Wright & Forbes, 2017). The Australian medical oncologists and the American surgical oncologists felt that palliative care providers' reluctance to consult patients receiving active anti-cancer treatment could deprive management of these patients with palliative care needs (Suwanabol et al., 2018; Ward et al., 2009).

3.3.2.5. Theme 5: Strategies to Facilitate Palliative Care Referral

This review found that oncologists and haematologists provided some strategies that might facilitate palliative care referral, which palliative care providers could consider using to change their policy and practice. These included developing an integrated model of care, changing the name of palliative care, and augmenting palliative care resources which could facilitate palliative care referral.

Oncologists and haematologists thought that an integrated model of care could be achieved by providing concurrent cancer treatment and palliative care (Cherny & Catane, 2003; Ward et al., 2009; Wentlandt et al., 2012), co-management of the patients (Johnson et al., 2008; LeBlanc et al., 2015; Ward et al., 2009) and by having excellent inter-team communication (Hay et al., 2017; Suwanabol et al., 2018; Ward et al., 2009). American oncologists felt that oncology and palliative care have complementary roles and preferred palliative care teams to be embedded in oncology clinics (Gidwani et al., 2017; Hay et al., 2017). Lung cancer specialists from Cyprus and American oncologists felt that palliative care rotation should be part of oncology training (Charalambous et al., 2014; LeBlanc et al., 2015). In some studies, oncologists and haematologists felt that rapport building between the palliative care team and patients and their families is essential to facilitate smooth transitions of care from oncology to palliative care (Johnson et al., 2008; Rhondali et al., 2013; Schenker et al., 2014; Tricou et al., 2019; Ward et al., 2009; Wentlandt et al., 2014) preventing an abrupt break in the therapeutic alliance and avoiding a sense of abandonment (Schenker et al., 2014).

Some oncologists and haematologists supported changing the name of palliative care (Rhondali et al., 2013; Sarradon-Eck et al., 2019; Tricou et al., 2019), and felt that palliative

care referral is likely to improve if the term palliative care was replaced with supportive care (Sarradon-Eck et al., 2019; Wentlandt et al., 2014; Wentlandt et al., 2012) suggesting that rebranding might overcome the label avoidance stigma, noted above, due to negative perceptions associated with the term (Sarradon-Eck et al., 2019).

As discussed before, perceptions of a lack of palliative care resources hindered referral. In this review, oncologists and haematologists felt that palliative care resource augmentation could change that perception and may facilitate referral. Oncologists and haematologists felt the need to improve the availability of services, consistency and continuity of care and more in-patient palliative care beds (Cherny & Catane, 2003; Schenker et al., 2014; Ward et al., 2009).

3.3.3. Subgroup Analysis of the Views on Palliative Care Referral

Oncologists versus haematologists, adult versus paediatric physicians, and location of the country were the three subgroups that were analysed. Five studies included in this review captured haematologists' views (LeBlanc et al., 2015; Morikawa et al., 2016; Prod'homme et al., 2018; Tricou et al., 2019; Wright & Forbes, 2017). Haematologists had a higher negative perception of palliative care due to the terms' association with death. They were less likely to refer and referred late due to the complex unpredicted course of haematological illness and complications. Two studies captured paediatric oncologists' views (Nyirő et al., 2018; Wentlandt et al., 2014). Like haematologists, the paediatric oncologists also preferred to avoid the term palliative care, used euphemisms and favoured waiting till the end of cancer treatment to make a palliative care referral. Moreover, paediatric oncologists experienced parental anxiety during palliative care referral and preferred the presence of a psychologist during the initial meeting of the families with palliative care providers (Nyirő et al., 2018). The

views of oncologists and haematologists across various countries included in the review were comparable.

3.4. Interpretation of Review Findings

In a cancer care setting, oncologists and haematologists have the discretionary authority to make treatment decisions for their patients and act as gatekeepers (McGorty & Bornstein, 2003). Their views impact palliative care referral. In this review, a few oncologists and haematologists expressed their concern regarding the referee's lack of professional competency and the referrer's self-efficacy to meet various palliative care needs. Competency-based trust is an expectation that the other person can perform a task effectively, and reduced trustworthiness can hinder engagement with a person or a service (Lee, 2004). The discourse of oncologists and haematologists in this review in terms of power to control and coordinate their patients' care and determining the timing of referral suggests power dependence in a relationship. Power relationships exist when a person depends on another for the things they value (Emerson, 1976). Palliative care is an end speciality, and its providers are dependent on oncologists and haematologists for a referral (Walshe et al., 2008). Moreover, the public stigma and label avoidance stigma due to the negative stereotyped association of palliative care with death gave them stigma power, where the stigmatisers had the power to exclude the stigmatised (Link & Phelan, 2014).

In this review, oncologists and haematologists have drawn symbolic inferences about palliative care referral. They felt that palliative care referral symbolised the loss of hope, abandonment, a break in the therapeutic relationship and role conflict. Symbolic perspectives

can influence human cognition and motivation and might act as internal reinforcement mechanism affecting referral behaviour (Lawler, 2001).

An integrated approach is to bring together and align professional inputs, services and clinical management (Gröne et al., 2001). In this review, a few oncologists have advocated for an integrated cancer care model where cancer care and palliative care are provided concurrently. Moreover, they felt that oncologists and palliative care providers have a complementary role where oncologists provide cancer treatment and palliative care providers manage symptoms and improve quality of life. An integrated approach is not limited to making a referral or transferring patient information (van der Klauw et al., 2014). It involves providing critical inputs that could change health care providers' attitudes (Davis et al., 2015). In this review, changing the name of palliative care and rebranding it as supportive care was a suggestion provided by oncologists to enable integration.

Moreover, palliative care rotation being part of oncology training and palliative care providers having knowledge and skills in oncology were the other changes that could facilitate integration, according to some oncologists. Palliative care participation in multidisciplinary cancer meetings and coordination of care between the two teams can assist integration (Ewert et al., 2016; Nottelmann et al., 2019; Siouta et al., 2016). In this review, oncologists emphasised the need for excellent inter-team communication and palliative care embedded in oncology clinics as a means to achieve integration in addition to having a standardised care pathway contextualised to the region (Kaasa et al., 2018).

3.4.1. Social Exchange Theory as a Framework for Interpreting Review Findings

The referral process is a social action where there is a temporary or permanent sharing of responsibility for patient care between the referrer and the referee (Shortell, 1974). Making a referral is a social behaviour (Shortell, 1974). Social Exchange Theory (SET) is the theorisation of social behaviour (Ekeh, 1974) viewed in terms of social actors interacting to meet their needs in which the purpose of the interaction is to seek reward and avoid cost (Ekeh, 1974). The initial SET proposed by Homans was limited to the task, rewards and cost of interaction (Homans, 1958). However, it was expanded by Blau and Emerson to include power relationships and cognitive perceptions of the social actors (Blau, 1968; Emerson, 1976). Referral behaviour is usually based on the referrer's presuppositions about the referee, the power relationship between the referrer and referee, the task of referral, rewards accrued, costs incurred and equity of relationship (Kinchen et al., 2004). Presuppositions are emotions or feelings, which is an internal response to a social event (Lawler, 2001). Sentiments are affective states of emotion that have an evaluative role and influence social action (Gordon, 2017; Shelly, 2016). Therefore, presuppositions about palliative care referral formed tendencies, which could influence referral behaviour (Collier, 1994; Danermark et al., 2019).

According to SET, the social actor's power and status are considered as key factors determining the nature of exchange (Gordon, 2017). In this review, a few oncologists have requested the palliative care providers to change their name (Rhondali et al., 2013; Wentlandt et al., 2014; Wentlandt et al., 2012). This request to rebrand (Berry et al., 2016) may also suggest a form of power imbalance as few services have conceded to that request (Dalal et al., 2011). Homans focused on the power of reward in social exchange (Homans, 1958). In this

review, the reward of palliative care referral was restricted to roles like pain management and psychosocial support. A study that used SET to understand non-terminal palliative care referral practices for Parkinson's disease patients showed that endorsement of the rewards of palliative care referral by the neurologists was one of the strong predictors of referral (Prizer et al., 2017). The focus of Emerson's modification of SET moved beyond the power of reward into coercive power (Emerson, 1976). Coercive power is the ability to control the negative events or the costs of exchange by the social actors in power advantaged position (Emerson, 1976). Inconsistencies in communication, curtailment of care and the challenges associated with accessing palliative care were perceived negatively by oncologists that hindered future referral.

The review findings pertaining to the stigma of palliative care referral and stigma as a barrier to social exchange were the other perceptions explored using SET. Cook and Emerson's work on SET added cognitive perspectives and social structures as essential components of the exchange (Cook & Emerson, 1978). It also facilitated elucidating the individual and organisational factors in this review hindering palliative care referral. According to Emerson, in an exchange relationship, the power inequalities between the social actors can be balanced by coalition formation, division of labour and network extension (Emerson, 1976). Coalition formation is a mechanism by which a social actor in a less powerful position can gain an advantage through collaboration (Emerson, 1976). In this review, a few oncologists have advocated for an integrated cancer care model where cancer care and palliative care are provided concurrently. Network extension occurs when the less powerful actor balances power by adding new partners to facilitate exchange (Emerson, 1976). The division of labour is where each social actor works according to his skills and specialisation towards fruition

(Emerson, 1976). In this review, oncologists felt that co-management of patients by both disciplines facilitated integration.

This review found that oncologists and haematologists offered some solutions to make this relationship equitable. From a SET perspective, equity in a relationship corresponds to the social actor appraising the rewards and costs of the exchange on the background of sentiments, the intricacy of the tasks and outcomes (Homans, 1958). People explore alternate choices in an inequitable situation, compare the present situations with alternate choices (comparison level for alternatives) and may leave the situation (Ekeh, 1974). However, in this review, oncologists offered strategies to facilitate palliative care referral instead of leaving the relationship. Sometimes people remain in inequitable relationships for reasons that go beyond simple economic logic (Redmond, 2015). For oncologists and haematologists, not referring to palliative care may not be an option, as there are limited alternatives to palliative care for patients with advanced cancer. Therefore, finding equitable solutions can be added to the social exchange theory alongside the comparison level for alternatives (Ekeh, 1974).

3.5. Limitations and Strengths

Three survey studies had a low response rate (Charalambous et al., 2014; Cherny & Catane, 2003; Johnson et al., 2008) which could create a potential response bias as the respondents who completed this survey were those familiar with palliative care. Although they were low response surveys, each of these studies had a significant number of participants who provided views on facilitators and barriers for specialist palliative care referral. Three studies had respiratory physicians, colorectal surgeons, and internists as participants, along with oncologists (Charalambous et al., 2014; Johnson et al., 2008; Smith et al., 2012). Although

some of the participants in these studies were not oncologists by training, their views were included in the review as they were actively involved in the patient's cancer care. Moreover, it wasn't easy to disaggregate their role in these studies. Some studies exploring the views of cancer providers about palliative care referral were excluded (Bakitas et al., 2013; Buckley de Meritens et al., 2017; Centeno et al., 2017; Dalberg et al., 2013; Dalberg et al., 2018; Fadul et al., 2009; Hui, Cerana, et al., 2016; Keim-Malpass et al., 2015; Kirby et al., 2014), as these studies had a heterogeneous mixture of physicians, physician assistants, nurses and social workers. It would not have been possible to disaggregate the physician views from those of the other healthcare providers. The year of publication of the studies included in the review ranged from 2003 to 2019. However, most of the included studies were published in the last five years which may suggest that the findings of the earlier studies may not truly represent contemporary attitudes of oncologists and haematologists towards palliative care referral.

The search strategy, appraisal and synthesis were carried out by two reviewers independently using a systematic review technology platform. The presence of two reviewers enabled the comparison of the search results, identified methodological strengths and weaknesses, and facilitated the synthesis of the findings transparently. Disagreements were resolved by mutual consultation. The search terms were finalised after consulting with the research supervisors and the Lancaster University librarian. Articles included in the review were selected after appraisal, checking for relevance and methodological rigour scoring. The synthesis was conducted systematically according to narrative synthesis steps. Despite a few limitations, the themes derived from the systematic review answered the review question satisfactorily. Findings from the surveys, qualitative studies and mixed methods studies mirrored each other, adding to the strength of the synthesis. The review had a mixed typology

of studies, and the participants had diverse oncology backgrounds, traversing four continents. This heterogeneity added depth to the findings and their generalisability.

3.6. Future Considerations

This review was conducted to inform research on oncologists' and haematologists' views on what facilitates or hinders the referral of a child with cancer to palliative care. The review helped develop the interview topic guide for the research and enabled a comparison of the review findings with the research findings. Although the review was updated before publication (Salins et al., 2020), the revised search did not change the main findings. In this review, paediatric oncologists' perspectives were underrepresented as only two studies included their views (Nyirő et al., 2018; Wentlandt et al., 2014). Palliative care referral in a paediatric oncology setting differs from that of adults due to higher cure potential, better treatment outcomes and socio-cultural factors (Murphy et al., 2013). Therefore, the transferability of review findings with predominantly adult studies to a paediatric setting is challenging. Moreover, two paediatric studies (Nyirő et al., 2018; Wentlandt et al., 2014) were from Hungary and the Canada, and there were no studies from India justifying the need to conduct future research to know the views of paediatric oncologists and haematologists on palliative care referral from an Indian perspective.

3.7. Conclusion

The review findings suggest that some oncologists and haematologists liked to control and coordinate the care of their patients at all stages of illness trajectories and determine the timing of referral. They considered palliative care referral as abandonment, a break in the therapeutic relationship and loss of hope. They also expressed concerns regarding the palliative care providers' professional competency and felt that they had the self-efficacy to manage palliative care needs. Although illness-related factors acted as triggers for palliative care referral, the stigma associated with palliative care, patient and family attitudes, organisational challenges, lack of referral guidelines and limited palliative care resources made referral a daunting task. This review suggests that the majority of oncologists appreciated the pain and symptom management and psychosocial support role of palliative care. Lesser-known roles of palliative care were seldom elucidated. Some oncologists and haematologists felt that palliative care referral comes with a cost due to incongruencies in communication and curtailment of care. They felt that an integrated care model, changing the name of palliative care and augmenting palliative care resources, might facilitate referral. This systematic review was disseminated through a publication in a peer-reviewed journal (Salins et al., 2020). As discussed above, nuanced differences in referral to palliative care in adult and paediatric settings and the lack of Indian studies exploring the paediatric oncologists' views prompted the conduct of this study. The methodology and methods used for this research are discussed in the next chapter.

Chapter 4: Methodology and Methods

4.1. Introduction

The previous chapter on the systematic review provided oncologists' and haematologists' views on palliative care referral in adult and, to some extent, paediatric populations. The PhD research focuses on palliative care in paediatric cancer settings in India and explores oncologists' and haematologists' perspectives about palliative care referral. In this chapter, the research question, philosophical underpinnings, theoretical lens, data collection and analysis methods are discussed. Ethical considerations pertaining to the research methods and how these were addressed conclude this chapter.

4.2. Research Question and Study Objectives

What are the views of oncologists and haematologists of what facilitates or hinders referral of a child with advanced cancer to palliative care in India?

The objectives of the study were

a. To explore oncologists' and haematologists' views about the scope of palliative care in a child with advanced cancer in India.

b. To explore oncologists' and haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.

4.3. Methodology

4.3.1. Philosophical Underpinnings

I work as a full-time palliative care doctor, and in my opinion, palliative care is uniquely placed at an intersection of clinical medicine and humanities (Franke, 2016). I believe that clinical research should have an emancipatory goal where the research inquiry intertwined with a social action agenda has the potential to change the lives of people and the society in which I live and work (Danieli & Woodhams, 2005). Therefore, the transformative paradigm is my research worldview (Mertens, 2008). Moreover, as discussed in the introduction chapter, at my workplace, children with cancer were infrequently referred to palliative care, or were referred late (Ghoshal et al., 2016). The referral practices of paediatric oncologists' drove me to conduct this study in the belief that exploring the facilitators and barriers for referral could inform policies and practice, which might enable more timely access to palliative care.

The purpose of this study was to explain the generative mechanisms causing the referral (Creswell, 2018). The emancipatory purpose of this research was aimed at addressing the power structures, barriers, equity and denial of a right in a marginalised and vulnerable population (Bhaskar, 1978). Therefore, the critical realist paradigm was my philosophical underpinning (Bhaskar, 1978).

Critical realism is a philosophical basis for transformative research (Egbo, 2005). It enables the identification of causal generative mechanisms influencing an event and can bring about an emancipatory social change (Walsh & Evans, 2014). It is the axiological dimension of research, where the value or moral position assumed by the researcher and research informs decision making in the research process (MacDonald, 2004). My axiological standpoint was to

identify the facilitators and barriers for referral that may help mitigate pain and suffering of children with cancer and their families. The purpose of this research was neither to determine effects or outcomes of a referral nor to test a hypothesis or a theory. Therefore, the positivist paradigm was not suitable for this study (Creswell, 2018).

Ontology is concerned with the nature of reality (Guba & Lincoln, 1994). In this study, critical realism is the ontological stance, where reality is viewed as tangible and layered and placed within social and institutional structures (Guba & Lincoln, 1994). Exploring the ontology might enable the identification of some of the generating mechanisms causing the event (McGhee & Grant, 2017). The phenomenon of palliative care referral could have several generative mechanisms causing the event. Some are empirically observed, and some are deeper and hidden, restricting the understanding of the ontology (Bhaskar, 1978). However, the deeper and hidden mechanisms known as actual and real mechanisms in critical realist terms are the preconditions for an event to happen (Danermark et al., 2019). These generative mechanisms may be layered as biological, physical, psychological, social and organisational and a complex interplay between these layers influence the event (Danermark et al., 2019). In the context of palliative care referral in cancer, the biology of cancer, response to treatment, relapse, performance status, personal motivations, prejudices, costs, affordability, hospital policies may form parts of layers influencing referral. Therefore, the nature of reality is stratified (Bhaskar, 1978). In critical realist terms, this is known as stratified ontology (Bhaskar, 1978).

In a critical realist paradigm, ontology is not readily reducible to epistemology (McGhee & Grant, 2017). It supports the "fallibility of knowledge" concept of critical realism, where knowledge about causal mechanisms change with context and time (Danermark et al., 2019).

Therefore, the ontology is not only structured and stratified but changing (Danermark et al., 2019). The goal of this study was to explain empirically observable social events, identify dominant mechanisms, learn about the interplay of the generative mechanisms, analyse and interpret them and discuss the importance of the contextual factors in the interplay of mechanisms. Epistemology refers to the nature of knowledge and how knowledge can be acquired (Crotty, 1998). In this study, the epistemology is subjectivist and transactional (Crotty, 1998). It is subjectivist, as the knowledge about the phenomenon is socially constructed, value-laden human perceptions (Creswell, 2018). It is transactional, as the investigator and participants are interactively linked and closely related to the research setting, which is likely to influence the research inquiry (Creswell, 2018). Therefore, knowledge is co-created with the researcher and participants interacting and exploring the phenomenon together. Some generative mechanisms are empirically observed and may remain unaltered, known as intransitive dimensions, and some are not readily apparent and might change over time, known as an transitive dimension (Bhaskar, 1978). Therefore, the purpose of this research is to explore the emergence, which is, what qualitatively new could be identified from understanding the lower level of reality, explaining the generative mechanisms causing the event (Bunge, 1993).

Friedrich Nietzsche introduced the concept known as perspectivism (Crosby, 2007). Social actors observe something from a particular perspective. They cannot rise above themselves and look at reality as it is. All observations are made from a certain point of view in a particular place (Crosby, 2007). Moreover, there are no transcendental perspectives that exist, which can unearth the phenomenon (Rorty, 1980). Therefore, knowledge is contextual to the socio-politico-cultural features of a region (Owen, 1995).

In critical realism, structure, power, generative mechanisms, and tendencies are the four concepts that form a perspective (Collier, 1994). From the perspective of palliative care referral in cancer, the presence of cancer, its biology, stage of the disease and response to treatment constitutes structure. The virtue of being an oncologist or haematologist constitutes power. The power to refer always exists, even if they are referring or not. The generative mechanisms are the cumulative set of conditions that are required to make the referral. Tendencies are triggers that activate the generative mechanisms. Even when structure and power are set in motion, generative mechanisms may not be triggered as social actors either intentionally or unintentionally choose an alternative (Collier, 1994). Therefore, causality is the power to bring about the change, and the tendency is the potentiality of exercising that power (Danermark et al., 2019). There is already empirically observable knowledge about structure and power. Therefore, this research aims to explore the tendencies facilitating or hindering the generative mechanisms.

One of the concepts of tendency is its transfactual nature (Danermark et al., 2019). Transfactualism means that there is no linear relationship between the generative mechanisms and the actual outcome of the event. Therefore, knowing only the empiric aspects may not explain the causal mechanisms. A transfactual approach aims to look beyond the actual event and identify the generative mechanisms leading up to the event (Danermark et al., 2019). The oncologists and haematologists participating in the study may have different views on palliative care referral when compared to palliative care providers, patients and families. Therefore, it is not possible to establish a linear relationship encompassing the perspectives of all stakeholders. One of the potentials of critical realism is to unpack and understand a complex social phenomenon (Cruickshank, 2002). It is beyond the scope of this

research to understand all generative mechanisms underpinning the referral. Therefore, this study focuses on unpacking only one aspect of the phenomenon, that is, the perspectives of oncologists and haematologists.

Critical realism is a philosophy and not a method, and it does not support any specific method of research (Frauley & Pearce, 2007). It provides a framework that aligns many methods and theories, and the methodological pluralism encouraged by critical realism enables researchers to surpass conflicts in the choice of paradigm (David, 2013). The application of critical realism in data collection and interpretation of study findings are discussed in the subsequent sections.

4.3.2. Theoretical Framework

The critical realist approach starts with a problem or question guided by a theory (Fletcher, 2017). The initial theory used in the study may facilitate a deeper understanding and interpretation of the study findings (Fletcher, 2017). The critical realist approach supports the critical evaluation of theories based on the empiric data, and the study findings may support, reject or modify the theory with explanation (Sayer, 1992). Moreover, critical realism embraces fallibilist epistemology, which means the knowledge of the world as socially constructed is contextual and changes with time (Miller & Tsang, 2011). I am using social exchange theory (SET) as the theoretical framework (Ekeh, 1974). SET has been previously used in a few other studies involving health care referrals (Byrd, 2006; Grembowski et al., 1998; Lamb, 1991; Prizer et al., 2017; Shortell, 1974).

The referral is a social event, and the act of referral can be seen as a social exchange behaviour (Prizer et al., 2017). Social exchange was first defined as a barter of assistances (Ekeh, 1974). The term barter in this context moved away from a commercial commodity to a non-utilitarian social behaviour, which means sentiments and efforts associated with the task were considered as necessary as the value of the task. However, sociologists subsequently describing SET in the 20th century described the social exchange process in terms of economic motives (Ekeh, 1974). As this research focuses on the social behaviour of individuals or groups of individuals, the discussion is restricted to individualistic SET (Blau, 1968; Homans, 1958). Homans was the first to introduce individualistic SET, which was adapted by other sociologists (Blau, 1968; Emerson, 1976; Homans, 1958; Thibaut & Kelley, 2008).

The social exchange process has eight aspects: sentiment, interaction, task, reward, cost, profit, value and comparison level (Ekeh, 1974). They are discussed in detail in **Table 4.1**. The application of these aspects of the social exchange process to the literature review was discussed in chapter three, and its application to this study is discussed in chapter six.

Table 4.1. Aspects of Social Exchange Theory

Sl. No	Aspect	Description
1	Sentiment	Sentiments are the views and attitudes of one social actor towards another involved in the exchange (Lawler & Thye, 2006). Presuppositions, power and motivation are the common social exchange sentiments (Chadwick-Jones, 1976). Presuppositions are a preformed notion about the exchange or the persons involved in the exchange based on previous experiences, knowledge or biases (Chadwick-Jones, 1976). Power in social exchange is linked to the social actor's virtues in the society or situation and depends upon another person's dependency on the social actor (Emerson, 1976). Therefore, it creates a power dependency relationship (Emerson, 1976). Motivation is the desire of the social actor to achieve something of value that is closely associated with the satisfaction of achieving it (Gergen et al., 1980).
2	Task	The task corresponds to the effort required to achieve an activity. Structural and contextual conditions determine the efforts needed to accomplish the task (Cropanzano et al., 2017). Moreover, emotions triggered by the task activities also determine the person's involvement in the task (Lawler & Thye, 2006). Therefore, the jointness of exchange does not only depends upon the reward of the exchange but also on the structural and contextual conditions constraining or enabling the task and the emotions triggered by it (Lawler & Thye, 2006).
3	Interaction	Interaction relates to the process of exchange (Chadwick-Jones, 1976). There are three kinds of exchange. The trade exchange is purely in terms of economic gains and losses, and the power exchange is hierarchical, where there is limited choice and freedom to the persons participating in the exchange (Chadwick-Jones, 1976). As the act of referral is a social behaviour (Shortell, 1974), in this research, I am focusing on the behavioural exchange, where the relationships are voluntary and interdependent, and behaviours act as tendencies in the exchange process (Gergen et al., 1980). The person participating in the exchange takes into account the task, reward and cost of interacting and will continue to interact if the interaction is in alignment with the person's expected outcomes (Gergen et al., 1980).
4	Reward	The rewards are the benefits of exchange. In the social exchange, rewards are discussed in terms of a person's gains and its influence on the exchange process (Blau, 1968; Homans, 1958). There are several dimensions to the reward. Immediate rewards are based on the behavioural choices associated with a single event or an outcome. In contrast, long-term rewards are relational rewards based on the long-term association of social actors and cumulative outcomes of interaction (Gergen et al., 1980). Anticipatory rewards are the potential future rewards expected by the person in the exchange process (Gergen et al., 1980). Rewards are a form of reinforcement, and social relationships cease to exist unless the exchange reinforces the person's expectations (Ekeh, 1974).
5	Cost	Cost in social exchange corresponds to the negative effects or losses sustained during achieving the reward (Blau, 1968; Emerson, 1976). When costs involved in achieving the reward are high, then there is less chance of a person taking up the task (Emerson, 1976). The person's decision to

6	Profit	Profit relates to a person's expectation of rewards and the costs incurred in the process. Moreover, in a social exchange, the proportion of rewards to the costs should be a fair process (Blau, 1968; Emerson, 1976).
7	Value	Value means not just the assessment of profit due to interaction but the feelings of satisfaction achieved by doing that activity (Chadwick-Jones, 1976). The value associated with doing an activity and the sentiments the person gets from another person during the process of activity determines the long-term association with the activity (Chadwick-Jones, 1976). The person continues to do the activity even if the activity does not bring profit if it provides satisfaction and adds value (Gergen et al., 1980).
8	Comparison Level	Comparison level is the standard against which the social actor measures the utility of the rewards (Thibaut & Kelley, 2008). The standard could be based on the previous or current experience of rewards and alternate choices that are available (Thibaut & Kelley, 2008). This perception is based not just on the magnitude of immediate rewards but also on the cumulative slope of the reward (Chadwick-Jones, 1976). Therefore, one activity or an outcome of a single palliative referral is unlikely to make a person choose an alternative or influence the referral behaviour (Chadwick-Jones, 1976). If the cumulative perception is negative and an alternative is more profitable, then the person may choose to terminate the relationship and choose the alternative (Chadwick-Jones, 1976; Thibaut & Kelley, 2008).

4.3.3. Qualitative Approach

The choice of research paradigm depends on the researcher's personal beliefs and values, goals of the research, research question, research environment and practical considerations (Proctor, 1998). As discussed earlier in this chapter, children with advanced cancer are referred late by oncologists. Through this research, I would like to explore oncologists' and haematologists' views about palliative care underpinning this behaviour. Their perspectives on the phenomenon of referral of a child with advanced cancer to palliative care in India are not known a priori. There are no studies from India exploring the study research question and, as such, is a new area of social science research contextual to the Indian paediatric oncology setting that explores the human behaviour of referral (Teherani et al., 2015).

Moreover, contextual new knowledge built from the data is not limited to a collation of observations but involves active co-creation of knowledge between participants and the researcher, its interpretation, theorising and modelling (Teherani et al., 2015). The participants' subjective interpretation is explored, clarified and discussed by the researcher having a personal knowledge of the social context where the data is collected (Brett, 1993). The researcher's beliefs, assumptions and theory influence data collection and interpretation, and the researcher's own background, history and social context cannot be separated from the research (Brett, 1993). Moreover, knowledge in this research setting cannot be free of human beliefs and is best understood through the lens of humans participating in the phenomenon and the researcher interpreting the participant's perspectives (Willis, 2007). Therefore, a qualitative approach was considered appropriate for this research.

Qualitative research also allows participants to offer rich descriptions of the phenomenon and the researcher to explore their meaning, which may not be possible by a pre-framed questionnaire in a quantitative approach (Creswell, 2018). Furthermore, the qualitative approach facilitates the creation of a three-way partnership between participants, researchers and audience (Brett, 1993). While writing a research report, unlike quantitative studies, participants are not passive and invisible. The descriptive narration and participant's quotes connect the participants with the audience, and the audience's understanding and interpretation contribute to the final shaping of research findings (Brett, 1993). A person reading a qualitative research paper not only has access to the researcher's elucidation of data but also to the participant's quotes that underpinned the interpretation (Brett, 1993). Although the critical realist paradigm is generally associated with mixed-methods research, it has a place in qualitative research that facilitates identifying causal processes and providing

a contextual explanation of them, which is one of the aims of this study (Gornall, 2013). The qualitative approach within a critical realist paradigm enables the exploration of a deeper causal process at work, constructs a model of possible mechanisms using a theoretical framework, and interprets the identified patterns in the data (Fletcher, 2017).

4.4. Methods

4.4.1. Setting

The study was conducted across various cancer centres in India. The sites were selected based on three essential criteria: a. Sites where paediatric oncology and haematology services were offered, b. availability of oncologists and haematologists managing children with cancer and c. availability of palliative care services. The majority of cancer centres participating in this study were situated in urban cities, except for two situated in semi-urban contexts.

4.4.2. Participants

The inclusion and exclusion criteria of the research participants is provided in **Table 4.2**.

Table 4.2. Selection Criteria of Study Participants

	Inclusion	Exclusion
Participants	Paediatric oncologists and paediatric haematologists Adult medical oncologists and adult haematologists if 25% of their clinical practice involved treating children with either solid or haematological malignancy Consultant level practice	Trainee oncologists and haematologists Radiation and surgical oncologists
Setting	Cancer hospitals or tertiary hospitals with cancer care services Have access to palliative care services	Private oncology and haematology consulting suites without inpatient facility situated outside a hospital setting. Hospital where the researcher is working

4.4.3. Sampling and Sample Size

Eligible oncologists and haematologists were purposively identified and invited to participate. Purposive sampling facilitates identifying those participants who will be able to provide detailed, reliable and insightful information about the phenomenon (Patton, 2007). Adherence to the inclusion and exclusion criteria **(Table 4.2)** during sampling enabled homogeneity of the participant's perspectives (Patton, 2007). Adopting saturation as the generic quality marker for sample size determination in other methodologies and methods has been challenged (O'Reilly & Parker, 2012). In a thematic analysis, it is estimated that twelve interviews identify 92% of the codes and new codes were seldom found beyond twenty interviews (Guest et al., 2006). According to Braun and Clarke, for a large research project that involves understanding and perceptions, the estimated number of interviews needed is around twenty (Braun & Clarke, 2013). The reflexive thematic analysis relies on the researcher's subjectivity, depth of engagement and reflexive interpretation (Braun et al., 2019). Therefore, this may not align with the concept of data saturation or information

redundancy, meaning no new information could be sought (Braun & Clarke, 2021). Provisional sample size could only be guesstimated, suggesting that the sample is adequate to narrate a rich, complex and multi-faceted story of the phenomenon explored (Braun & Clarke, 2021). Moreover, the notion of no new information forthcoming contradicts the fallibility of knowledge concept of critical realism, where the knowledge about the phenomenon is dynamic and changes with context and time (Danermark et al., 2019). I had permission from the institutional ethics committee to recruit up to 24 participants.

4.4.4. Research Recruitment

The potential list of study participants was identified through professional societies. A bulk email was sent to the secretaries of:

a. Paediatric Haematology and Oncology Chapter of the Indian Association of Paediatrics

b. Indian Paediatric Oncology

c. Indian Cooperative Oncology Network and

d. Indian Society of Paediatric and Medical Oncology.

The secretaries of these professional societies bulk emailed the potential participants a flyer **(Appendix 4.1)** and the expression of interest form **(Appendix 4.2)**. The participant information sheet (PIS) **(Appendix 4.3)** was sent to the participants returning the completed expression of interest form by email or post. The research flyer and the expression of interest forms were also placed at the registration desks of two annual paediatric haematology and oncology conferences in 2018 and 2019 and two paediatric oncology state meetings. A bulk email with an expression of interest form was sent to around 300 cancer centres on "contact us" email addresses requesting them to display the flyer on the hospital notice board. My department secretary acted as the liaison between the research participants and me. The

interested parties were given a week to consider participation. After a week, the liaison contacted the participants by email to invite their response. If they were willing to participate, the liaison scheduled the research appointments at a date and time mutually convenient to both researcher and participants. Two copies of the informed consent form (ICF) **(Appendix 4.4)** were completed before the interview. All participants received one copy of the signed ICF to keep.

All initial communications were through email, and I did not attempt to contact the participants directly. However, if the participants needed more information about the study, the liaison scheduled a meeting via telephone to answer participants' questions. Non-responders received a reminder email and one telephone reminder from the liaison after a fortnight. If they did not respond to the reminders, it was assumed that they did not wish to participate, and they were not contacted again. Among the 41 potential participants initially expressing interest to participate, 16 participants did not respond after the PIS was sent. Three participants who agreed to participate cancelled the research interview later. No oncologists or haematologists for the study were recruited from the cancer centre where I was working in order to avoid any conflicts of interest in the study due to ongoing collegial relationships with the participants (McDermid et al., 2014). However, I had interacted with some of the participants before at oncology conferences. I have reflected on the implications of these in chapter six.

Research recruitment was a laborious process, as the research participants were scattered across India. As all the interviews were conducted face to face, I had to make nine trips by flight and two trips by road to conduct the interviews. Although many participants had

expressed interest, the liaison found it challenging to arrange appointments for a research interview. As I worked as a full-time consultant in a hospital, I found it very difficult to match the research appointments and my work commitments. I did not choose telephone or video interviews for data collection due to challenges associated with scheduling virtual meetings in the pre-covid era. Moreover, I feared call interruptions, shorter and shallow interviews.

4.4.5. Data Collection

Research data were collected through individual, face to face, semi-structured qualitative interviews. Semi-structured interviews conducted using an interview topic guide enables optimum use of interview time and facilitates the exploration of the phenomenon systematically and comprehensively (Jamshed, 2014). It also helps the interview to remain focused on the research question and allows interview data to be captured effectively (Jamshed, 2014). In a research setting, interviews are conversations with a purpose (Berg, 1995). The setting is formal, and the interviewer will use the information obtained as data (Johnson, 2002). Therefore, ethical considerations like consent and confidentiality apply to research interviews, which is discussed further in section 4.5 (Smith, 1992). Interviews were the chosen method for data collection as these are effective in getting detailed information from the participants on the phenomenon researched (Boyce & Neale, 2006) and facilitates the expression of deeper information about their views, lived experiences, ideologies, values and decisions about the phenomenon (Johnson, 2002).

Critical realism perspectives were used for the formulation of the semi-structured interview topic guide and conducting the interviews. The critical realist paradigm focuses on ontological depth and knowing the multi-layered nature of social reality and the intertwined generative

mechanisms within these layers, causing a social event (Pawson, 1996). Critical realism interviews share ground with the interpretivist paradigm recognising the significance of the social construction of reality (Smith & Elger, 2014). However, from a critical realist point of view, social events happen in the context of pre-existing structures and social relationships, which has both facilitating and hindering implications on the causation of the event (Elder-Vass, 2010). As discussed earlier, illness-related factors form the structure, and the referrer-referee association is the social relationship. Therefore, the focus of the interviews was to collectively explore the participant's interpretations and my interpretations about the facilitators and barriers for palliative care referral (Smith & Elger, 2014).

The initial set of questions in the semi-structured interview topic guide (**Appendix 4.5**) were about the work and challenges faced by the oncologists and haematologists which helped in establishing the social context that is the practice in the Indian paediatric oncology setting. The next set of questions focused on the scope of referral, the experience of accessing palliative care services, views on referral and facilitators and barriers for a referral. Probes mainly focused on the decision-making process, attitudes, motives and emotions of the participants. The last set of questions were "recollect and reflect" questions where the participants were asked to recollect a positive and a negative critical incident and were reflectively probed to know the participant's interpretation of the meaning of the experience and how these experiences may constrain and enable the social event.

The interview topic guide was initially formulated in consultation with two paediatric oncologists and parents of two children with advanced cancer. Subsequently, two pilot interviews were conducted using this initial interview topic guide, and it was further modified

in consultation with the research supervisors. Over the next few interviews, I found that question five on the experience of working with palliative care was becoming redundant as most of the participants answered in response to question four on accessing palliative care services. Similarly, questions seven and eight were becoming redundant as participants answered these along with question three and six dealing with the scope of palliative care referral and views on referral. I did not find a need to add new questions to the interview topic guide.

Critical realism interviews are theory-driven (Pawson, 1996). The researcher has expertise in the subject, understands the context, and has his own views about the generative mechanisms and the social event (Smith & Elger, 2014). The researcher's expertise facilitates exploring the explanatory mechanisms discussed by the participants that focus on motivations, reasoning, attitudes, choices and decision-making (Smith & Elger, 2014). Therefore, the researcher's theory and participant's view facilitated the co-creation of knowledge during research interviews. In this study, I have more than twelve years of experience in paediatric palliative oncology and a fair understanding of the context and referral practices. My scholarship in the field helped me to know the deeper generative mechanisms from the perspective of the participants. However, I was mindful not to overbear the participants with my own agenda and biases, and at the same time, not alienate the research participants (Smith & Elger, 2014). Being reflexive during the interviewing enabled me to clarify and elaborate on participants' views, which facilitated a collective understanding of participants' perspectives and experiences (Pessoa et al., 2019).

The face-to-face interviews were conducted in a private environment at the premises of the participant's hospital. Before commencing the interview, participants were given time to reread the PIS, and I answered any questions and explained the purpose and scope of the research. Two copies of ICF were completed and one copy of the ICF remained with the participant.

Participants were informed that the findings of the individual interviews would be kept confidential and any identifying information from the transcripts or any direct quotes from the participant revealing the identity of the participant will be removed from the thesis and future publications (Loukides et al., 2010). The participants were advised that during the interview, if they provided any confidential or dangerous information about their patients, peers or institution, then I would have to override the confidentiality clause and inform appropriate authorities (Surmiak, 2019). Participants were advised that if they felt upset during the interview, I would stop the interview and initiate the distress protocol (Haigh & Witham, 2013). The distress protocol used in this study is provided in **Appendix 4.6** and was initiated twice during this study (discussed further in section 4.5 and chapter 6). If the participant or I felt that the participant needed additional help, they were encouraged to access their hospital staff physician who could initiate a referral to the hospital clinical psychology services, if required.

Most of the audio recordings were between 45 to 60 minutes, except for four interviews where the interview duration was between 60 to 90 minutes. During the interview, I made brief comments in the interview notebook. The majority of these comments turned into probe questions, and a few observations made during the interview became part of data

analysis as memos. This helped me to log my subjectivity and recognise some broad patterns while familiarising myself with the data. After the research interview, a debrief session was conducted with participants. During this session, the participants were asked about their interview experience. They were provided with an opportunity to add extra information and clarify their remarks made during the interview. Although the participants seldom clarified their remarks during debriefing, most felt that the interview was a cathartic experience. Some felt light and good after the interview as they had an opportunity to express some of their bottled-up feelings. Participants were informed about the management of the interview data and thanked for their participation. They were told that if they had to add anything further, they could contact me using the contact details provided in the PIS. However, no participants did so.

Immediately after the interview, I spent some time making field notes and documented some of my initial thoughts and reflections. This information was useful during data analysis and in contextualising the information during the interpretation of findings. All the audio recordings were transcribed verbatim into a word document, encrypted and stored safely in a password-protected laptop. Audio files and interview files were alphanumerically coded, and the master sheet linking the participants and interview data was separated and stored securely. Audio files were deleted from the recorder after transcription.

I am aware that by working in paediatric palliative care, I may have personal views and presuppositions that may skew data collection, analysis and interpretation of study findings (Dodgson, 2019). I maintained a log of my thoughts and personal viewpoints as a reflective journal, which is provided as a summary in **Table 4.3** (McCabe & Holmes, 2009). This helped

me to have an open mind during interviews and data analysis. However, it is not possible to know and record the subconscious and unconscious processes about the phenomenon explored, and perhaps these may have had an influence. An illustration of the intrusion of my subjectivity during the study interview is provided in **Table 4.4**.

Table 4.3. Subjectivity Statement

As a palliative care physician, I work at the intersection of paediatric oncology and palliative care.

A significantly higher number of children with cancer need palliative care compared to those referred

Children with cancer are infrequently referred to palliative care or referred late, often after completion of all cancer-directed treatment or at the end of life.

Children and their families referred to palliative care have poorly controlled physical symptoms and unaddressed psychosocial distress, which is often unrecognised by the referring oncologists.

Oncologists and haematologists gatekeep the referral process.

A timely palliative care referral could mitigate physical symptoms and address psychosocial issues of children and their families.

Children with cancer are vulnerable, and they are unable to voice their need for help.

Families of children with cancer in India are not empowered to demand a palliative and supportive care referral for their children.

Voices of children and their families are lost in the busy cancer management practice, where the disease gets more attention than the person and their families having the illness.

A hierarchical power relationship exists between oncologists and palliative care providers, where oncologists feel that they are superior.

Oncologists feel palliative care referral as failure to cure and often feel bad about it.

Palliative care services are still not considered essential service in a cancer centre. Therefore, the majority of cancer centres in India lack the capacity to deliver palliative care.

Some oncologists with whom I have worked were hesitant to use the word "palliative", "terminal", or "end of life". They preferred "integrative oncology" and "supportive care"

Oncologists have a limited understanding of the scope of palliative care. It is often equated to pain management and counselling.

Palliative care providers have a minimal role in child's cancer treatment decision-making during joint clinics and tumour board meetings.

Table 4.4. Illustration of Intrusion of Researcher's Subjectivity during Study Interviews

<div style="border:1px solid black">

Illustration 1:

Participant: The only disadvantage I can see is the naming…because the patient feels that you are already in the last stage… so that's why it's better to get them as symptom control.

In this section of the interview, I probably started to think that this is another oncologist who has a limited understanding of the scope of palliative care and has a problem with its nomenclature.

Illustration 2:

Participant: we need to hand them (children) over to trained specialists who can do a better job… multiple bad experiences that I am seeing… the palliative care department people need training…

During this interview section, I was thinking that I am dealing with an oncologist who clearly thinks that they are better qualified, trained and experienced than palliative care providers and the power dynamics that exist are becoming more apparent.

</div>

4.4.6. Data Analysis

Research data were analysed using Braun and Clarke's Reflexive Thematic Analysis method (Braun et al., 2019). This reflexive approach allows for the researcher's subjectivity as a resource during data analysis (Braun et al., 2019). It enabled me to use my paediatric palliative oncology experience while exploring the phenomenon of palliative care referral and permitted me to maintain an active role in the knowledge creation process. In a reflexive approach, themes are meaning-based patterns, conceptualised and analysed by the researcher and not merely a superficial summary of the data. It involves the significant critical engagement of the researcher with the dataset, where the researcher is actively interpreting the data through the lens of his or her scholarly knowledge, socio-cultural view, ideology and theoretical suppositions. Furthermore, reflexive thematic analysis is often associated with social justice motivated research, which is coherent with my philosophical underpinning and research motivation (Braun et al., 2019).

Although reflexive thematic analysis outlines a systematic six-step approach for qualitative data analysis in social sciences, it is a recursive and reflexive process and not a linear approach (Braun & Clarke, 2006, 2013; Braun et al., 2019). Thematic analysis is a data-analysis method, which is independent of ontology, epistemology and theoretical frameworks (Braun & Clarke, 2006). The reflexive thematic analysis is a recent development of the original method that allows researchers to incorporate their subjectivity and locate a theoretical and interpretative framework for analysis (Braun et al., 2019).

The first analytic step is to become thoroughly familiar with the interview data (Braun & Clarke, 2006; Braun et al., 2019). I listened to each interview recording and read its corresponding transcripts simultaneously many times. The purpose was to be familiar with the entire dataset. I transcribed the interviews myself, and the exercise of listening to the audiotapes and transcribing facilitated familiarisation. While reading and listening, I made notes on certain observations that were relevant to the research questions **(Appendix 4.7)**. These observations were used in data analysis. All interviews were in English as it is the professional language of medicine in India.

The second step involves generating codes (Braun & Clarke, 2006; Braun et al., 2019). All interview transcripts were uploaded to the NVivo software version 12.6.0 for Mac, and the coding was done using the NVivo software. In this step, all data relevant to the research question were identified and coded. Transcripts were coded line by line, and the initial codes created were data-driven or semantic. It means that the code stays very close to the semantic meaning of the data and does not include any researcher's interpretation. An example of the line-by-line semantic coding of one participant's entire transcript is provided in **Appendix 4.8**.

Initial coding was followed by latent coding, where a deeper or conceptual level meaning was identified. The dataset had a combination of both semantic and latent codes.

The third step is to construct themes (Braun & Clarke, 2006; Braun et al., 2019). Codes across the datasets were examined for broad patterns, and similar codes (called nodes in NVivo) were collapsed together to create a higher code (top-level node) in NVivo software. A set of these higher codes (top-level nodes) were further collapsed as a candidate theme. The candidate theme represented a central organising concept **(Appendix 4.9)**, which is a meaningful aspect of the data in relation to the research question (Braun & Clarke, 2013). It aims to capture the intersection of research data, research question and researcher's subjectivity (Braun et al., 2019).

The fourth step in reflexive thematic analysis requires a review of the themes (Braun & Clarke, 2006; Braun et al., 2019). Candidate themes were examined to see if they have sufficient data to support the theme. A few candidate themes collapsed, and some merged to form a new candidate theme. The candidate themes were also scrutinised for coherence between themes, codes and the coded extract (Braun & Clarke, 2013). Candidate themes were organised as a thematic map with main themes and subthemes represented.

The fifth step is to define and name the themes (Braun & Clarke, 2006; Braun et al., 2019). Each theme was defined succinctly in terms of its focus, purpose and boundaries (Braun & Clarke, 2013). This step facilitated creating a rich and meaningful picture of a set of broad patterns identified within that theme. Each theme was labelled with a unique name, a short phrase representing its content and interpretation (Braun & Clarke, 2013).

The final sixth step is writing up the research data analysis as a report (Braun & Clarke, 2006; Braun et al., 2019). Information about the themes generated in this research is textually narrated and visually represented. Codes and excerpts from the transcript support the nuanced story of each theme, and each theme is described in detail for its meaning and relevance to the research question (Braun & Clarke, 2013). The detailed report of research data analysis can be found in chapter five.

NVivo software allowed me to write a description to a code (node) and add a memo. The memos were remarks about my thoughts and observations during coding, which aided data analysis. Moreover, adding a description to some codes during coding helped me capture an initial opinion about the codes and the candidate themes.

The data analysis process was checked using a 15-point checklist of criteria for good thematic analysis, which is provided in **Appendix 4.10** (Braun & Clarke, 2006).

4.5. Ethical Considerations

As the study was conducted in India, it was initially approved by the Kasturba Medical College and Kasturba Hospital Institution Ethics Committee (IEC) on 09/05/2018 for two years **(Appendix 4.11)**. As it involved recruiting participants across India, it was prospectively registered with the Clinical Trials Registry of India (CTRI) on 04/06/2018 **(Appendix 4.12)**. Secondary ethics approval was sought from the Faculty of Health and Medicine Research Ethics Committee (FHMREC) of Lancaster University on 05/06/2018 **(Appendix 4.13)**. The first participant was recruited on 13/07/2018, and the last one was on 28/01/2020.

In this research, I followed the ethical framework developed by the Economic and Social Research Council, UK (Economic and Social Research Council, 2015). The first step was to know if the research is beneficial and for whom (Ramcharan & Cutcliffe, 2001). The research concept was discussed with two stakeholder groups. First, the study proposal was presented in the paediatric oncology disease management group meeting and then discussed with several parents during a paediatric cancer support group meeting. Both stakeholders felt that it was a beneficial topic with the potential to change practices and will help children and families with advanced cancer.

After ethics approval, clinical research ethics governance arrangements were made (Shaw et al., 2005) through the hospital research ethics committee and had two onsite monitoring meetings in two years. Research progress reports were submitted every six months to the CTRI. Moreover, my research supervisors monitored the research progress through monthly supervision.

During the recruitment phase, care was taken not to recruit any participants that I was working with. Interviewing participants who are peers and having a collegial relationship can be challenging due to my dual role in the interview context. Presuppositions, pre-existing relationships, and emotions can influence study interviews (McDermid et al., 2014; Quinney et al., 2016). Participants may not be open about their views, and may feel confronted and challenged (Quinney et al., 2016). Moreover, I did not make any direct contact with the participant before the interview. All communications to the participants were through the liaison designated for the study.

The autonomy of the research participant was ensured by the complete disclosure of information about the study. All participants received a detailed PIS, which consisted of a standard set of statements ratifying the rights of the research participants (Steinke, 2004). It provided a summary and purpose of the study, the nature of participation, and its risks and benefits. The PIS also had the name and details of the investigators, details of the IEC secretariat and name and contact details of the person to contact if they would like to complain or raise issues about the study. Participants received the PIS at least a week before the study, which allowed them to have sufficient time to decide before consenting (Bergler et al., 1980). Before consenting, the participants were told that the participation was voluntary and they could withdraw anytime during the study period (Hammer, 2016).

It is essential to maintain research participants' confidentiality and anonymity (Wiles et al., 2008). Participants were advised that any information provided by them would not be disclosed to anyone, and quotes disclosing their identities would be anonymised from the transcripts, thesis and future publications. The participants were informed about the process of research data management in detail. All audio files and transcript word files were encrypted and stored in a password protected laptop only accessed by me. All audio and interview transcripts were alphanumerically coded, and an identifying master sheet was stored separately and securely. After completing the research, the research data is stored securely at my IEC in India for five years, after which it will be destroyed as per the IEC regulations.

One of the significant ethical concerns in research is to avoid harm to the research participants. Qualitative interviews, while exploring sensitive topics, can cause distress among

the research participants (Kavanaugh & Ayres, 1998). In this study, the purpose was to explore palliative care referral practices in children with advanced cancer. The interviews involved recounting stories about children dying and the grief of their parents. It is a sensitive topic, and the research participants were forewarned that discussion around these topics could cause distress (Corbin & Morse, 2003). Participants were told that during the research interview process, if they felt upset or distressed, the research interview would be stopped immediately, and I would talk to them about their distress. Moreover, they would be advised to see their hospital staff physician, who may refer them to a clinical psychologist.

Two participants felt distressed during the research interviews, and the distress protocol was initiated **(Appendix 4.6)**. One participant became distressed while recounting a story about a child's mother ending her life after her child's death. The other participant became upset while recounting her stressful experience of dealing with a string of deaths at the hospital and the countertransference of these experiences to her home environment. In both these interviews, I stopped the interview and initiated the stage one response of the distress protocol **(Appendix 4.6)**. Adequate time was provided to the participant to express their feelings and compose themselves. On both occasions, we moved out of the room to the café for a break, and I asked the participants about their plan for the day and how will they manage themselves. I have experience of handling distress from my years of working the patients. I had a conversation with the participant exploring some of their emotional concerns. After the break, both participants wanted to resume the interview. After the interview, both participants expressed that they never imagined that they had so many bottled-up feelings inside. One volunteered to see the clinical psychology team, and the other said that she would

see the psychiatry liaison of the psycho-oncology team. I have discussed the emotional impact of conducting study interviews on myself in chapter six.

Costs to the participants and disclosures of sources of funding are important ethical concerns. The research interviews were conducted at the participant's workplace. There were no costs involved for the participants for research participation. Moreover, I ensured minimal disruption of the clinical services by scheduling the research appointments at the start or end of the day. The participants were not compensated in any way for their participation. They will be duly acknowledged in the thesis and publications without names.

4.6. Conclusion

In this chapter, the rationale for choosing the research paradigm, theory, data collection methods and data analysis was discussed. The critical realist paradigm facilitates inquiry into the generative mechanisms underpinning the palliative care referral phenomenon (Danermark et al., 2019). Social exchange theory was previously used in the literature review to explore referral in a healthcare setting, and it facilitates the interpretation of the study findings (Ekeh, 1974). A qualitative approach is used as the phenomenon explored in this research has not been studied before in the Indian context (Creswell, 2018). Qualitative interviews are considered the most appropriate method for data collection as these facilitates focused enquiry of the perspectives, practices, motivations and emotions of the research participants (Jamshed, 2014). Reflexive thematic analysis allows researcher's subjectivity as a resource and enables an iterative process to develop a conceptual and contextual meaning of the phenomenon explored (Braun et al., 2019). The study findings are discussed in the next chapter.

Chapter 5: Research Findings

5.1. Introduction

In this chapter, the key findings of the study, identified during data analysis as themes and subthemes, are presented. The study's focus was to explore the views of oncologists and haematologists on what facilitated and hindered the referral of a child with advanced cancer to palliative care in India. Oncologists and haematologists managing children with cancer were the research participants. The research participants participated in qualitative interviews, and data were analysed using reflexive thematic analysis (Braun et al., 2019).

Section 5.2 provides demographic descriptions of the research participants. Section 5.3 describes the four themes and their subthemes generated during the thematic analysis of the data. The four themes developed were: 1) presuppositions about palliative care and palliative care referral, 2) the task of making a palliative care referral, 3) cost-benefits of making a palliative care referral, and 4) strategies for developing an integrated palliative care model in paediatric oncology.

5.2. Demographics of the Participants

Twenty-two eligible oncologists and haematologists managing children with cancer were purposively recruited from 13 tertiary cancer centres traversing seven cities in India. All participants were working in paediatric cancer units as consultants in paediatric oncology or haematology. Twenty participants practised both paediatric solid tumour oncology and paediatric haemato-oncology, and two participants practised only paediatric haemato-oncology. Fifteen participants were men, and seven, women. The participant's experience as

a consultant ranged from 1 to 19 years. Among the participants, ten completed their specialist paediatric oncology training in India, nine in the UK and one each from Australia, Singapore and the USA. All overseas trained participants had practised in India as a consultant for a minimum period of five years. Despite varying lengths of practice at a consultant level, it was a relatively homogenous group of paediatric oncologists and haematologists, who had in-depth, insightful information about the phenomenon explored. Moreover, the participants were not limited to a single cancer centre or geographic location.

The participants' names were alphaneumerically coded, and their name and place of work were kept confidential. A detailed description of the participants can be found in **Table 5.1**.

Table 5.1. Description of the Research Participants

Participant	Gender	Area of Specialisation		Oncology Training Site	Number of years as a consultant in India at the time of interview
		Paediatric Solid Tumours	Paediatric Haemato-Oncology		
P001	Male	Yes	Yes	UK	10
P002	Male	Yes	Yes	UK	12
P003	Female	Yes	Yes	India	3
P004	Male	Yes	Yes	India	1
P005	Male	Yes	Yes	India	2
P006	Male	Yes	Yes	UK	6
P007	Female	Yes	Yes	UK	19
P008	Male	Yes	Yes	UK	6
P009	Male	Yes	Yes	UK	10
P010	Male	Yes	Yes	UK	16
P011	Female	Yes	Yes	India	11
P012	Male	Yes	Yes	India	5
P013	Male	Yes	Yes	India	2
P014	Male	Yes	Yes	India	5
P015	Male	Yes	Yes	UK	6
P016	Female	No	Yes	India	1
P017	Male	Yes	Yes	Singapore	5
P018	Female	Yes	Yes	India	4
P019	Male	Yes	Yes	UK	8
P020	Male	Yes	Yes	Australia	7
P021	Female	Yes	Yes	USA	12
P022	Female	No	Yes	India	1

Figure 5.1. Thematic Map of the Research Findings
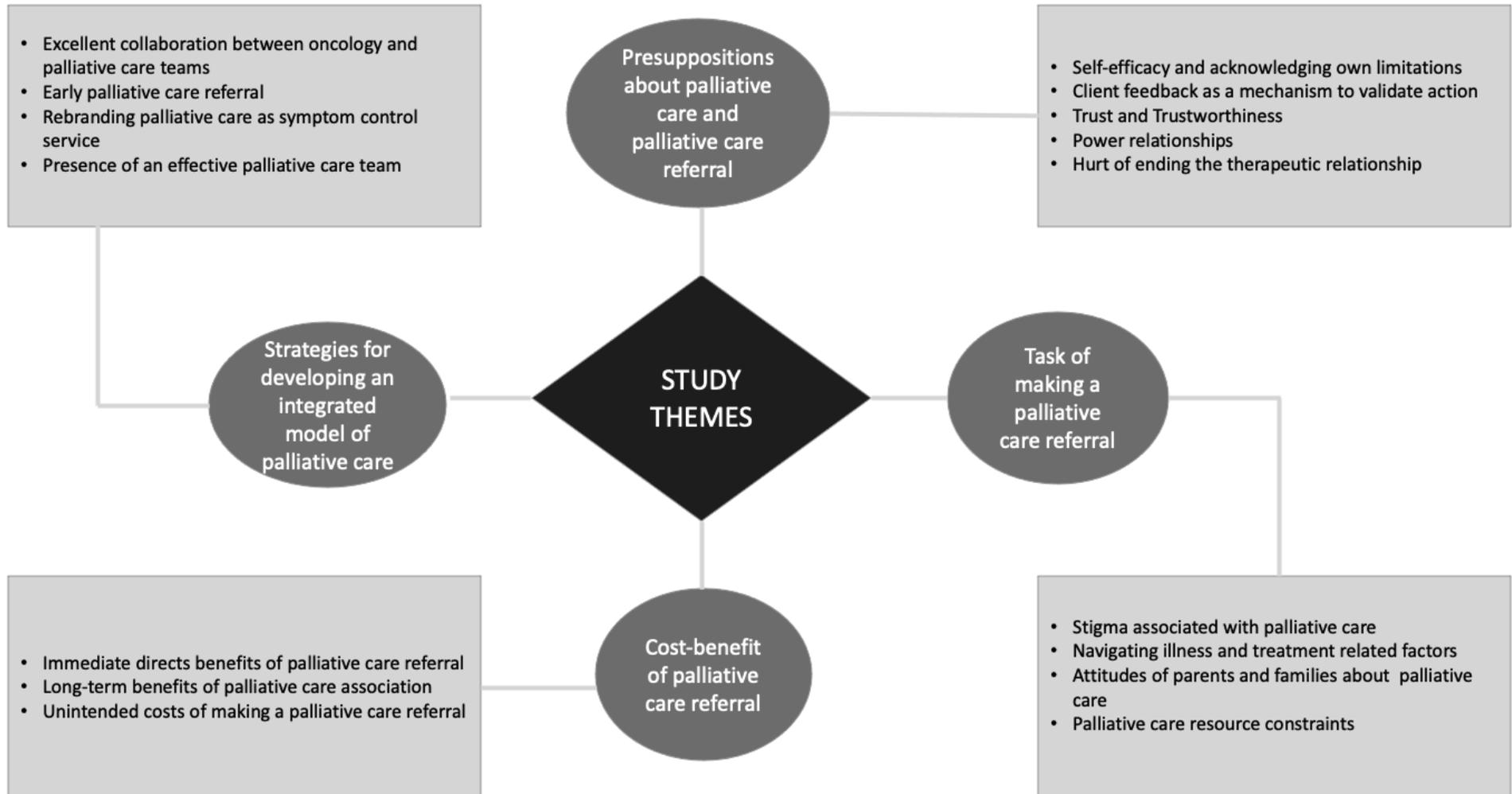
5.3. Study Themes

The four themes were generated during data analysis. All study themes and subthemes were inductively developed from the study findings. The study themes are not imposed on the themes or subthemes generated from the synthesis of literature review findings. The social exchange theory (Ekeh, 1974) was used as the theoretical framework for the interpreting review and study findings. Reflexive thematic analysis method (Braun et al., 2019) recommend using a theoretical framework for the interpretation of review and study findings. Although the main themes of literature review and study appear similar, the subthemes, review and study findings informing them differed. The study themes are represented as a thematic map in **Figure 5.1.**

Apart from using the social exchange theory (Ekeh, 1974) to describe the study findings, from a critical realist perspective, the study findings can also be described as various layers of generative mechanisms (Bhaskar, 1978). In chapter six, section 6.2.1, the study findings are represented as layers of stratified ontology.

5.3.1. Theme 1: Presuppositions about Palliative Care and Palliative Care Referral

In this theme, the presuppositions of participants about palliative care and palliative care referral are discussed. From a critical realist perspective, tendencies refer to factors influencing the generative mechanisms causing the event (Fleetwood, 2011). The presuppositions form a part of tendencies in social exchange theory (Danermark et al., 2019). In the presence of triggers for referral, tendencies have the potential to influence decision-making processes and the choice of referral action (Danermark et al., 2019). The subthemes

describe various presuppositions expressed by the participants. They are self-efficacy and acknowledging own limitations, client feedback as a mechanism to validate action, trust and trustworthiness, power relationships, and hurt of ending the therapeutic alliance.

5.3.1.1. Self-efficacy and acknowledging own limitations

The self-efficacy and limitations acknowledged by the participants about their ability to cater to the palliative care needs of children with cancer is discussed in this subtheme. Self-efficacy is the person's belief in their own capacity to perform a task.

In this study, some participants felt that they had the self-efficacy to address palliative care needs as they could manage pain and physical symptoms. They thought that symptom management is an integral component of oncology care, and they have skills in counselling. They also believed that palliative care referral is not warranted for minor symptoms during the treatment phase.

"symptoms like constipation, loose stools, some headaches, body pains. I think those are symptom care issues we as clinicians are trained to do that and we kind of manage it quite all right". (P 020)

However, the majority had a contradictory view of their ability to meet palliative care needs and acknowledged their limitations. They felt that their ability to assess and manage pain and physical symptoms was suboptimal and thought a specialist service should address these needs.

"the pain management that we were giving in the end-stage was not good enough. The sedation that we were giving was not good enough, and I just felt that we were doing a very bad job". (P 016)

Some acknowledged the need for help in communication during the child's terminal phase and recognised that they were not providing sufficient emotional support. A small number of participants attributed their shortcomings to lack of training, expertise, and time constraints.

"the mother told me that it's okay if he dies, because at least I have got somebody to listen to me and to my child [referring to the palliative care team]*. So that was the first time I realised that we don't really speak to them well". (P 011)*

The participants had a mixed view of their ability and limitations to provide palliative care. The interplay of views on self-efficacy and knowing one's own limitations constituted a part of the presuppositions that impacted whether a referral is made or not.

5.3.1.2. Client feedback as a mechanism to validate action

In this subtheme, the participants expressed the role of client feedback as a mechanism to validate their referral action. The participants believed that the feedback of parents and families provided an opinion of the quality of palliative care services that informed future referral to palliative care. Participants experienced families returning after the child's death and thanking the oncologists for the end-of-life care provided. They felt that it was usual for the families to thank the oncologists when the child is cured, but unusual for the families to

thank the oncologists after the child's death. A positive family feedback enhanced their confidence in the palliative care team, which facilitated future referral.

"when somebody comes back, they themselves are in a very traumatic state to lose a child. And within a couple of weeks of the child's funeral, to come back, seek us out and specifically mention what went well. It's not just a general thanking, it was specifically about the care the boy received when he was dying". (P 007)

"parents of some of the children who died actually came and thanked us which is very unusual". (P 001)

Feedback from the patients and their families on the palliative care provided is an external factor that influenced the presuppositions of paediatric oncologists and haematologists about palliative care referral. Therefore, these presuppositions influencing referral are in a state of flux, as they adapt continually to external conditions like client feedback.

5.3.1.3. Trust and Trustworthiness

In this study, participants emphasised the need for a trusting relationship between oncology and the palliative care team and felt that a lack of trust is a barrier to referral.

"you need to know whether they are going to do a good job of taking care because you have been taking care of them for such a long time". (P 016)

Participants perceived that competence, training in oncology and paediatrics, assessment and management skills and a benevolent approach made the palliative care providers trustworthy.

"so, faith in their competence is important… I would refer to somebody, but if that person is not very good then it is not helpful, it makes a huge difference". (P 007)

A minority of participants had concerns about the ability of palliative care providers to care for children with cancer as they lacked training in oncology and paediatrics. These may be valid concerns as most providers of medical palliative care in India are adult physicians, and palliative care trainees have limited exposure to oncology during their training.

"they should have a paediatric perspective of dealing with care or symptom control…, dealing with a child is always different than dealing with an adult". (P 017)

A few participants also expressed concerns about the palliative approach. They believed that a lack of clarity and objectivity in palliative care assessment and management made them less reliable. Participants also considered that both undertreating and overzealous symptom management approaches by palliative care providers were barriers to referral.

"we are trained to look at things objectively… the response rate is 56% versus 63%... the overall survival is 90% versus 95%. Even if it's not the same language used in palliative care, probably that clarity of thoughts is not present". (P 014)

A small number of participants identified some palliative care providers to be less benevolent. They felt that a few palliative care providers had a mechanistic approach and lacked proactiveness and empathy, which hindered future palliative care referrals.

"they were not wholeheartedly in it… I felt a lot of lack of empathy in there... the parents have come back and told me that… it's better that you handle this than them … I feel the compassion is a big thing in palliation. You have to be having that amount of empathy towards them, though you do it as a job". (P 003)

Trustworthiness is a dynamic concept that is continuously updated based on the social actor's experience of the phenomenon. Some participants felt that their past experiences of making palliative care referrals boosted their trust in the palliative care team.

"trust comes from experiences… if you've worked in centres where you have seen good examples of palliative care". (P 019)

Participants liked palliative care providers to be competent, trained, clinically sound and benevolent. Participants believed that some palliative care providers were less able, unreliable, and unkind while caring for a child with advanced cancer. Therefore, trustworthiness is a crucial component of presuppositions that tend to influence social actors' participation in the referral process.

5.3.1.4. Power Relationships

From a social exchange perspective, power relationships exist where a social actor has the ability to exert an influence on another social actor to comply (Ekeh, 1974). In this study, the participants described different forms of power relationships between paediatric oncologists and haematologists and palliative care providers that could influence referral behaviour. Some participants felt that the virtue of being an oncologist or haematologist, expertise and qualifications, and years of professional experience conferred that power.

"we are always a little more one level higher… a shared care concept has not come in… It's more like I'm referring a patient to you, and you do what I want you to do and take care of them… because of the difference in… seniority and also one is DM [highest subspecialist qualification in oncology]*, the other one is a DCH* [basic diploma in paediatrics]*". (P 011)*

A minority of participants thought that they have the power to make the palliative care providers comply with an instruction. They would not make the referral if the palliative care providers were found to be non-compliant. They felt that palliative care providers should agree to the line of clinical management proposed by the oncologists. They also believed that the palliative care team would not receive referrals if they do not deliver what is expected of them.

"they don't deliver what I think they should deliver. Then I would not refer to them". (P 019)

Data from this study suggests that oncologists and haematologists possess the power to refer and influence the action of the palliative care providers by virtue of their position, higher

qualifications and greater experience. Power and its perceived influence have the ability to shape one's behaviour and action (Ekeh, 1974). In an exchange relationship like a referral, these form a part of tendencies that could determine a social actor's participation in the exchange (Ekeh, 1974).

5.3.1.5. Hurt of ending the therapeutic alliance

In this study, some participants equated palliative care referral as a break in the therapeutic alliance. They held a view that palliative care referral caused emotional hurt to oncologists and haematologists and perceived it as a therapeutic failure and failing the child, which was attributed to a sudden shift in the treatment goals. Moreover, they believed that as oncologists, they are trained to cure and save and not give up. They compared referral to palliative care as handing over their family member and not seeing them again and breaching the bond established between them.

"it is that kind of a feeling that you're handing them over to somebody else, but you're not sure whether they will take the same care of them and whether they will form the same bond with them. As I said they are like family. So, you know, it feels like you are handing over your part of your family to somebody and telling them, now you take care of them, but you always wonder whether they are doing a good job of it". (P 016)

Above excerpt also suggest participants' fear of moving away from a therapeutic relationship. These fears may have the potential to alter the thinking and beliefs of participants that may preclude them from participating in the referral process.

In summary, presuppositions of paediatric oncologists and haematologists about their self-efficacy and knowledge of their own limitations of catering to palliative care needs and how family feedback provided an opinion on the quality of the palliative care team were discussed. Participants expected a trusting relationship between oncology and palliative care providers and emphasised the trustworthiness of palliative care colleagues. Power relationships exist between the oncology and palliative care teams and impacted their referral behaviour. The fear of a break in the therapeutic relationship made the referral process hurtful.

5.3.2. Theme 2: Task of making a palliative care referral

In this theme, the task of making a palliative care referral is discussed. From a social exchange perspective, the task refers to the efforts needed to complete an activity, and if the effort needed is significant, the social actor may choose not to pursue the task (Ekeh, 1974). In this study, participants perceived that stigma associated with palliative care referral, navigating illness-related factors, parental and family attitudes and limited palliative care resources made palliative care referral a daunting task. These were the subthemes informing the theme.

5.3.2.1. Stigma associated with palliative care

Participants felt that stigma associated with palliative care hindered palliative care referral. Participants expressed the presence of stigma among patients and families about palliative care due to a negative stereotyped association of palliative care with death, end of life and the terminal stage of illness. Public endorsement of a negative stereotype may lead to prejudices and negative affective reactions. The negative stereotyped association of palliative care with death led to a diminished motivation of the families to see the palliative care team as the final option of care for their children. The participants sensed that families associated

palliative care referral with a child not going to survive, a change in treatment intent, or stopping active treatment. Families also perceived palliative care as a treatment offered just before death and palliative care physicians as doctors dealing with death.

"when you refer to the palliative team, some of the parents think that it is for end of life management...parents think that some major issue is going on, and that's why they have been referred to palliative care" (P 008)

"one thing is that family feels that you have sent to the doctor dealing with death" (P 006)

The stigma of palliative care was not just restricted to families. Some participants expressed the view that many oncologists also associate palliative care with death. They felt that these perceptions need to change to facilitate referral.

"palliative care is associated with end-of-life care… if we have that thought process and we are not able to get over that thought process, how do we expect our patients and families to get over that thought process" (P 020)

Participants believed that families hesitated to pursue a line of management due to stigma associated with its name. Participants also suggested that both oncologists and families would like to avoid the term palliative care. A few felt that oncologists perceive the term palliative care as a disadvantage, symbolic of a loss of hope and negative attributes. Some participants thought that the families also associate the term palliative care with hopelessness, treatment failure and terminal stages of illness.

"the family hears this word, palliative… they say… but you are trying to treat, cure my child… why do you want me to engage with it [referring to palliative care]*?... that means you're telling me that my child is not really going to live"* (P 009)

The negative view of palliative care among the public and the stigma associated with its name could prompt oncologists and families to exclude palliative care providers in the care process, perhaps leading to gatekeeping behaviour that could make the task of palliative care referral challenging.

5.3.2.2 Navigating illness and treatment related factors

Oncologists and haematologists have to navigate complex permutations and combinations of illness-related factors that predispose the patient for a referral. The course of illness, complications, stage of the disease, presence of symptoms, cure potential, the intent of treatment, prognosis and performance status of the patient were predisposing factors influencing referral. However, even in the presence of predisposing factors, the social actor's tendencies towards the phenomenon impact their involvement in the exchange process (Ekeh, 1974). From a critical realist perspective, the illness-related factors constitute the biological layer of stratified ontology (Danermark et al., 2019). Exploring the interplay of ontological layers might facilitate the understanding of generative mechanisms causing the referral event (Danermark et al., 2019).

An acute course of illness and complications seldom triggered a palliative care referral. The need for continued monitoring and therapy in haematological malignancies hindered a

palliative care referral. Solid tumour malignancies with an indolent course were more likely to be referred.

"child needs continued input in leukaemia, which is relapsed/refractory … continue to need blood support because there is going to be bleeding and they need blood all the time. So, these children we like to keep them under our cover" (P 007)

Advanced stages of illness, recurrent cancers and illness relapses often triggered referral. However, even in advanced stages, the potential for a cancer treatment made referral less likely.

"child may not be an eligible candidate for curative therapy at that time because of advanced cancer, poor general condition… we usually give reference to palliative medicine" (P 022)

The presence of symptoms is a usual trigger for a referral. Asymptomatic patients are seldom referred unless they have a poor prognosis or were anticipated to develop symptoms shortly.

"you know, which way it is going to go. I usually refer to the palliative care team at that point before the child has got any symptoms". (P 001)

Intent and intensity of treatment, and cure potential influence referral behaviour. Patients managed with curative treatment and receiving intensive chemotherapy were seldom referred. Hope for cure and expectation of treatment success precludes a referral. Patients who are not eligible for treatment, inability to receive treatment due to low-performance

status and patients who have completed all cancer-directed therapies are more likely to be referred.

"if the curative option of treatment is going on … then there will not be any referral to the palliative care. I don't think that it will go well with the patient's mind, but unless it is for symptom control". (P 006)

The interplay of closely entwined illness and treatment factors predisposed the patient to receive a palliative care referral. It is possible that oncologists might find it challenging to navigate a complex set of illness-related factors underpinning the palliative care referral decision which could make the task of referral daunting.

5.3.2.3. Attitudes of parents and families about palliative care

In this study, participants felt that understanding the palliative care team's role by families and parents, acceptance of palliative care, and readiness to engage with palliative care influenced palliative care referral. If the parental and family perceptions and expectations are not congruent with that of the healthcare provider, it could be a barrier to accessing a health service.

Most of the participants considered that parents and families lacked clarity about the role of palliative care. Uncertainty about the role was attributed to parents and families having a different perspective about illness and due to a mismatch of goals and expectations. A lack of comprehension of palliative care benefits referral also hindered families from engaging with a palliative care team.

"What is really their role? They are not counsellors, they are not social workers, they are not doing psychological medicine. So, you know, what exactly is their role?... that is what the family thinks and likes to know". (P 005)

Participants also perceived that the parents and families' reluctance to involve palliative care teams hindered palliative care referral. Families were disinclined to attend meetings concerning palliative care referral. Doctors presumed that discussing palliative care triggered a sense of abandonment, and families preferred the oncologists to continue the care instead of a new service provider caring for their child.

"from the family perspective, they, they will think that the doctor has completely, you know, abandoned this patient by referring to other departments". (P 012)

Readiness to engage with the palliative care team was another aspect that influenced referral. Readiness was better when the child had pain and symptoms. Families were hesitant to consent to palliative care referral when the child was well and asymptomatic. A steady transition facilitated readiness rather than an abrupt referral.

"when a family is not ready, then there's no point thrusting... they will agree for symptom management... but they want disease directed management as well" (P 010)

Uncertainty about the role of palliative care and hesitancy of the families to engage with the palliative care team hindered palliative care referral. Therefore, to facilitate a referral, the oncologists and haematologists may have to invest more time and effort to negotiate these

family attitudes. From a social exchange perspective, these are the additional efforts needed to accomplish a task that may impact a social actor's future participation in the exchange (Ekeh, 1974).

5.3.2.4. Palliative care resource constraints

The majority of participants believed that restricted access to palliative care and limited capacity to provide palliative care were the significant resource constraints that hindered palliative care referral. The value assigned to a resource by a social actor influences one's participation in the exchange; hence resource scarcity negatively impacts the pattern of the exchange process (Ekeh, 1974).

Participants felt that patients and their families had restricted access to palliative care due to the limited availability of palliative care services, limited inpatient beds and outpatient clinics. Continuity of care is interrupted due to inadequate community palliative care resources. Moreover, access to palliative care in rural and remote communities was almost non-existent, and families have to travel long distances to access palliative care services.

"it is difficult for patients with advanced malignancies to access palliative care or with complications to get admitted under palliative care. It is because of lack of inpatient beds and most of them had to be managed on outpatient basis, which again, becomes very difficult… because titrating medicines and pain control on an outpatient basis becomes quite challenging" (P 005)

The participants thought that the capacity to provide care was limited due to fewer specialists, inadequate staffing to handle caseloads, limited space to provide palliative care and restricted access to opioids.

"Seeking and asking for referral is easy. If today every single deserving patient is sent to the department of palliative care of my hospital, they will be completely overwhelmed. I do not think that they have the people to handle that kind of a load" (P 014)

Palliative care resource constraints like restricted access and limited resources hindered palliative care referral. From a social exchange perspective, resource constraints translate to excessive efforts for task completion that may impede the social actor's participation in the exchange (Ekeh, 1974).

In summary, participants had to address the stigma associated with the term palliative care due to the negative stereotyped association of palliative care with death by both the families and oncologists. They had to navigate the complex maze of illness-related factors before deciding on palliative care referral. They found the families' attitudes towards palliative care challenging, and a disinclination of families to engage with the palliative care team made the task of referral difficult. The challenges involved in accessing a palliative care team and engaging with a resource-constrained palliative care service deterred the oncologists and haematologists from making a referral.

5.3.3. Theme 3. Cost-benefit of palliative care referral

From a social exchange perspective, benefits correspond to the rewards of participating in the exchange process, and cost corresponds to unintended negative effects sustained while achieving the reward. A cost-benefit analysis is the appraisal of the rewards gained to the costs incurred, and the social actor expects it to be a fair process. If the costs involved in achieving the reward are high, there is less chance of a person taking up the task (Ekeh, 1974). In this study, participants have elucidated a wide range of palliative care referral benefits and some negative outcomes. The participants have described rewards like immediate direct benefits of palliative care referral and long-term association benefits with a palliative care team. They also discussed the unintended cost of palliative care referral. These are the subthemes informing the theme.

5.3.3.1. Immediate direct benefits of palliative care referral

In this subtheme, participants have discussed the immediate direct benefits of palliative care referral to patients and their families. As elucidated earlier, although a small number of participants perceived that they had the ability to manage pain and symptoms, the majority of the participants appreciated the pain and symptom management benefit of a palliative care referral, believing that palliative care providers have exceptional skills in prescribing medications for symptom management, for example:

"we call the palliative team because they are much better at doing things like pain control than we are, so we utilise their expertise over there. We do that quite a lot especially in sarcomas when there is complex pain that we find difficult to control" (P 007)

The participants also discussed several benefits of palliative care referral beyond the symptom management role. Participants thought that palliative care referral facilitated less intensive care and hospital resource utilisation and avoided potentially inappropriate medical interventions at the end of a child's life. Moreover, engaging with the palliative care team helped parents and families understand and accept the clinical situation better, discuss prognosis, and enable participation in decision-making and future planning meetings. Palliative care referral facilitated access to the end of life care, and end of life symptoms were well controlled. Families and caregivers were supported throughout the illness trajectory and beyond the child's death. Children referred to palliative care were more expressive and interactive and were able to communicate their intimate thoughts. Moreover, palliative care enabled normalising experience for children as the team routinely involved them in play activities.

"it was so nice to see that difference because first three weeks, there was no interaction. Just nothing. Later she just opened up so much and family was happy. I am not saying happy would be the right word, but they were more accepting of the things, which I thought was really good" (P 004)

"palliative team has made an effort to, you know, to be with them during the end of life, after the child has passed away, they have been with the parents. And they have made an environment which was very conducive for both parent and the child" (P 016)

Additionally, some participants valued two important gains of palliative care referral, that is the child can live at home and die at home. From a social exchange perspective, value

corresponds to not just the benefit of the activity, but the feelings of satisfaction associated with it (Ekeh, 1974). A few participants held a view that a child who has completed all cancer-specific treatment should continue to live at home as enormous efforts are needed to transport the child back to the hospital. Moreover, parents and families found it stressful as they had to travel long distances to access care. Families preferred to stay at home and liked to be remotely supported from the hospital either telephonically or by home visits from the palliative care team. The participants also liked the children with no prospects of oncological treatment to die at home. Dying at home enabled the child to be with the parents during the last moments and avoided unnecessary hospital-based interventions. Moreover, families also preferred their child to be at home during the terminal stages and thanked the oncologists for facilitating home death.

"coordination of care at home is something that can help the patient a lot. So, if they need just a prescription for narcotics, then they don't have to go through the hassle of coming to the hospital and getting the prescription and going back" (P 015)

"when we decided that the child is progressing on second line chemotherapy. They saw the palliative care team. Finally, the patient died at home, the parents actually phoned and said the child died, but you did everything, and palliative care did everything and thanked us. I think that is one of the things which was really the highlight as all these patients didn't die in the hospital. They died at home." (P 001)

Symptom management, enabling acceptance of no treatment, discussing poor prognosis, limiting inappropriate treatment at the end of life, coordination of care at home, facilitating

home death and supporting children and families throughout the illness trajectory were the immediate direct benefits of palliative care referral that facilitated future referral.

5.3.3.2. Long-term benefits of palliative care association

In this study, the participants expressed long term benefits of association with a palliative care team like stress reduction, finding a clinical partner to share responsibility, better treatment outcomes and time-saving benefit to the oncologists. Participants felt that a long-term association with the palliative care services reduced their stress and made them feel unburdened.

"it is too much of a burden of already existing work which I have… it's sometimes emotionally draining… palliative care physician will obviously take care of certain things… and actually it decreases some amount of your stress" (P 013)

Some participants thought that by making a palliative care referral, they found a partner to share their responsibility of care. They felt that the palliative care team shouldered certain responsibilities like symptom management, family meetings, communication, counselling, and emotional support. The palliative care team also assisted oncologists in the medical management of the patients and conducting minor procedures.

"it gives the chance of sharing the responsibility… instead of you being the sole physician in charge, you get somebody else who will also be their doctor. It always helps to share responsibility, especially when things are not going well" (P 021)

A small number of participants thought that patients referred to palliative care had better treatment outcomes attributed to improvement in treatment compliance and reduced treatment abandonment rates.

"we are working together to make sure that we bring down the treatment abandonment rate. Families should feel that they were being taken care of. It can only happen if curative and palliative teams are working together" (P 011)

They also believed that making a palliative care referral can save oncologists' time spent on symptom assessment and management, and family communication. Moreover, participants felt that they had little time within their busy clinical practice to spend with children and their families, which could be compensated by the time provided by the palliative care team.

"and when you struggle to take care of your normal patients, curative patients or patient without symptoms… how would you spend time and resources for patients who need end of life care or symptom control" (P 017)

A minority of participants perceived that the long-term association with the palliative care team also conferred several benefits towards their self-improvement. Working with the palliative care team made them resilient and compassionate. It improved their confidence in managing children in the terminal stages and bettered their decision-making and prognostication skills. They also felt that working with the palliative care team enhanced their ability to handle emotions and counsel families.

"I feel I have become more empathetic … I feel I have become much calmer as a person and It's more of a positive effect". (P 003)

"I'm able to forecast and able to predict and able to pre-empt. So that is the skill that I've learned by engaging with palliative care physicians". (P 010)

The long-term association with a palliative care team benefitted oncologists and haematologists by creating a less stressful sharing environment that optimally utilises their limited time and improves patient outcomes. It made them resilient, compassionate, and bettered their communication, decision-making and prognostication skills. These perceived long-term association benefits facilitated palliative care referral.

5.3.3.3. Unintended costs of making a palliative care referral

In an exchange process, unintended costs refer to inadvertent negative outcomes accompanying the benefits of exchange (Ekeh, 1974). In this study, participants felt that palliative care referral is associated with unintended costs due to interference in cancer management, lack of congruence in communication, and an additional fee for accessing the palliative care service.

A small number of participants believed that palliative care referral during cancer treatment could cause interference in cancer management. Morphine prescribed by the palliative care team can mask cancer symptoms and could lead to disease progression. It can also mask the clinical signs of complication and worsen complications. Moreover, oncologists feared that morphine prescribed to children could cause addiction, respiratory depression and hastened

death. They disliked children receiving polypharmacy. They felt that the opportunity to resume chemotherapy is diminished if children are referred to palliative care.

"I remain sceptical about the role of palliative during the curative setting because the worry is that Morphine is interfering with the ability to detect symptoms so that this abdominal pain could be a complication. And I don't know if the child is getting worse, or there's going to be respiratory depression and then the child will die because of that" (P 011)

A minority of participants felt that the palliative care team might provide conflicting information about the child's clinical condition to the families which could lead to a lack of congruence in communication and cause families to receive mixed messages about their child's illness. They suggest this incongruence is due to palliative care providers having a different perspective of illness trajectory and treatment outcomes, and poor inter-team communication might have contributed to their belief. Moreover, participants disliked the palliative care provider's perceived excessive discussion with the family about the child's prognosis.

"if you go and give information to family about a cancer and the cure rate and the relapse rate and something else, and the palliative care person team goes and completely paint a different picture, they may not be wrong. It's just how you give the message. So, in a multi-disciplinary set up, the message has to be given consistently the same way" (P 019)

Some participants felt that additional fees paid for the palliative care consultation hindered referral. They thought that it might be one of the reasons for families refusing to consult

palliative care. They also felt that the palliative care consultation cost could be built into the oncology costs.

"if patients have to shell out more money because they have to see them, that becomes a deterrent… so, if that is built into the whole oncology costs, like if everything is paid for that includes palliative care team… so that the patients don't feel that they have to pay separately" (P 021)

In this subtheme, participants' perceived interference in cancer treatment due to palliative care prescribing, incongruencies in the communication of clinical information, and an additional financial burden of palliative care consultation were the unintended palliative care referral costs that hindered referral.

In summary, the participants discussed the benefits and costs of palliative care referral, and the benefits clearly outweighed the costs. The participants appreciated the direct benefits of palliative care referral, like the symptom management role. Teamwork, stress reduction and improved patient outcomes were other key long-term benefits of palliative care association. Oncologists valued the personal-growth benefit of working with a palliative care team. Interference of palliative care treatment during the curative phase of cancer treatment, and communication by the palliative care team not congruous with the oncologist's views were some of the unintended costs that might have hindered referral.

5.3.4. Theme 4: Strategies for developing an integrated model of palliative care

In this theme, participants discussed strategies that could facilitate the development of an integrated palliative care model in paediatric oncology. According to the participants, an integrated palliative care model in paediatric oncology can be achieved by having an excellent collaboration between oncology and palliative care teams, early palliative care referral, rebranding the palliative care team as a symptom control service and the presence of an effective palliative care team. These were the subthemes informing this theme.

5.3.4.1. Excellent collaboration between oncology and palliative care teams

The participants emphasised the need for excellent collaboration between oncology and palliative care teams. Participants felt that palliative care awareness and training of oncologists and haematologists, palliative care providers seen as part of the oncology team, providing concurrent care, effective inter-team communication, and having policies and procedural guidelines for palliative care referral could facilitate collaboration between oncology and palliative care.

The participants perceived that limited awareness about the scope of palliative care hindered palliative care referral and that improved palliative care awareness and education of both consultants and trainee paediatric oncologists could improve it. Some participants believed that palliative care should be part of paediatric oncology training and curriculum, and paediatric oncology trainees should have palliative care rotations. Palliative care training should not be didactic, but it should rather be case-based teaching and should facilitate the trainees to develop basic skills in symptom management and communication. The imbibed learning from the mentors and supervisors can influence the palliative care referral attitudes

of the trainees. Moreover, information from the data suggests the importance of palliative care education for oncologists, which could be achieved by including palliative care sessions in the scientific program of oncology conferences.

"our fellows need to go to the palliative medicine unit and see, pick up skills… understand, and see things from the eyes of the palliative medicine physicians" (P 010)

"as a resident, it was actually based on practices. We actually learnt from our seniors or consultants who guided us what exactly to do… when to refer… once we started practicing, we did the same" (P 004)

Participants emphasised the need for palliative care providers to be seen as part of the oncology team. A few opined that a physical presence during initial consultation was necessary even when there is a limited role for palliative care and essential for families to recognise palliative care providers as part of the oncology team. It could facilitate trust and bonding between families and the palliative care team and open communication channels. They liked palliative care providers to participate in oncology clinics, ward rounds and family meetings, avoiding the need for a separate introduction to the palliative care team, a formal referral process and handover, and physical transfer of patients. Moreover, a minority of participants felt that a referral-based service is less optimal than an integrated service and advocated for both teams to share the same work environment. They also felt that an experienced palliative care provider should participate during the initial consultation, as it facilitated better rapport building between the palliative care team and families. Participants believed that both teams should understand and respect each other's role and that palliative

care should be part of routine oncology management and should be provided to every patient.

"in India it is more of a personal relationship with the physician. So, they still want to see the oncologist, but if the palliative care team is there in the clinic and sitting with you and they recognise you as one of the physicians in the team, it will be easier for them to manage the patient" (P 015)

"we all have a checklist [management plan] *in which what teams should be involved during diagnosis, for example, for all children we request a cardiac evaluation, so same way palliative care" (P 022)*

The participants believed that cancer care and palliative care should be provided concurrently. The palliative care team has a role at diagnosis, during treatment and after completion of treatment with the understanding that the different palliative care approach could complement the care provided by the oncologist. Moreover, oncologists felt that families perceive a concurrent care approach positively. Some participants suggested a parallel planning model where children will have both curative and palliative treatment, planned together. The child may receive either one of them or both based on the need.

"while we are handling chemo, blood products, nutrition... the palliative care team was taking care of her pain medicines… spending time with her, have a painting or drawing or just play some music and try to distract her" (P 003)

"we used to call it parallel planning. So, I might be giving somebody a treatment which could save the child but at the same time it might not work, and it could go, to a life extending or life ending situation. So, we bridge that gap with parallel planning where child is ready to receive both treatments and you choose what is the best" (P 009)

In this study, participants discussed the role of effective inter-team communication in facilitating a palliative care referral. Participants felt that communication has to be transparent and bi-directional, and that clarity of communication facilitates referral. Inter-team communication should have a clear purpose that discusses patient management goals enabling both teams to arrive at a mutually agreed-upon plan. Communication need not always occur during the team meeting and can be an informal process or at a personal level. Participants liked palliative care providers to give feedback about the referrals made, helping both teams to be on the same page. Some participants preferred to be remotely involved and receive communications about the patients even when they are not directly involved in the patient's care.

"if there is no proper communication between the two teams then it's going to be a problem because even if I made a referral to the palliative care team, unless we have discussed as to what is the purpose of making the referral? What are the goals of care? And what is the communication that has been made to the family?... and vice versa expecting some kind of feedback from my colleague about the referral" (P 002)

"so, I have referred him to palliative care, but I have not got any feedback. They have not closed the loop. So, I don't know what is happening with that child. So, when I think of it, it troubles me" (P 015)

Participants felt the need for policy and referral guidelines for facilitating a palliative care referral. A small number of participants liked to register all children with cancer with palliative care and thought that nurses should be empowered to make palliative care referrals directly. Participants believed that having referral criteria makes it easy to refer, providing clarity and objectivity, which may help junior doctors and nurses to make timely referrals. Some participants suggested creating an automatic referral trigger system based on pain scores, prognosis and complications.

"you should know when to specifically call the palliative care team. So, when to make that referral, that at what time points do we make it. It can be a set thing for the department" (P 008)

In summary, educating oncology trainees and consultants in palliative care can enable referral, and representing palliative care providers as part of the oncology team facilitates family acceptance of palliative care. Moreover, families perceive concurrent care positively. Good inter-team communication and patient progress feedback enhances the oncologist's confidence while making a palliative care referral. The presence of a palliative care referral policy might act as a trigger facilitating a timely referral.

5.3.4.2. Early palliative care referral

Participants discussed the role of early palliative care referral in developing an integrated model of palliative care, suggesting that early referral to palliative care can help patients to access supportive care during curative treatment, may enhance rapport building between families and the palliative care team, and could facilitate a smooth transition of care from curative to palliative care.

Participants felt that there might be a supportive care role of palliative care during cancer treatment. Symptom management during cancer treatment can help children to tolerate chemotherapy toxicities better. Palliative care referral might facilitate the identification of psychological concerns of children and their families during chemotherapy and before surgery. Children receiving chemotherapy need emotional support, and patients and their families require counselling before surgery.

"patients who need enucleation* or amputation, those undergoing chemotherapy… they are going through probably as much distress as a child who has relapsed at least for that period of time" (P 018) [*removal of the eye leaving behind the contents of the orbit intact]

Participants perceived that rapport building is central to all therapeutic relationships, and it takes time to develop rapport between families and the palliative care team. Families preferred oncologists to manage symptoms and provide end of life care if rapport was not developed. Rapport building was difficult when patients are referred late or seen at the end of life. Participants thought that rapport building between families and the palliative care

team could enhance the end of life experience for the families and enable the child to die at home instead of a hospital.

"I find it very difficult to allow patients with the advanced cancer to die at home. That's because, we have not involved palliative care right since the diagnosis… rapport hasn't developed" (P 013)

Participants felt that a lack of smooth transition might cause an abrupt shift in relationships; families would not accept palliative care if referred late, and there is a likelihood of patients remaining with the oncologist at the child's end of life. Families are emotional and distressed during the child's end of life and accepting a new provider might be challenging. Moreover, a late referral could lead to inadequate management of the end of life symptoms and a sense of abandonment among family members.

"mother came and said these last words, we had such a long relationship with you, you were looking after my son for four months now. Last day you completely disowned him. Why?" (P 012)

Participants described the ideal transition as a slow reversal of roles where initially, oncologists have a more significant part, and when the disease becomes incurable, the palliative care provider plays a significant role. They also felt that hospital-based palliative care facilitated a smoother transition of care than a direct referral to a community palliative care service.

"when I say that it's not curative, they go to palliative care team. It's almost like watershed, we don't need watersheds. They can work in parallel. One team works takes the lead up to a point of time. The other team always remains in the background, helps whenever they need to, and if need to be, they become the primary team and the other team takes the backseat" *(P009)*

In summary, early palliative care enables patients to access symptom management and supportive care during treatment, facilitates rapport building between palliative care providers and families, and ensures a smooth transition of care from oncology to palliative care. It enables both teams to work together and facilitates the development of an integrated palliative care model.

5.3.4.3. Rebranding palliative care as symptom control service

Some participants preferred to rebrand palliative care as symptom control services. They liked to introduce the palliative care team as a pain management or supportive care service. They felt that not using the term palliative care during the initial consultation enabled them to introduce the palliative care team early and facilitated the referral process. The term symptom control helped in overcoming the stigma associated with the term palliative care. Changing the name helped reduce family resistance and provided an opportunity for the palliative care team to bond with the family. The term palliative has a negative connotation when used by oncologists, and they were not comfortable using that term. They also felt that the term symptom control should encompass all the services provided by palliative care.

"not as a palliative care team… we counsel and tell them that this is the symptom control team which takes care of your pain, gives you supportive management, and will help you out" (P 018)

"when you say palliative care, I'm sure they're [families] *quite concerned and apprehensive about what's going to happen to their kid. We tell them it is a symptom control program… probably is an all-encompassing term and probably more comforting to the parents, and I would say for doctors as well" (P 022)*

In summary, rebranding the palliative care service as a symptom control service might facilitate early referral by overcoming stigma and improving family acceptance of palliative care, contributing to the development of an integrated service model.

5.3.4.4. Presence of an effective palliative care team

In this subtheme, participants emphasised the need for an effective palliative care team. They described effectiveness in terms of a palliative care team that is readily available, accessible, proactive, comprehensive, and has the required expertise to deliver the care. Participants felt that round the clock availability of palliative care services is the key, and interruptions in palliative care availability hindered referral.

"I think the biggest factor hindering is periods of non-availability of the palliative care" (P 002)

Most of the participants favoured accessing palliative care services easily, quickly and without any hurdles. They preferred phone contact as this facilitated discussion of the patient's clinical

condition and avoided the inconvenience of making a written referral. Phone access enabled close bonding between two teams. They also felt that working in close proximity and sharing the same workspace promoted access. Participants suggested that the palliative care team should be accessible after-hours and at night.

"when I pick the phone and I call them to discuss they were more than happy to discuss. We were able to discuss and come up with a consensus kind of plan" (P 002)

A small number of participants liked palliative care providers to be proactive and not wait for the referral. They did not like the passive attitudes of palliative care providers and preferred them to lead and take ownership of the patients.

"they never waited for the referral from us, they used to do ward rounds and find out any child is having any kind of pain and or any kind of suffering… and they used to just point it out to us and suggest treatment and that way it was good" (P 013)

Participants felt that the team should be adequately staffed, and able to provide an entire spectrum of services. The team should provide comprehensive care to their patients, and their approach should be holistic. Some disliked the idea of solely an acute pain management team equated to palliative care and did not like pain physicians without palliative care training managing children with cancer as they lacked a comprehensive approach.

"it is not like you give a problem, like pain, you come and give Morphine, not that kind of palliative care, but actually assess, check, look at all the aspects. Okay, and then come up with a full plan rather than telling patient has pain give Morphine" (P 001)

Participants preferred to engage with palliative care providers having adequate expertise and skills. The majority of participants held a view that the palliative care provider should have training and skills in paediatrics and oncology. Skills in managing complex symptoms and psychosocial issues are necessary and they should be able to provide end of life care at home.

"I personally feel all palliative care people should work in an oncology unit and paediatrics for a few months to see the spectrum and kind of work we do. They should not be just like coming and doing palliative care only with no understanding of oncology and paediatrics" (P 012)

Participants liked to engage with an effective palliative care team that is constantly available, easily accessible on the phone, proactive in seeking out referrals, having dual expertise in oncology and paediatrics and providing comprehensive palliative care to children and their families. Engaging with an effective team is likely to boost the oncologists' confidence furthering the alliance between the two teams and promoting an integrated model of palliative care.

In summary, some oncologists and haematologists preferred an integrated model of palliative care over referral practice. They felt integration could be achieved by enhanced collaboration between the oncology and palliative care teams through improving palliative care awareness among the oncologists and representing palliative care providers as part of the oncology

team. They felt that referring early could ensure access to supportive care for patients receiving cancer treatment, enable rapport building between palliative care team and families and promote a smooth transition of care from oncology to palliative care. They felt it is necessary to rebrand palliative care services as symptom management to overcome palliative care stigma and family resistance. They preferred to engage with an effective palliative care team that could meet their expectations.

5.4. Conclusion

In this chapter, research findings were presented as themes and subthemes. The majority of participants valued palliative care benefits in terms of symptom management, communication, emotional support, and end of life care. They acknowledged their limitations in catering to palliative care needs. However, some participants felt that they could address palliative care needs themselves. The benefits of palliative care were not limited to the terminal phase. Participants felt that providing palliative care early in the curative phase facilitated patient access to supportive care during treatment, enabled rapport building between families and the palliative care team, and smooth transitions from oncology to palliative care. However, some participants did not like the idea of palliative care referral during the curative phase of treatment due to the interference of palliative drugs in cancer management. Moreover, some participants reported negative palliative care referral outcomes due to incongruence in the clinical information shared with the families by the palliative care providers.

The participants had some pre-conceived notions about palliative care that probably hindered palliative care referral. They considered palliative care providers less trustworthy due to a

lack of training in oncology and paediatrics and inadequacies in clinical competence. A power relationship existed between the teams where the oncologists had the power to gatekeep the referrals owing to their position, experience, and qualifications. They perceived making a palliative care referral as a painful process due to the potential break in the therapeutic alliance. They relied upon the families' feedback to validate their referral action.

The participants faced some challenges while making a referral. These were primarily due to the stigma associated with the term palliative care among the families and oncologists. The negative family attitudes towards palliative care also hindered referral. They felt that rebranding the palliative care services as a symptom control team might help overcome the palliative care stigma and family resistance. Navigating illness-related factors was another challenge. Participants felt that having an institutional referral policy could overcome this challenge and trigger a timely referral.

The participants expressed concerns about palliative care resources specifically relating to access and capacity to provide palliative care. They preferred to engage with an effective palliative care team that is readily available, easily accessible, proactive and has the expertise to deliver the care. Participants felt that the expert palliative care team should seamlessly collaborate with the oncology team to facilitate the development of an integrated model of care, which could be achieved by representing palliative care providers as part of the oncology team and improving the awareness of oncologists about palliative care. Conversely, a small number of oncologists preferred to move on from a referral-based practice to an integrated practice where both teams work synchronously and provide concurrent care. Participants felt that a long-term association of oncology and palliative care teams reduced their stress, saved

oncologists' time, and the responsibility of care was shared between the teams. Moreover, they also experienced the personal growth benefits of palliative care association. These findings will be discussed in relation to broader literature and theory in the next chapter.

Chapter 6: Discussion of Research Findings

6.1. Introduction

In this chapter, key research findings identified in chapter five will be discussed in relation to the research objectives. The research findings will be reviewed and compared with the previous literature identified in the systematic review and with the broader literature. They will be interpreted using a critical realist lens (Bhaskar et al., 1998), social exchange (Ekeh, 1974) and feedback intervention theories (Kluger & Denisi, 1996). The strengths and limitations of conducting this research, its implications on policy and practice, future research opportunities, and contribution to knowledge will conclude the chapter.

6.2. Interpretation of Research Findings: Philosophy and Theories as Analytic Lenses

Critical realism was the philosophical approach underpinning this research as the purpose was to explain the generative mechanisms influencing the referral (Bhaskar et al., 1998). Social exchange theory was chosen as the initial theoretical framework because a referral is a social event, and the act of referral may be seen as a social exchange behaviour (Ekeh, 1974).

6.2.1. Interpreting Research Findings using a Critical Realist Paradigm

Critical realism is a philosophical basis for transformative research (Egbo, 2005). The foundation of conducting this research was that children with advanced cancer in India are infrequently referred to palliative care or are referred late (Ghoshal et al., 2016). In this study, participants have provided valuable insight into how effective collaboration and a well-developed palliative care team can facilitate referral. These perspectives could bring about

emancipatory social change (MacDonald, 2004) by facilitating palliative care referral and mitigating the pain and suffering of children and their families with cancer.

There are several generating mechanisms causing the social event, some of them are empirically observed, and some are deeper and hidden (Sayer, 1992). The interplay of stratified layers of generative mechanisms triggers the event (Danermark et al., 2019). In this study, illness-related factors such as the stage of cancer, the intent of treatment, cure potential, prognosis, course of illness and complications form the biological layer. They are the preconditions for a referral. However, biological factors triggering the referral are moderated by a psychological layer. Knowing referrers own limitations or excessive self-belief, negative sentiments about palliative care providers, trust issues, presuppositions, and past experiences constitute the psychological layer. Social and organisational layers further impact referral behaviour. Family acceptance of palliative care and palliative care stigma are some examples of the social layer. Availability and access to palliative care, limited resources, hospital-based services, and consultation cost are few illustrations of an organisational layer. Moreover, I may not be able to fully uncover the stratified ontology of referral (Schiller, 2016), and some of the generative mechanisms may not be readily apparent (Bhaskar et al., 1998). I do not make claims to know or unearth all the generative mechanisms causing referral, and I have explored the perspectives of some participants who can provide reliable and insightful information about the phenomenon (Crosby, 2007). The knowledge generated in this study is contextual to the Indian setting (Owen, 1995), and the perspectives of oncologists and haematologists about palliative care referral might change over time. It supports the "fallibility of knowledge" concept of critical realism, where knowledge about causal mechanisms changes with context and time (Danermark et al., 2019).

Structure, power, generative mechanisms and tendencies are the four concepts that form a perspective (Collier, 1994), and some of these concepts overlap with social exchange theory (Ekeh, 1974). In this study, oncologists have discussed various illness-related factors that constitute a structure, which is a precondition for making a referral. Oncologists and haematologists decide and control the palliative care referral, embodying the power to refer by virtue of their status. Their appraisal of benefits and costs of referral, presuppositions, sentiments about the palliative care providers are some of the tendencies impacting referral behaviour (Collier, 1994). Therefore, even when structure and power are set in motion, the referral may not be initiated as participants either intentionally or unintentionally choose not to refer (Collier, 1994).

The palliative care referral phenomenon has oncologists, palliative care providers and patients and families as the stakeholders (Snaman et al., 2020). The oncologists and haematologists participating in the research may have different views on palliative care referral when compared to palliative care providers, patients, and families. One of the potentials of critical realism is to unpack and understand a complex social phenomenon (Cruickshank, 2002). This research has unpacked the phenomenon only from the perspectives of oncologists and haematologists. Future research focused on the perspectives of palliative care providers and patients and families may facilitate a comprehensive and holistic understanding of the referral phenomenon.

6.2.2. Social Exchange Theory as a Framework to Interpret Research Findings.

6.2.2.1. Human Cognition and Emotions

Human cognition is an essential motivation for social exchange that goes beyond the process or outcome of the exchange (Poonamallee & Goltz, 2012). The social actors are emotive and cognising, and the emotions experienced by the social actors' act as internal reinforcement for the exchange behaviour (Lawler & Thye, 2006). However, sentiments go beyond emotions, representing an affective state or feeling where emotions are linked to a social object or social unit (Lawler, 2001). It is a social construct that leads to an affective response, which is the psychological state of the social actor, shared meaning or an expressed behaviour (Cook & Rice, 1989). The presupposition is an implicit assumption or belief about a phenomenon (Simons, 2013). Presuppositions trigger cognitive responses that impact decision-making and social behaviour (Domaneschi et al., 2014).

In both the review and research findings, oncologists and haematologists expressed presuppositions about the trustworthiness of the palliative care providers. Trust is a cognitive process where one social actor expects another social actor to be trustworthy (Nunkoo & Ramkissoon, 2012). Trustworthiness refers to a measure of belief in another person's ability, reliability, integrity, resourcefulness and benevolence (Kim & Kuo, 2015). In both review and research findings, oncologists and haematologists highlighted the role of competence-based trust while making a referral in the expectation that another person (or team) has the ability to perform a task effectively (Lee, 2004). Oncologists regarded palliative care providers to be less competent due to a perceived lack of clarity and objectivity in clinical assessment and management. The training of palliative care providers in oncology and paediatrics was considered to be inadequate. Moreover, they believed that the palliative care team lacked

skills in managing a patient receiving cancer-directed therapies. A lack of palliative care resources as a factor contributing to reduced trustworthiness was seen in both research and review findings. It was corroborated by a study that showed a lack of confidence in paediatric palliative care providers by oncologists hindered palliative care referral (Yu et al., 2020).

This research brought out benevolence as a facet of trustworthiness. Benevolence corresponds to a disposition of doing good and being kind (Colquitt & Rodell, 2011). In this study, participants felt that some palliative care providers were less benevolent due to a perceived lack of empathy and a lacklustre approach. The study also highlighted the role of social identities of the social actors on trustworthiness, cognition and exchange behaviour (Lawler, 2001). Participants embodied social identities by labelling them as adult and paediatric palliative care providers and the presence of a paediatric trained palliative care provider facilitated referral.

In the review, the oncologists and haematologists had expressed self-efficacy to cater to palliative care needs. However, in this study, the participants had mixed feelings about their ability to cater to these needs. Perceived self-efficacy is a person's belief about their capabilities to produce a level of performance to accomplish a task successfully that meets the expectation of the self and others (Bandura, 1997). The perception of self-efficacy influences the cognitive and affective processes and impacts social behaviour and action (Bandura, 1997). In this study, only a small number of participants had a perception of self-efficacy about providing palliative care. The majority of participants valued the benefit of palliative care referral and acknowledged their constraints in terms of limits to their skills and knowledge needed to provide palliative care. The equipoised appraisal of perceptions of their

own limits and self-efficacy formed the presuppositions that impacted the referral behaviour.

As detailed in section 2.3.5, specialist palliative care is delivered by trained specialist palliative care providers managing patients and families with complex symptoms, psychosocial needs and palliative care situations (Kaye et al., 2016), whereas the palliative approach or generalist palliative care refers to general practitioners or non-palliative care specialists with basic training in palliative care catering to simple palliative care needs (Kaye et al., 2016). In Canada, patients and families access generalist palliative care providers twice as much as they do specialists (Brown et al., 2018). Generalist and specialist palliative care providers working together could create a more sustainable model as increasing demand for palliative care could outstrip the supply of specialist providers (Quill & Abernethy, 2013). Effective collaboration between them could be achieved through proactive communication, role negotiation, shared problem-solving and recognising generalists' expertise (Firn et al., 2016). A lack of policy and structure to organise generalist palliative care resources in a setting where specialist resources are non-existent often hindered their development (Bergenholtz et al., 2015). A mentoring model between specialists and generalists could enhance generalists' palliative care expertise furthering their self-efficacy (Donovan et al., 2019).

Emotions triggered by task activities are central to social exchange behaviour (Lawler & Thye, 2006). The exchange process can trigger a host of emotions. Some are general feelings like pleasure or dissatisfaction, and some are specific feelings like anger, shame, trust, confidence, gratitude or pride (Lawler & Thye, 1999). The exchange outcomes also produce emotions and emotions that influence the social actor's commitment to the exchange process (Lawler & Thye, 1999). A positive emotion triggered will make the social actor repeat the experience,

whereas a negative emotion deters future participation in the exchange process (Lawler & Thye, 1999).

In the review, referral to palliative care made oncologists and haematologists experience therapeutic failure, abandonment, and a break in the therapeutic alliance. Moreover, they felt emotional and loss of hope. These emotions triggered by the task of referral could hinder future engagement. In this study, participants believed that feedback from families provided an opinion about the quality of palliative care services. Therefore, they relied upon family feedback, and positive family feedback acted as a reinforcement for future referrals. Client feedback refers to clients' information about their experiences of accessing a service, and it is often sought to validate the performance of a service (Lambert & Shimokawa, 2011). Client feedback helps the clinicians to know about the effectiveness of a treatment, therapy relationships and adverse outcomes. It alerts them to change the course of treatment and institute risk mitigation strategies (Lambert & Shimokawa, 2011). However, in an early bereavement phase, feedback provided by the emotional family members might not always truly represent the quality of palliative care services (Stajduhar et al., 2017).

Moreover, in India, paediatric oncology services are limited to large cities (Arora & Banavali, 2009). They have limited oncology beds, and often these are not provided to children receiving palliative care (Sengar et al., 2019). The inpatient palliative care beds are few, and the care is mainly provided at home as paediatric hospices are non-existent (Muckaden, 2013). Families are very grateful for whatever support the child can receive at home (Sengar et al., 2019). In this study, oncologists also wanted the child's care to be continued at home, and the child to die at home. Although oncologists preferred children to die at home, often

in a resource-constrained setting, the patients have limited access to professional expertise and medications in a home setting (Salifu et al., 2020). The feedback from families to oncologists about the care provided at home and dying at home was an essential factor influencing future referrals. However, achieving home-based palliative care for all the patients might be challenging in the Indian setting.

Apprehension about the opioid prescription to patients with cancer by the palliative care team was seen as a barrier for referral in both the review and research findings. In this study, participants felt that morphine could cause respiratory depression, mask symptoms of cancer, cause complications and lead to disease progression. Uneasiness about opioid use is common in Indian settings (Viswanath et al., 2018) as most specialists in India, barring pain or palliative care specialists, have limited experience and knowledge about opioids (Lebaron et al., 2014).

6.2.2.2. Power, Status and Expectations

In social exchange, the social actor making the referral retains the reward power, where another social actor is rewarded with the referral if they meet the expectations of the referrer (Blau, 1968). In this study, participants made a referral to palliative care if they met referrer expectations and agreed with the line of management advised by the oncologists. This one-sided dependency leads to asymmetrical relationships where the person receiving the referral is obliged to comply with the person's wishes making the referral (Blau, 1968). This unilateral dependency leads to coercive power where a social actor has the power to obtain compliance of the other (Blau, 1968). This phenomenon was observed both in the review and research findings. Oncologists and haematologists preferred to control and coordinate the care at all stages of the illness trajectory and wished to retain control over the patient even when the

palliative care providers managed them. In an exchange relationship, a social actor's status or superior attributes allow them to command others' compliance (Emerson, 1976).

Expert power is where the social actor believes that she or he has expert skills and knowledge in a domain not possessed by another social actor, and legitimate power is derived from the virtue of their position (Yukl & Falbe, 1991). In this study, the qualifications and experience of the palliative care provider influenced referral. The participants from the more established specialities of paediatric oncology and haematology thought that they had higher qualifications by virtue of their training in paediatrics and oncology and were more experienced than palliative care providers. There are fewer palliative care specialists in India as specialist palliative care training in India only started in 2012 (Salins, 2015). Only a few centres in India offer palliative care physician training (Salins, 2015). Barring a few overseas trained specialists, most of the palliative care specialists trained in India have less than five years of consultant level experience. The bulk of India's palliative care workforce are generalists with limited training in palliative care (Kumar, 2013). Generalists, as described earlier, mostly practice in standalone hospices and provide home-based palliative care (Kumar, 2013). Paediatric oncology training in India is twice as long as palliative care training, and paediatric oncology is an established speciality for more than two decades (Arora & Banavali, 2009). Therefore, there is a hierarchical relationship between oncologists and palliative care providers determined by qualifications and experience and paediatric oncologists felt that they had expert and legitimate power or authority to control and coordinate all referral activities (Blau, 1968). These observations were supported by the review findings where oncologists and haematologists had the power to gatekeep the referral

process and perceived palliative care referral as loss of control and interference in the care process.

6.2.2.3. Symbolism and Stigma

Exchange behaviour also has a symbolic perspective where social actors interact and communicate about a phenomenon using symbolic inferences (Cook & Rice, 1989). In the review, oncologists and haematologists felt that palliative care referral symbolised the loss of hope, a break in therapeutic relationship and abandonment. In this study, participants felt that the relationship between oncologists and patients is akin to a family relationship where palliative care referral was equated to handing over the family member to another person symbolising therapeutic failure and failing the child. This symbolic perspective was not limited to oncologists and haematologists. The participants felt that families equated palliative care referral as a change in the child's condition, the intent of treatment or that the child was not going to survive.

Stigma refers to a complex phenomenon characterised by social structures like stereotypes, prejudices and discrimination (Major & O brien, 2005). In both the study and review findings, the oncologists and haematologists expressed stigma associated with palliative care due to the negative stereotyped association of palliative care with death. Public stigma refers to stereotyped thoughts based on public opinion (Vogel et al., 2013), and due to the public stigma associated with palliative care, families were disinclined to associate with palliative care. According to the study participants, both families and oncologists had negative views about palliative care. Label avoidance stigma refers to not pursuing a line of management due

to the stigma associated with its name (Strickland, 2018). In the review, oncologists and haematologists avoided the term palliative care as it induced fear. Families got alarmed on mentioning palliative care, and the oncologists had to provide explanations about palliative care. In this study, participants avoided the term palliative care as it symbolised the loss of hope and negative attributes. A mixed-methods study explored public knowledge, attitudes and perceptions towards palliative care (McIlfatrick et al., 2021). It showed that public understanding of palliative care is derived mainly from the experiences focused on the end of life care and not the holistic journey contributing to stigma (McIlfatrick et al., 2021). The perception of public stigma and label avoidance stigma among oncologists and haematologists conferred them the social power to exclude palliative care providers from the care process (Link & Phelan, 2014).

6.2.2.4. Task and Efforts

The efforts needed to complete the task has a significant bearing on the future exchange (Lawler, 2001). The social actor's contribution to the task depends on the perceived fairness of the effort to reward ratio (Cropanzano et al., 2017). If the effort-reward ratio is inequitable, the social actor may have diminished interest in the exchange relationship (Lin & Huang, 2010). Therefore, social exchange behaviour is moderated by the social actor's perception of the effort to reward ratio (Janssen, 2000). In both review and in the study, oncologists felt that efforts needed to make a palliative care referral were significant as they had to deal with a palliative care team with limited resources and capacity. Limited access to palliative care was a significant barrier for paediatric palliative care integration in Eurasian countries (Ehrlich et al., 2020). India also has similar barriers regarding the capacity to provide palliative care (The Economist Intelligence Unit, 2015). Overcrowding and long waiting times are due to a

significantly smaller number of palliative care physicians when compared to oncologists, which reduces accessibility and effectiveness (Daniel & Varghese, 2019). Moreover, in most cancer centres, adult palliative care providers see children and adults with cancer together in the same outpatient clinic (Palat et al., 2018). The majority of patients with moderate to severe cancer pain have poorly controlled pain due to limited access to opioids secondary to the complicated opioid licensing system in India (Lebaron et al., 2014). Therefore, considerable caseload, lack of dedicated space and time for children with cancer, poorly controlled pain and symptoms could lead to a negative perception of palliative care among parents and families. The absence of standard referral criteria could make the task of referral challenging. Furthermore, paediatric oncologists are more likely to refer if there is a screening tool for identifying children with palliative care needs and standard referral practices (Cuviello et al., 2021).

6.2.2.5. Rewards, Cost, Profit and Value

Anything that leads to a selective repetition of a previous behaviour is a reinforcer (Ekeh, 1974). Reinforcement is a central concept in a social exchange relationship, and reinforcement behaviour is strongly linked to rewards, cost, profit and value (Chadwick-Jones, 1976). Socially significant behaviour will not be repeated unless it is reinforced (Chadwick-Jones, 1976). From a social exchange perspective, several kinds of rewards are described (Gergen et al., 1980). Moreover, rewards are not restricted to physiological or materialistic benefits but can extend to higher self-actualisation needs (Gergen et al., 1980).

Behavioural rewards are linked to immediate outcomes of activity that determine future exchange (Gergen et al., 1980). Social actors notice these rewards first as they are outcomes

of short-term association (Gergen et al., 1980). In both the review and this study, most oncologists appreciated behavioural rewards in the form of pain and symptom management, improvement in the quality of life, better family coping, enabling prognostic discussion, decision-making support, and advance care planning. The study found that they also appreciated the support children received at home during the terminal phase of the illness.

Relational rewards are the long-term benefits of continuous and extended association (Gergen et al., 1980). Social actors may notice these rewards late as they result from a longer-term relationship (Gergen et al., 1980). Some participants in this study felt that a collaborative relationship between the oncology and palliative care teams could enhance the productivity of the oncologists by reducing stress, saving time, improving treatment outcomes and sharing the responsibility of care. Saving the time of oncologists was the only relational reward noted in the review. Self-actualisation rewards are those that can transform the social actor and bring about personal growth (Gergen et al., 1980). Self-actualisation rewards were only seen in the study findings. A small number of participants felt that the association with palliative care has improved their symptom management and prognostication skills and has made them more empathetic and compassionate. A systematic review showed that paediatric oncology providers experience severe stress and burnout due to the child's pain and suffering, disease progression, the child's death, talking to families, workload and a lack of practical resources (Mukherjee et al., 2009). Work-related factors were often the most common cause for burnout (Roth et al., 2011), and collegial support was viewed as the mitigating factor that enabled paediatric oncologists to overcome it (Moody et al., 2013). In this study, oncologists and haematologists appreciated the collegial support of palliative care colleagues, which cemented the relationship between the two teams and facilitated referral.

In social exchange, the cost is characterised as the loss incurred during the pursuit of rewards (Homans, 1958). and is considered the withdrawal of a positive reinforcer or application of a negative reinforcer (Chadwick-Jones, 1976). It causes the social actor to forego the exchange process or choose an alternative (Chadwick-Jones, 1976). The more costly the activity, the less often it is undertaken. Profit is reward minus costs, and the social exchange process will continue when the social actor stands to profit from the exchange (Gergen et al., 1980). In both the review and this study, oncologists experienced the disadvantage of palliative care referral as the palliative care team provided conflicting information about the patient's clinical condition, prognosis and outcomes causing families to receive mixed messages from the oncology and palliative care teams. In the review, oncologists felt that patients' cancer and supportive care treatment got curtailed while receiving palliative care. Moreover, the financial cost of treatment could poses a significant challenge in accessing care in a resource-constrained setting (Salifu et al., 2018). A small number of participants in this study felt that the additional fee for a palliative care consultation also hindered referral.

Beyond reward, cost and profit, the social actor also considers the value of exchange (Gergen et al., 1980). Value is the social actor's satisfaction from performing the activity and the positive feelings derived from another social actor during the exchange (Chadwick-Jones, 1976). Beyond the immediate and relational rewards, in this study, participants felt that early palliative care adds value to patients and their families in terms of rapport building with the palliative care team, smooth transitions of care and an opportunity to receive symptom control and supportive care concurrently during cancer treatment. There is value in addition to oncologists and haematologists in terms of having a partner in the care process whom they can trust, work together and share responsibilities. According to the reciprocity norm, the

benefit should be returned, and one who gives the benefit should not be harmed (Blau, 1968). Study participants felt that palliative care providers should also feel valued. According to the oncologists, requesting palliative care providers to be part of the oncology team and inviting them to participate in joint clinics might improve family acceptance of palliative care as families may identify them as part of oncology services.

6.2.3. Going beyond the Social Exchange Theory

6.2.3.1. Need for going beyond the Social Exchange Theory

The entire research and review findings can be divided into two parts, appraisal and feedback. The first three study themes and the initial four review themes related to presuppositions, task and cost-benefit of palliative care referral. The oncologists and haematologists appraised their palliative care referral experience and provided views on what facilitates and hinders referral. In the fourth study theme and the fifth review theme, they expressed views on what strategies might be employed to facilitate referral and develop an integrated palliative care model.

From a social exchange perspective, a comparison level is a form of appraisal, where the social actor assesses the exchange relationship to determine how far it is satisfying to the individual (Thibaut & Kelley, 2008). Comparison level for alternatives means the lowest level of profit acceptable in the face of available alternatives (Thibaut & Kelley, 2008) and is dependent on the social actor's knowledge of other available relationships, and the potential reward-cost potential believed to exist in those (Chadwick-Jones, 1976). Moreover, it also depends on the lowest level of outcomes or profit acceptable in the current relationship (Chadwick-Jones, 1976). If the profit is more significant in the other available relationships, the social actor may

break the relationship and choose the alternative (Chadwick-Jones, 1976). In both, the study and review, oncologists and haematologists never discussed the possibility of choosing an alternative approach or services for their patients. It could be because there is no alternative to palliative care in advanced cancer setting apart from managing these children themselves. They instead provided strategies through which relationships between oncology and palliative care teams can be fostered, their perspectives on how palliative care team can be bettered, and the exchange process of referral may be improved.

The first three study themes and the initial four review themes fitted well with the social exchange theory (Ekeh, 1974). However, I felt that social exchange theory was inadequate to discuss the last study and review theme as the comparison level as described earlier was the limit of social exchange theory (Ekeh, 1974). Therefore, I searched for a new theory that could complement social exchange theory and explain the study findings. Among the various theories considered, I felt that feedback intervention theory (Kluger & Denisi, 1996) effectively complemented social exchange theory (Ekeh, 1974) and was found helpful in interpreting some study and review findings. The justification of my choice to consider feedback intervention theory is provided in the next section.

6.2.3.2. Justification for introducing Feedback Intervention Theory

Appraisal and feedback are the essential quality improvement strategies required to bridge the gap between actual and desired clinical practice (Ivers et al., 2012). It promotes change in behaviour and improves the performance of the health care providers and healthcare (Foy et al., 2005), and can improve patient care effectively across various clinical settings (Hysong

et al., 2017; Ivers et al., 2012). In feedback intervention theory, the social actor appraises the situation in terms of the discrepancy between actual goals and desired goals, evaluates the performance relative to the goals and then provides feedback (Kluger & Denisi, 1996). The purpose of appraisal in social exchange theory is to decide whether to continue or discontinue the relationship, whereas the purpose of appraisal in feedback intervention theory is to reduce the discrepancy between actual and desired goals by improving performance through feedback (Kluger & Denisi, 1996; Shortell, 1974). In both the review and study findings, appraisal of palliative care engagement in terms of facilitators and barriers for referral was followed by strategies to foster integration. In my study, the researcher is a palliative care physician exploring the phenomenon of palliative care referral. Therefore, there was a process of co-construction of knowledge where paediatric oncologists and haematologists provided their views and strategies to better palliative care integration to a researcher with palliative care expertise as a feedback mechanism. Feedback intervention theory is visually represented in **Figure 6.1.**

Figure 6.1. Feedback Intervention Theory
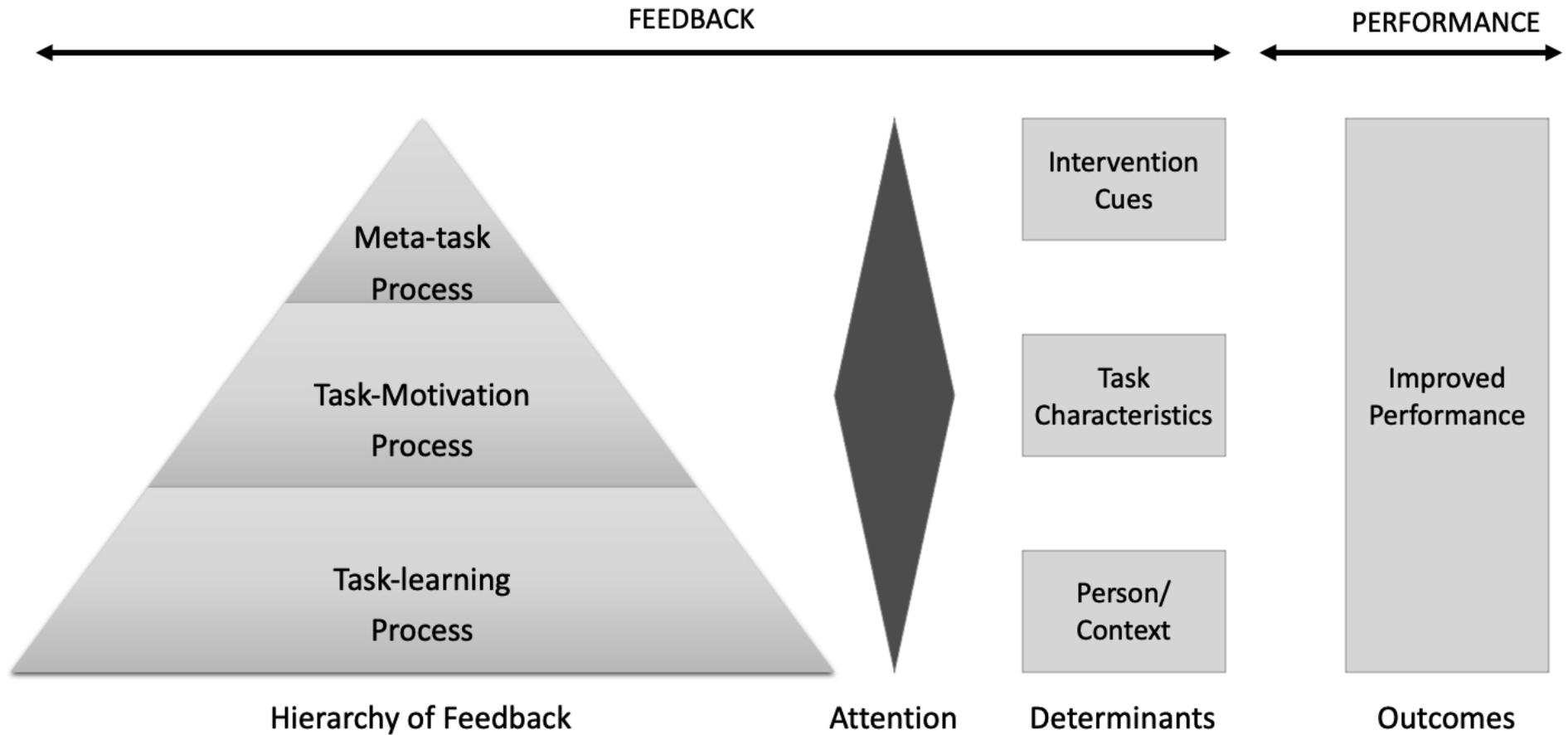
6.2.3.3. Interpreting Research Findings using Feedback Intervention Theory

Feedback intervention theory describes four different coping mechanisms of feedback (Kluger & Denisi, 1996). A person may increase the effort without lowering the standard, lowering the standard, abandoning the standard or disregarding the feedback message (Kluger & Denisi, 1996). In both review and study findings, the oncologists preferred to work with a palliative care team with the highest standards. Therefore, palliative care providers might have to focus on their team development to agree with the standards expected by the oncologists.

Three levels of feedback hierarchy have been described (Kluger & Denisi, 1996). At the top of the hierarchy is the meta-task process, where feedback is directed at a personal level or self. It addresses self-efficacy, self-discrepancies and the emotional response to feedback. The middle-order is the task motivation process that addresses the focal task processes that stimulate motivation to improve performance. The lower order is the task-learning process that deals with details of the task and the learning process needed to complete the task. For the feedback to be successful, the focus of attention should be on the task motivation process. Feedback focused on the self or the task details are often perceived as negative and less acceptable by the social actor receiving the feedback (Kluger & Denisi, 1996). In this study, the participants provided all three types of feedback to the researcher.

Representing palliative care providers as part of the oncology team was a task motivation feedback (Kluger & Denisi, 1996). They liked palliative care providers to be at the same level as oncologists by introducing them as part of the oncology team, palliative care providers to be present during the initial consultation, and palliative care to participate in oncology team

meetings. They believe this motivates palliative care providers to provide concurrent care and facilitates collaboration. A lack of concurrent care and advance care planning hinders palliative care integration in paediatric oncology (Kaye et al., 2018). Therefore, these suggestions could fit well with the embedded paediatric palliative oncology model where the paediatric palliative care team is situated in the oncology clinic, ward round and meetings, and identified as part of the oncology team (Desanto Madeya et al., 2017). Although embedding is an excellent suggestion for an integrated palliative care model (Kaye et al., 2017), it may not be a practical suggestion considering paediatric palliative care resource constraints in India (Palat et al., 2018).

Task-level feedback (Kluger & Denisi, 1996) was to rebrand the palliative care service and covertly introduce it early as a symptom control team. Other task-level feedbacks were improving awareness among oncologists about palliative care, inter-team communication and having institutional palliative care referral guidelines. Oncologists liked to introduce palliative care early and covertly as a symptom control team. Oncologists felt that a covert introduction minimises palliative care stigma and family resistance. Negative parental attitudes about palliative care were an important barrier for referral in a paediatric oncology setting (Levine et al., 2017). Literature on early palliative care integration in paediatric cancer settings (Kaye et al., 2016; Liberman et al., 2016; Mahmood et al., 2016; Rapoport et al., 2012) has not explored covert relationships as a strategy for early integration. Perhaps this is a new finding that needs further exploration. A paper describing nurse-patient covert negotiations mentions how a covert relationship over a period of time can emerge into a mutually satisfying clinical relationship (Morse, 1991). Furthermore, an ethnographic study showed

how health care providers in a palliative care setting use interpretive repertoires to covertly negotiate their role in decision making (Bélanger et al., 2016).

The meta-process or personal feedback (Kluger & Denisi, 1996) was present in relation to oncologists expecting palliative care providers to be readily available and accessible, comprehensive in their clinical approach, and to have training in oncology and paediatrics. When adult palliative care providers consult children, the paediatricians often have concerns about their medication management, communication and prognostication skills (O'Leary et al., 2006). Although adult palliative care principles are relevant, many fundamental differences influence its application in the paediatric setting (Hynson & Sawyer, 2001). Paediatric palliative care has distinct challenges and needs a different skill mix (Spathis et al., 2012). Training can be achieved by adult palliative care physicians having exposure to paediatric palliative care and working in paediatric palliative care inpatient settings (Spathis et al., 2012). Therefore, this feedback has a practice-changing application where adult palliative care providers seeing children with palliative care needs ought to have some training in paediatrics.

Three factors determine the effect of the feedback intervention on performance. The first factor was the cues for the intervention (Kluger & Denisi, 1996). Feedback has to be very specific, like a particular task, potential action or goals to be achieved. Specific feedback is much better accepted and improves performance compared to general feedback (Kluger & Denisi, 1996). The specific feedback from oncologists corresponds to palliative care providers creating a referral pathway, making efforts to improve awareness of palliative care among oncologists and participating in oncology team meetings.

The second factor is the nature of the task. If the task is highly complex and cognitively demanding, feedback is unlikely to change performance (Kluger & Denisi, 1996). The feedback provided by the oncologists had a mix of tasks that were both easy and complex. Rebranding palliative care services, training palliative care providers in oncology and paediatrics, having palliative care teams embedded in oncology services, and round the clock availability of palliative care services were complex tasks that could take increased time and efforts to accomplish. A lack of palliative care awareness among oncologists (Rost, 2020), and limited access to palliative care providers and resources (Ehrlich et al., 2020) hindered palliative integration in paediatric oncology. Furthermore, interprofessional palliative care education for paediatric oncologists was identified as a crucial task to facilitate integration (Dalberg et al., 2018; Green & Markaki, 2018). Improving awareness among oncologists about palliative care, preparing referral guidelines and improving inter-team communication can be attained with less effort. Identifying high-yield triggers for paediatric palliative care consultation and incorporating these triggers into a screening tool facilitated an early integration of palliative care in paediatric oncology (Cuviello, 2021). In a situation where the quantum of change needed to improve performance is less, feedback is better accepted compared to situations demanding drastic changes to improve performance (Kluger & Denisi, 1996). In this study, feedback provided by the oncologists suggests that the quantum of change needed to develop an integrated model of palliative care has tasks with wide-ranging efforts. The third factor is the person receiving the feedback and the context. Those with functional self-efficacy and self-esteem accept feedback better. In my opinion, the palliative care providers working in a non-hierarchical multidisciplinary team might be able to accept these feedbacks graciously and adapt. I have incorporated some of these suggestions positively in my clinical

practice. However, it will be interesting to see how other palliative care providers might respond to oncologists' suggestions when these findings are disseminated.

6.2.4. Review of Theory based on Research Findings

6.2.4.1. Proposing Modifications to Social Exchange Theory

The critical realist approach supports the analytical evaluation of theories based on research findings and allows suggestions to modify the theory with explanation (Sayer, 1992). The social exchange theory (Ekeh, 1974) has been critiqued as a theory with overlapping constructs (Cropanzano et al., 2017), poor characterisation of the domains (Davies, 1995), and representing the exchange as an economic phenomenon (Zafirovski, 2005). Based on the study and review findings I would like to propose a critique and modification to the social exchange theory (Ekeh, 1974).

One of the elements of social exchange theory is a comparison level for alternatives (Thibaut & Kelley, 2008). The comparison level and comparisons level for alternatives are the two levels of appraisal (Smith et al., 1990). The comparison level is the benefit-cost appraisal of the social exchange, and the comparison level for alternatives is the exploration of other potential relationships that are more rewarding than the existing relationship (Smith et al., 1990). Social actors continue their commitment to the relationship as long as they find them more profitable than the alternatives (Thibaut & Kelley, 2008). In both the systematic review and study findings, oncologists appraised the exchange relationship in terms of benefit and cost. There were no suggestions regarding exploring an alternate relationship or strong preferences about providing palliative care themselves. Instead, they suggested strategies, which they perceive as important for the development of palliative care teams. People can

continue to stay in the relationship for want of better alternatives or due to dependency in a relationship (Gelles, 1983; Sabatelli & Cecil-Pigo, 1985). However, in both the systematic review and study findings, the participants valued the benefit of the relationship and indicated their voluntary continuation of the relationship by providing feedback and solutions. Therefore, it is suggested that adding feedback and solutions alongside a comparison level for alternatives represents a modification to the social exchange theory resulting from this study (Ekeh, 1974).

6.2.4.2. Developing an Infinite Loop Model

The concept of an infinite loop is derived from computer programming, where a sequence of commands makes a loop infinite, and the computer program runs endlessly unless an external intervention terminates the command sequence (Hoare, 1969). In a computer, these non-terminating programs caused by an infinite loop often consume resources without any output. However, the infinite loop in the context of integrated palliative care may be aspirational and advantageous in creating a self-activating system for oncology and palliative care to collaborate and improve palliative care access and outcomes.

Figure 6.2 shows the first loop formed by the social exchange theory (Ekeh, 1974), where previous involvement in the exchange and presuppositions about the provider form assumptions. The social actor appraises the exchange situation for benefits, constraints, task, and value of the exchange. The immediate and long-term experience of the exchange influences assumptions. The assumptions are tendencies, which in the presence of triggers sways the social actor to choose or refuse to participate in the exchange.

Figure 6.2 shows the second loop formed by feedback intervention theory (Kluger & Denisi, 1996), where the social actor appraises the exchange situation and provides feedback to improve performance. Feedback by a social actor is directed at processes that improve self-efficacy, motivation, or another social actor's task learning. The purpose of the feedback is to reduce the discrepancy in the desired and actual goal by improving the collaborating team's performance and collaboration.

The infinite loop is formed when social exchange theory and feedback intervention theory are joined together at the appraisal level. **Figure 6.2** provides a visual representation of two theories before the formation of the infinite loop. The union of two theories at the appraisal level demonstrates the interdependency and influence of these theories on the exchange process. Feedback improves collaboration and performance, which will have an impact on future appraisals. Appraisals determine the experience and assumptions. The assumptions form tendencies, which in the presence of triggers, impact referral behaviour and appraisals. The infinite loop model is visually represented in **figure 6.3**.

Figure 6.2. Two Theoretical Frameworks Joining Together to Form the Infinite Loop

Loop 1: Social Exchange Theory

Loop 2: Feedback Intervention Theory
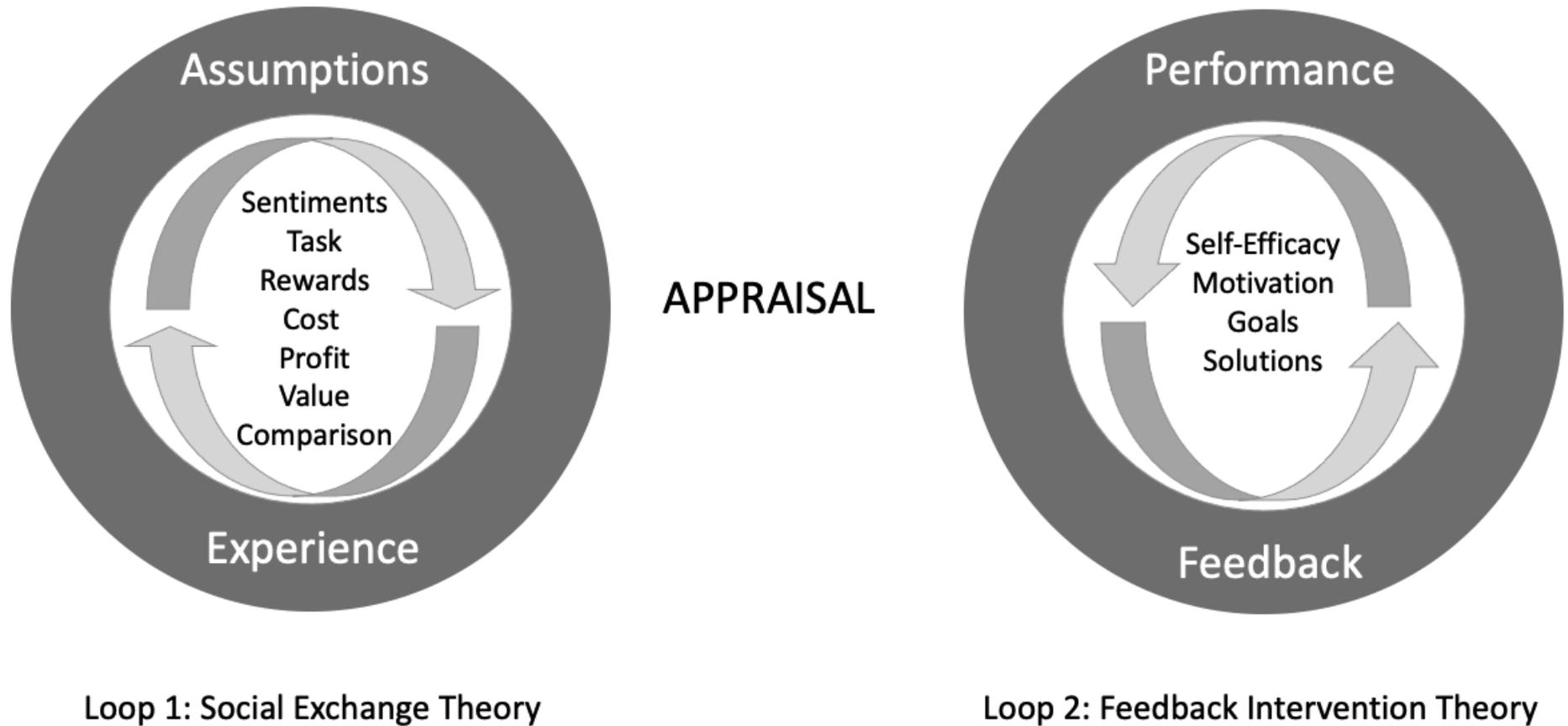
Figure 6.3. Infinite Loop Model: An Aspirational Model for Integrated Palliative Care
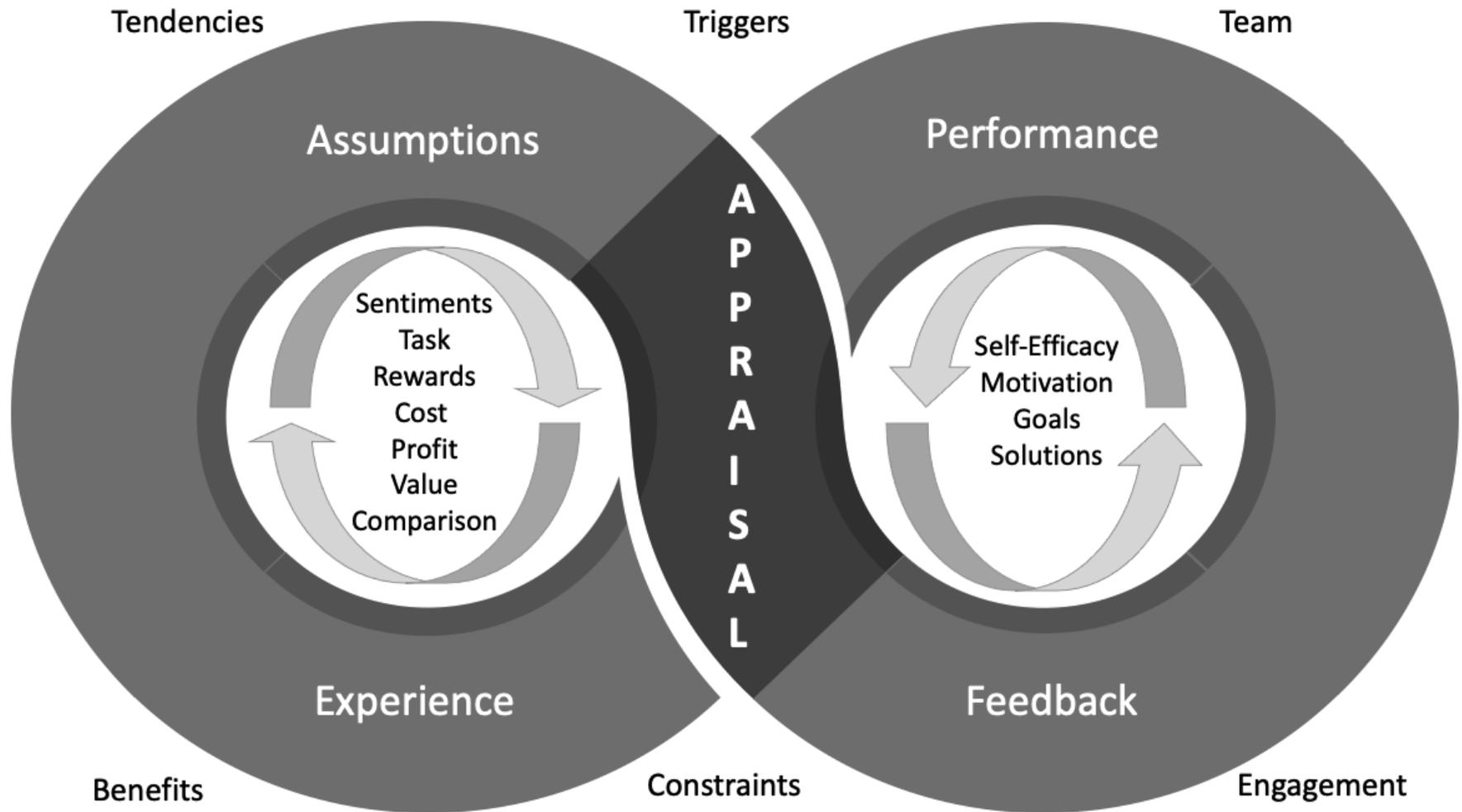
6.2.4.3. Proposing the Infinite Loop Model as an Aspirational Model for Integrated Palliative Care

In one of the earlier definitions, integrated care is described as bringing together inputs, delivery and services management (Gröne et al., 2001). Inputs in integrated care have a wide-ranging role, from the transfer of patient information at an individual level to the development of a patient navigation system (van der Klauw et al., 2014). Some inputs are directed towards professionals and aim to change healthcare providers' attitudes (van der Klauw et al., 2014). Feedback provided by the oncologists and haematologists in this study is a form of professional input directed at developing the palliative care team. Oncologists feel that there should be a more robust integration between palliative care and oncology (Davis et al., 2015). A professional network between two teams based on personal relationships, trust and shared values facilitate integration (Eerden et al., 2018). Participation of palliative care providers in multi-disciplinary cancer meetings and seamless coordination of care between the two teams can facilitate professional networking and integration (Ewert et al., 2016; Nottelmann et al., 2019; Siouta et al., 2016). However, the inputs provided in these meetings are often regarding a patient's clinical condition (Siouta et al., 2016). Professional input to improve palliative care providers' attitudes and performance are seldom provided (van der Klauw et al., 2014). Therefore, palliative care providers may continue to remain within their silos, oblivious to the needs and expectations of oncologists and haematologists.

The infinite loop model shown in **figure 6.3** aims to bridge a crucial missing link in the integrated model of palliative care, hypothesising that oncologists' continuous feedback might facilitate development of the palliative care team and vice-versa, thereby influencing appraisal. Appraisal during the referral process creates experiences, and these experiences

influence assumptions. Assumptions are the tendencies that influence referral behaviour. However, a lack of change in performance following feedback, limited or non-availability of services and strong presuppositions of the oncologists could interrupt the infinite loop. Ideally, the feedback process should be a bidirectional process where palliative care providers both receive and give feedback to the oncologists. As described before, the power differentials between oncology and palliative care team might hinder bidirectional feedback. Furthermore, I am not suggesting that the palliative care team should simply accept and acquiesce to this hierarchical system. Therefore, the infinite loop model is proposed as an aspirational model. Future testing is required to ascertain its role in integrated palliative care.

6.3. Reflections: My Soul-Searching Journey as a Researcher

The last five years of doctoral education and conducting doctoral-level research has immensely furthered my personal growth. I can now say my journey was my destination. It has taught me critical reasoning, a discursive approach, academic writing and most importantly, how to be reflexive. In many ways, it has complemented my skills as a physician. However, the journey from physician to physician-scientist had its share of trials and tribulations.

In the initial days, my decision to pursue a PhD was questioned by my peers. They wanted to know as a clinician what I stand to gain from doing a PhD. It has been my existential question throughout the PhD journey, more so when faced with unexpected challenges that life throws at you. The beginning of my taught phase was very perplexing, and on a few occasions, I contemplated discontinuing the program. It took me a long time to fit in and understand the

subtleties of the research world. I had to unlearn many things from my physician training to grasp the nuances of research.

The research topic was a sensitive subject. My research participants and I found it challenging to navigate some conversations, especially recounting stories of a child's death. Two participants experienced distress during the interview, and the interview had to be temporarily suspended. I had chosen the research topic before my son was born. My son was three months old when I commenced my first interview and almost two years old during the last interview. On a few occasions, interviews triggered intense emotions, which prompted me to seek the help of my colleagues and debrief.

Conducting this research was challenging due to participant recruitment. The research participants were busy clinicians and getting research appointments was an uphill task. I had to undertake many air travels to various cities in India that involved considerable cost and time away from work. Working as a full-time palliative care consultant, I had to manage work commitments and interview appointments. Some last-minute cancellations of interview appointments were frustrating. On many occasions, I had to wait for a few hours outside the consulting room before interviewing the participant.

Some of the research findings have challenged my presuppositions and practice. Some participants thought that paediatric training and oncology training are essential for providing palliative care in paediatric oncology. I am an adult palliative care physician. My paediatric palliative care work is around 50% of full-time equivalent work. The research findings have posed a moral dilemma about my appropriateness to continue as a paediatric palliative care

practitioner due to my lack of training in general paediatrics. That said, there are only a few palliative care practitioners in my country with paediatric training. Moreover, I have worked closely with the paediatric and paediatric oncology team for more than twelve years, participating in joint clinics, multi-disciplinary meetings, and ward rounds. I am hoping that some imbibed learning is still relevant. Another research finding that has challenged me personally is that some participants felt that palliative care practitioners lacked compassion and empathy. I believed we took the high moral ground and condescended other specialities for their lack of compassion and empathy. These claims need thoughtful introspection.

Although I enjoyed the process of being a student and a researcher, my mind can never cease to think about the sacrifices my family has made to make this happen. Most parts of this thesis were written working full-time in a COVID-19 hospital during a pandemic situation. Uncertainty, work pressure, multiple exposures to COVID-19 patients, quarantine, significant stress bordering burnout compounded by untimely deaths of near and dear ones led to frequent interruptions in my thesis writing. In all these uncertain times, I constantly wondered if this thesis will ever make sense in the future.

6.4. Limitations and Strengths

6.4.1. Limitations

The phenomenon of palliative care referral in a child with advanced cancer has multiple stakeholders. The study findings only reflect the views of paediatric oncologists and haematologists. It is a one-sided view. To understand the phenomenon completely, we need to know the perceptions of patients and their families and palliative care providers.

The research invitation email was sent to a large number of paediatric oncologists and haematologists across India. Many did not respond, and a few declined the invitation without reason. There is a possibility that participants with a particular view of palliative care responding to the invitation and participating in the study skewed the study results.

Only those oncologists and haematologists who were already referring to palliative care were included in the study as they would have detailed, insightful information about facilitators and barriers for palliative care referral. The views of those who were not accessing palliative care services are unknown. Only participants practising in the hospital setting were included in the study. The majority of paediatric oncologists and haematologists practising in the hospital setting are in public-funded and trust hospitals. The views of private oncologists' practising in standalone cancer clinics not attached to hospitals are not known. All the participants included in the study are paediatric oncologists and haematologists working in paediatric cancer units. In India, many adult oncologists care for children with cancer. Their views are not captured in this study.

There was a gender gap in research participation. Less than one-third of the research participants were women. However, this is consistent with the gender split among paediatric oncologists and haematologists in India. More than half of the participants were trained overseas, where they had exposure to palliative care during oncology training. The majority of paediatric oncology training centres in India lack paediatric palliative care services. It would be interesting to see whether palliative care referral views remain the same or change when there are a higher number of paediatric oncologists trained in India.

At times it was challenging to disaggregate my role as a clinician and researcher during research interviews. Some participants had googled me and knew who I was before the interview, which could have coloured their responses. There were occasions when the participants prompted me to answer the questions asked to them during the research interviews. What do you think about it? What is your opinion? I had to politely decline and tell them that I will take these questions after the researcher interview. Moreover, there is a possibility that my knowledge and experience in the phenomenon explored could have influenced my line of questioning in the research interviews and varnished my data analysis.

6.4.2. Strengths

Before finalising the research topic, I presented the research protocol in a paediatric oncology meeting and received their inputs. The research protocol was also discussed informally with a few parents in a paediatric oncology support group meeting to know their views and determine the utility of conducting this research. Both the parents and the paediatric oncologists supported my study proposal and felt it was beneficial.

The interview topic guide was discussed with two paediatric oncologists, and two pilot interviews were conducted. Post pilot interviews, the interview topic guide was reviewed by the research supervisors and finalised, which contributed to the robustness of the research process.

Twenty-two research participants were recruited from thirteen cancer centres traversing seven cities across India. The research participants were a homogenous group of paediatric

oncologists and haematologists practising in a paediatric cancer unit and referring to palliative care. They were familiar with the phenomenon and provided in-depth, insightful information during the research interviews. The research had good country coverage, and unlike a survey-based data collection, these research interviews were generally detailed and provided excellent information about the research question explored.

Using reflexive thematic analysis (Braun et al., 2019) as the data analysis method facilitated going beyond the domain summaries of participant's views at a semantic level to a latent level interpretation of the data. I work as a paediatric palliative care physician. I know about palliative care in paediatric oncology, regularly interact with paediatric oncologists and haematologists and have presuppositions about palliative care in paediatric oncology. Reflexive thematic analysis (Braun et al., 2019) allows for the use of the researcher's subjectivity and acknowledges the researcher's active role in the knowledge production process.

6.5. Implications of Research on Policy and Practice.

The research findings have many implications for policy and clinical practice. There is a need for palliative care trainees to have training in both oncology and paediatrics. This could be achieved by a combination of classroom teaching and clinical rotations. Likewise, there is a need for oncology trainees to have palliative care training and to include palliative care in the oncology curriculum. Oncology trainees also should have palliative care rotations and could benefit by participating in palliative care case-based discussion. Awareness about palliative care among oncology consultants can be improved by incorporating palliative care topics in

oncology medical conferences. Adult palliative care providers may need to receive additional training in general paediatrics to make them qualified to see the paediatric population. This may be relevant to India and other resource-limited settings where there is a shortage of paediatric palliative care providers. These findings may not be generalisable to resource-rich settings where there is sufficient coverage of both specialities. Furthermore, public awareness about palliative care may dispel any myths and misconceptions about palliative care. It may help in mitigating the stigma associated with palliative care.

Research findings suggest a need for capacity building of paediatric palliative care services. The existing palliative care services can create a separate space in palliative care outpatients to see children and their families. Moreover, training palliative care providers in communication and emotional aspects of care may help them manage children and their families sensitively and compassionately. There is also a need to develop community-based services to ensure the child receives care at home and dies at home.

Oncologists prefer palliative care providers to join them in consultations, family conferences and multi-disciplinary team meetings which may provide an excellent opportunity for both teams to bond and build confidence. Moreover, it may help children receiving cancer treatment to receive symptom management and supportive care from the palliative care perspective. Oncologists preferred palliative care providers to close the referral loop by providing information about the patients, which could be achieved during the multi-disciplinary team meetings. Oncologists have expressed the need for hospital policy and referral criteria. The palliative care team could advocate for an institutional policy on paediatric palliative care that could become a norm for accreditation of paediatric cancer

centres across the country. Creating referral criteria based on disease factors, symptoms and psychosocial needs might advance standardising paediatric palliative care referral.

The palliative care community in India might need to explore a less threatening nomenclature that is acceptable to oncologists and families to ensure children in the initial phases of the illness trajectory are not excluded from receiving palliative care benefits.

6.6. Areas for Further Research

This qualitative study interviewed twenty-two participants across India. However, India has around 300 cancer centres with many paediatric oncologists and adult oncologists caring for children with cancer. A survey study using a questionnaire developed from the study findings could enhance knowledge in this topic. It would be advantageous to know if the adult oncologists' views caring for children with cancer on palliative care referral are the same as those of paediatric oncologists. Moreover, it would also add to our understanding to know the views of paediatric oncologists practising in private clinics.

This research has identified views about palliative care referral from the perspectives of oncologists and haematologists about referring a child with cancer. A similar study exploring the views of palliative care providers and families in India about referral practices would fill a knowledge gap.

One of the research participants' suggestions was for palliative care staff to be part of the oncology team and be present during consultations, family conferences and oncology team

meetings. The feasibility and effectiveness of the embedded clinic model in the Indian setting would need evaluation. The infinite loop model was the concept developed from this research where feedback influences the performance of the palliative care team, which influences appraisal, experience and assumptions and impacts referral behaviour. Future research is needed to test the infinite loop model hypothesis proposed by the researcher.

6.7. Conclusion

In this study, oncologists and haematologists' views of what facilitates and hinders referral of a child with advanced cancer to palliative care in India were explored. Twenty-two paediatric oncologists and haematologists participated in this study. The critical realist paradigm was the philosophical foundation informing this study (Bhaskar, 1978). Participants were interviewed using a semi-structured interview (Jamshed, 2014), and the interview transcripts were analysed using Braun and Clarke's reflexive thematic analysis (Braun et al., 2019).

The views of oncologists and haematologists managing children with cancer on facilitators and barriers for palliative care referral were discussed in relation to broader literature, philosophical underpinnings, and theoretical frameworks. Several new findings were identified and were discussed in relation to the research question and research settings. The stratified layer of generative mechanisms leading up to the phenomenon of palliative care referral was explored, discussed and interpreted using social exchange theory (Ekeh, 1974) and feedback intervention theory (Kluger & Denisi, 1996).

6.7.1. Contribution to Knowledge and Clinical Practice

6.7.1.1. Summary of Novel Study Findings in Relation to Literature Review

In this section, I outline the novel findings of this study after considering the literature review and the wider literature, and how these develop our previous understanding of the phenomenon.

Oncologists acknowledged their limitations in providing palliative care and were willing to seek help. They expressed their inability to meet all palliative care needs comprehensively and wished to engage with a specialist palliative care service. Unlike the review, the benefits of palliative care engagement were not limited to patients and families. Oncologists felt that long-term palliative care collaboration helped them develop symptom management, counselling and prognostication skills. They became more compassionate, confident and resilient. They felt less stressed, saved their time, and they found a clinical partner to share the responsibility. Although in the review, palliative care referral benefits were predominantly restricted to the terminal phase, in this study, the oncologists equally emphasised the significance of the supportive care role of palliative care during both treatment and terminal phases. Apprehension about opioid use was found in both review and research findings. However, in this study, the concern about opioid use was mainly during the active treatment phase, where the participants felt that morphine use could mask symptoms and cause complications.

The review findings suggested a change of the term palliative care. However, the call for rebranding was more pronounced in this study as some oncologists had already rebranded it themselves and introduced palliative care teams as symptom control services. One of the

strategies identified in this study is that oncologists introduced palliative care teams covertly as a symptom control team. There is no published literature reporting this covert practice. Perhaps branding of palliative care (Dai et al., 2017) as supportive care (Dalal et al., 2011) to enhance referrals might also amount to a form of covert practice.

In both the review and study findings, oncologists and haematologists expected high competency levels from palliative care providers. However, in this study, competencies were not restricted to clinical competency but were expanded to include attributes of emotional competencies like proactiveness and empathy. Paediatric oncologists and haematologists questioned their trust in the palliative care providers. Trustworthy providers were seen as benevolent, clinically competent, and had a thorough understanding of oncology *and* paediatrics an important finding given this study was about paediatric palliative care. Furthermore, oncologists relied on the families' feedback, which provided them with an opinion about the quality of palliative care services, which was another way of knowing the competencies, and informed future referral. As reported by the oncologists, positive feedback from families about the palliative care service received enhanced their trust in the palliative care team.

Although the nature of the power relationship between oncology and palliative care teams was identified in both review and research findings, the use of coercive power was more evident in the study findings. Coercive power was exercised by withholding referrals when palliative care providers were not meeting the oncologists' expectations and not agreeing to their proposed line of management. Furthermore, the expertise and qualifications of oncologists also conferred them the power to refer.

6.7.1.2. Theory Modification and Theory Development

The oncologists provided several strategies to facilitate an integrated paediatric palliative oncology model. Being available, proactiveness, comprehensive approach, embedding palliative care providers in the oncology team, providing concurrent care, inter-team communication, written policies for referral, and improving palliative care awareness amongst the oncologists fostered the partnership between two teams, facilitating a referral. A novel model of integrated palliative care known as the infinite loop model was proposed based on the research and review findings. Strategies suggested by the oncologists could be considered as feedback to a palliative care provider as professional inputs directed at further development of the palliative care team. The infinite loop model is derived from the union of social exchange theory (Ekeh, 1974) and feedback intervention theory (Kluger & Denisi, 1996) and is an aspirational model of integrated palliative care where feedback has the potential to improve the palliative care team's development, which might positively impact the appraisal and experience of palliative care referral from oncologists. A positive experience of referral could influence the presuppositions of oncologists and haematologists, facilitating future referral. At present, an integrated palliative care model is understood in terms of effective collaboration (Davis et al., 2015; Gröne et al., 2001; van der Klauw et al., 2014). Collaboration alongside continuous feedback directed at the palliative care providers could facilitate development and might foster integration (van der Klauw et al., 2014). This new awareness could inform clinical practice and has the potential to be part of the integrated palliative care approach. Furthermore, based on the study findings, I have suggested a modification to the social exchange theory (Ekeh, 1974), in that feedback and solutions may be included as concepts alongside the concept of comparison level (Ekeh, 1974).

6.7.2. Dissemination

The systematic review on views of oncologists and haematologists on palliative care referral was published in BMC Palliative Care (Salins et al., 2020). Moreover, the implications of the review findings on clinical practice were discussed in a national webinar on 09.01.2021. Many oncologists across India and my research supervisors participated as panellists. The final study results are accepted for presentation at the 17th World Congress of the European Association for Palliative Care to be held virtually in October 2021. The implications of the study results on paediatric palliative care practice in India was presented in the 28th International Conference of the Indian Association of Palliative Care held virtually in March 2021.

I am hoping to publish the final study results in Palliative Medicine. The needs of children with cancer and their families, palliative care referral practice and referral outcomes will be submitted as a review article to the Indian Journal of Palliative Care. I feel that the infinite loop model for integrated palliative care proposed based on study and review findings might find a place in an international cancer journal. Discussion on palliative care referral phenomenon using the critical realist paradigm and social exchange theory, its critique and theory modification could be published in a social science or nursing research journal.

Furthermore, I plan to disseminate the final results and its practice implications in the following conferences in 2021-22. A. Annual Conference of Paediatric Haematology and Oncology Chapter of Indian Academy of Paediatrics, B. Paediatric Haemato-oncology Conference and C. Conference of Indian Society of Medical and Paediatric Oncology. I am also planning to send a report on the research findings to all the research participants with all identifying details removed or anonymised.

6.7.3. Final Words

Competence, capacity building, collaboration, criteria for referral, and changing the name were the key research and review findings that might facilitate palliative care referral in a paediatric cancer setting. Training in oncology and paediatrics might enhance the competence of current palliative care providers. The capacity to provide palliative care has to be augmented by increasing palliative care training positions, hospital and home-based palliative care and increasing inpatient palliative care beds. Close collaboration could be achieved by palliative care providers participating in cancer consultations and meetings. Easy access and completing the communication loop of palliative care referral by providing feedback to oncologists might facilitate care coordination. Having clear referral criteria and guidelines on the referral process could offer clarity on referral practices. A change in name to symptom control or supportive care can be explored after seeking palliative care providers' consensus to facilitate early palliative care integration.

To ensure enhanced integration of paediatric oncology and paediatric palliative care, there is a need to further explore the facilitators and barriers for referral internationally in various practice settings. Except for the two studies included in the review, all other studies explored oncologists and haematologists' views in the adult setting. Although some adult palliative care principles are relevant in the paediatric setting, paediatric practice has its distinct challenges and nuances. The new research findings identified in this study could bridge some of the gaps in knowledge in palliative care referral in paediatric oncology settings and has the potential to provide some strategies to enhance collaboration between paediatric oncology and paediatric palliative care.

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Appendices

Appendix 3.1. Search Terms

	PubMed	CINAHL	PsycINFO	EMBASE	Free Text Terms
	MeSH terms	MH terms	DE terms	Emtree terms	
Concept 1 Views	1. Attitude of health personnel 2. Motivation 3. Emotions	1. Attitude of health personnel 2. Perception 3. Health behaviour 4. Health beliefs	1. Health personnel attitudes 2. Motivation 3. Health behaviour	1. Health personnel attitude 2. Health behaviour 3. Health belief 4. Motivation	1. Attitude* 2. Motivation* 3. View* 4. Perception* 5. Belief* 6. Behavio* 7. Perspective* 8. Opinion* 9. Think* 10. Thought* 11. Feel* 12. Emotion*
Concept 2 Oncologists Haematologists	1. Neoplasms 2. Hematologic Neoplasms 3. Oncology Service, Hospital 4. Hematology	1. Neoplasms 2. Hematologic Neoplasms 3. Oncologists 4. Oncology 5. Oncologic Nursing 6. Oncology care units	1. Neoplasms 2. Oncology	1. Neoplasm 2. Hematologic disease 3. Oncology 4. Oncologist 5. Cancer centre 6.Hematologist	1. Cancer* 2. Oncologist* 3. Hematologist* OR Haematologist 4. Tumour* OR Tumor* 5. Malignan* 6. Oncology
Concept 3 Referral	1. Referral and consultation 2. Practice patterns, physicians	1. Referral and consultation 2. Practice patterns	1.Professional referral 2. Professional consultation	1. Patient referral 2. Professional practice 3. Integrated health care system	1. Refer* 2. Cordinat* 3. Consult* 4. Collaborat* 5. Integrat* 6. Simultaneous 7. Concurrent 8. "Shared care" 9. Combin* 10. Engage* 11. Cooperat* 12. Continu*
Concept 4 Palliative Care	1. Palliative Care 2. Palliative Medicine 3. Hospice Care 4. Terminal Care 5. Home care services	1. Palliative Care 2. Hospice Care 3. Terminal Care 4. Hospice and Palliative Nursing 5. Home health care	1. Palliative Care 2. Hospice 3. Home Care	1. Palliative therapy 2. Terminal Care 3. Hospice 4. Home care	1. Palliat* 2. Hospice* 3. "Terminal Care" 4. "End of life care" 5. "Supportive Care" 6. "Supportive Oncology" 7. "Home care"

Appendix 3.2. List of Journals Hand Searched

1. American Journal of Hospice and Palliative Medicine

2. Journal of Clinical Oncology

3. BMJ Supportive and Palliative Care

4. Annals of Oncology

5. Palliative and Supportive care

6. Supportive care in cancer

7. Journal of Pain and Symptom Management

8. BMC Palliative Care

9. Palliative Medicine

10. Journal of Palliative Medicine

11. Indian Journal of Palliative Care

Appendix 3.3. Hawker's Tool

APPENDIX A
Assessment Form 1: Reject/Accept

Author(s):   Date of Publication:
Abbreviated Title:
Reviewer:

Relevance to Research Questions

APPENDIX C

Author and title: _____
Date: _____

	Good	Fair	Poor	Very Poor	Comment
1. Abstract and title					
2. Introduction and aims					
3. Method and data					
4. Sampling					
5. Data analysis					
6. Ethics and bias					
7. Findings/results					
8. Transferability/generalizability					
9. Implications and usefulness					
Total					

1. Abstract and title: Did they provide a clear description of the study?
Good	Structured abstract with full information and clear title.
Fair	Abstract with most of the information.
Poor	Inadequate abstract.
Very Poor	No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?
Good	Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge.
	Clear statement of aim AND objectives including research questions.
Fair	Some background and literature review.
	Research questions outlined.
Poor	Some background but no aim/objectives/questions, OR
	Aims/objectives but inadequate background.
Very Poor	No mention of aims/objectives.
	No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?
Good	Method is appropriate and described clearly (e.g., questionnaires included).
	Clear details of the data collection and recording.
Fair	Method appropriate, description could be better.
	Data described.
Poor	Questionable whether method is appropriate.
	Method described inadequately.
	Little description of data.
Very Poor	No mention of method, AND/OR
	Method inappropriate, AND/OR
	No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?
Good	Details (age/gender/race/context) of who was studied and how they were recruited.
	Why this group was targeted.
	The sample size was justified for the study.
	Response rates shown and explained.
Fair	Sample size justified.
	Most information given, but some missing.
Poor	Sampling mentioned but few descriptive details.
Very Poor	No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
Good	Clear description of how analysis was done.
	Qualitative studies: Description of how themes derived/respondent validation or triangulation.
	Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed.
Fair	Qualitative: Descriptive discussion of analysis.
	Quantitative.
Poor	Minimal details about analysis.
Very Poor	No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed.
	Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above (i.e., these issues were acknowledged).
Poor	Brief mention of issues.
Very Poor	No mention of issues.

7. Results: Is there a clear statement of the findings?

Good	Findings explicit, easy to understand, and in logical progression.
	Tables, if present, are explained in text.
	Results relate directly to aims.
	Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given.
	Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?

Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very Poor	No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?

Good	Contributes something new and/or different in terms of understanding/insight or perspective.
	Suggests ideas for further research.
	Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very Poor	None of the above.

Appendix 3.4. Data Extraction Sheet

Section 1 General Information	
Citation:	
Country:	Year:
Name of Reviewer 1:	Name of Reviewer 2:

Section 2 Study Description and Population			
Typology of evidence	Survey ☐	Qualitative Study ☐	Mixed Method Study ☐
Research Question			
Aim and Objectives			
Study setting/context			
Study duration			
Target population			
Role of the researcher in the study			

Section 3 Methodology	
Sample size and sampling strategy Appropriateness of sampling method and sample size	
Participant recruitment	
Characteristics of participants	
Inclusion and Exclusion Criteria	
Research Design	
Theoretical underpinnings	
Data Source	

Methods/Tools used for data collection	
Methods used for data analysis	
Time points for measurement	
Ethics approval	

Section 4 Findings	
Outcomes measured	
Key findings/Themes identified	
Missing data	
Reflexivity	
Author's conclusions	
Author's recommendation	

Section 5 Critical Appraisal	
Strengths and Limitations of the study	
Potential biases	
Reviewer's critical appraisal	
Quality of the study Reliability / Validity /Generalisability Dependability / Credibility/ Transferability	
Reviewer's score	
Agreement with another reviewer	

Screenshot from Mind-Map program used during Narrative Synthesis

Research study exploring the views of oncologists and haematologists on referring child with advanced cancer to palliative care in India

Student number 31692189, a PhD Palliative Care student at the Lancaster University is conducting a qualitative study exploring the views of oncologists and haematologists on what facilitates or hinders referral of a child with advanced cancer to palliative care in India.

Would the study be a good fit for me?

The study might be a good fit for you if you are a

1. Consultant Paediatric Oncologist or Paediatric Haematologist treating children with solid or haematological malignancies and accessing palliative care services.
2. Consultant Adult Medical Oncologist or Adult Haematologist treating children with solid or haematological malignancies and accessing palliative care services.

What would happen if I took part in the study?

If you decide to take part in the study, you will have to

1. Complete the informed consent form.
2. Participate in an in-depth semi-structured interview for 60 minutes.
3. Be willing for your interview to be audio recorded.
4. Be willing to provide your feedback on the interview transcripts.

Interested to take part in the study?

If you are interested to take part in the study, please complete the "Expression of Interest form" and return it to the investigator by email. Alternatively, you can either email or speak to the investigator should you need more information about the study. You can contact the investigator on email: n.salins@lancaster.ac.uk or on phone: +91-9969683669

Research Flyer v 1.0 16/04/2018

Appendix 4.2. Expression of Interest Form

Date:

Dr. Naveen Salins
Department of Palliative Medicine and Supportive Care,
Kasturba Medical College Hospital, Manipal 576104

Dear Dr Salins,

I would like to learn more about the study titled **Oncologists' and Haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India,** with a view to possible participation in the study.

I also agree to your contacting me to discuss the study further.

Signature: _____

Print Name: _____

Email: _____

Phone number: _____

Expression of Interest Form v 1.0 16/04/2018

Project title: Oncologists' and Haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.

Principal Investigator: Dr. Naveen Salins
Department of Palliative Medicine and Supportive Care
Kasturba Medical College Hospital, Manipal Academy of Higher Education, Manipal
Email: n.salins@lancaster.ac.uk , naveensalins@gmail.com
Mobile number: +91-99696 83669

Please read this form carefully. If you do not understand the language or any information in this document, please discuss with the investigator. Your participation in this study is voluntary, and you can enquire about all the details before providing your written consent to participate in this study.

1. Introduction to the research study:

I am conducting this research titled "**Oncologists' and Haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India**" as a student in the PhD Palliative Care programme at the Lancaster University, Lancaster, United Kingdom. You are being invited to take part in a research project that seeks to explore the views of oncologists and haematologists on what facilitates or hinders referral of a child with advanced cancer to palliative care in India. You are being invited to take part in this study because you treat children with solid or haematological malignancies and access palliative care services.

2. Purpose of the study:

The purpose of this study is to explore the facilitators and barriers for referring a child with advanced cancer from the perspectives of the oncologists and haematologists.

3. Who can take part?

Consultant level paediatric oncologists and paediatric haematologists. Consultant level adult medical oncologists and adult haematologists seeing children with solid or haematological malignancies.

4. Information about the study (as a whole):

Children with advanced cancer have physical symptoms and psychosocial issues, which affect their quality of life. Referral to palliative care is known to improve the quality of life of the children and their families. The majority of children with advanced cancer are not referred to palliative care or referred late in the illness trajectory. The purpose of this study is to know the views of oncologists and haematologists on what facilitates or hinders referral of a child with advanced cancer to palliative care in India. The study participants will be recruited purposively and will be interviewed using a semi-structured interview guide. The participant interviews and the data analysis will take place concurrently and transcribed interview data will be analysed to generate themes. The study findings will be used to facilitate review of current referral practices and development of policy and practice in this area.

5. What will happen to you (the individual participant) during the study?

The investigator will seek an appointment from you for an interview of around 60 minutes. The investigator will visit your workplace at the time of mutual convenience for conducting the interview.

Alternatively, you may be interviewed remotely using Skype or Zoom. An informed consent will be obtained prior to the interview. The signed informed consent has to be handed to the investigator in person for face-to-face interview or has to be signed, scanned and emailed prior to Skype/Zoom interviews. You will be individually interviewed using a semi-structured interview guide only once. Only audio recording will be made in the zoom/skype based interview. During the interview, the investigator will ask you open-ended questions about your experience and practice of referring a child with advanced cancer to palliative care. After completion of the interview, if you wish to add something further or wish to reflect, you will be provided with an opportunity to speak again, or to communicate your reflections in writing to the researcher.

6. Your (the individual participant) role/responsibility in the study:

During the interview, you are expected to provide your views about referral of a child with advanced cancer to palliative care. Participation is voluntary. If you decide to take part in the research project, you will be asked to sign the informed consent form, and you will be given a copy of the participant information sheet and the informed consent form to keep. You can decide not to take part in this research project. If you decide to take part in this research project and subsequently change your mind, you are free to withdraw from the project at any stage

7. What are the risks?

There are minimal risks anticipated with participating in this study. There is a small risk of participants getting upset while recounting stories about children's terminal illness and death. The participants may or may not be comfortable to share the intimate details of their clinical practice. They may feel that their views will become known, or their practice will be criticised

8. What are the potential benefits of participating in the study?

Although you may find participating interesting, there are no direct benefits in taking part. However, your participation will be acknowledged in the thesis and subsequent publications without names. Knowing the facilitators and barriers for referral could influence the future referral practices and may influence policy and practice development in this area.

9. What are the alternative treatments available?

Not applicable as this is an interview-based study using a qualitative approach.

10. Cost of participating in the study:

There is no cost involved in study participation. The participants will not receive any financial or non-financial incentive for participation. However, all the participants participating in the study will be duly acknowledged in the acknowledgement section of the thesis and publications without names.

11. Compensation for injury:

If you feel upset during or after the interviews, you will be encouraged to speak to the investigator. However, if you experience any distress following participation you are encouraged to inform the investigator and contact the resources provided at the end of this sheet. Should you need additional support, you will be requested to contact the clinical psychologist at your centre.

12. Confidentiality of information:

The information you provide is confidential. The findings of the individual interviews will be kept confidential. To protect identities of the individuals, sites, and places, the researcher will use pseudonyms. The printed interview transcripts will be securely stored in the record room of the IRB in India for the period of ten years. Only the principal investigator or the other investigators nominated by the principal investigator will have access to these files. After the period of ten years, the printed interview transcripts will be safely destroyed. The encrypted password protected anonymised audio files will be stored in the IRB data storage computers. All these audio files will be archived at the local IRB in India for the period of ten years. The personal identifier code will be stored separately from the anonymised interview transcripts, and the encrypted password protected anonymised audio files. There are some limits to confidentiality; if what is said in the interview makes the investigator think that you have provided any information that could compromise the patients, carers, health professionals and hospital safety, then the investigator may have to break the confidentiality and speak to the other members of the research team. If possible, the investigator will tell you before this.

13. New information about the study:

Written information about the conclusion of the study and the research findings will be communicated to the institutional review board. On request, the research participants will receive a summary report of the research findings. It will be disseminated through the peer-reviewed journals and conference presentations. The findings of the study will be communicated to the Indian paediatric oncology and palliative care networks.

14. Voluntary participation:

Participation is voluntary. You can decide not to take part in this research project. If you decide to take part in this research project and subsequently change your mind, you are free to withdraw from the project at any stage. If you decide to withdraw from the research project, please inform the researcher as soon as possible. Your data can be withdrawn up to two weeks after you participate in the study. However, if you withdraw two weeks after the interview, it may not be possible to exclude your data. Your decision about taking part in the study or withdrawal from the study, will not affect your relationship with the researcher.

15. Whom to contact in case of any questions:

If you experience adverse effects as a result of participating in this study, you may contact the Principal Investigator Naveen Salins, as detailed above. If you have any questions about the informed consent process or your rights as a participant, you may contact the Member Secretary of the Kasturba Medical College and Kasturba Hospital - Institutional Ethics Committee at Room 22, Ground floor, KMC Faculty Rooms, adjacent to KMC Administrative Block, Kasturba Medical College, Manipal - 576104. Phone: 0820 29 33522. Timings: 9: 00 AM to 5: 00 PM. If you have any questions about this form or any study related issue, you may also contact the following person.

Name: Dr. Krishna Sharan, Professor, Department of Radiation Oncology
Address: Kasturba Medical College Hospital, Manipal.
Mobile number available for after office hours is +91-99696 83669

Participant Information Sheet v 1.1 Dated 21/5/2018

Appendix 4.4. Informed Consent Form

Project title: Oncologists' and Haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.

☐ I confirm that I have read the Participant Information Sheet (version 1.1 dated 21.05.2018) for the above study and its contents were explained to me. I was given the opportunity to ask questions and I have received satisfactory reply to my queries.

☐ I consent for the audio recording of my interview, and I understand that the principal investigator will ensure my confidentiality.

☐ I understand that my participation in the study is voluntary and that I have the right to withdraw at any time without giving any reason. I understand that taking part in the study or withdrawal from the study, will not affect my relationship with the investigator.

☐ I agree to take part in the above study. I confirm that I have received a copy of the Participant Information Sheet along with this signed and dated informed consent form.

Name of the Research Participant:

Age of the Research Participant:

Contact Details of the Research Participant:

_____   _____
Name & Signature of the research participant   Date

_____   _____
Name & Signature of the impartial witness   Date

_____   _____
Name & Signature of the PI/person explaining the consent   Date

Informed Consent Form v 1.0 Dated 16/4/2018

Appendix 4.5. Interview Topic Guide

Sl. No	Questions	Probes
1	Can we please talk about your work that involves managing children with cancer?	Work involving paediatric cancer practice Experiences of paediatric cancer practice
2	Can we please talk about the challenges you face during managing a child with advanced cancer?	Child specific challenges Family specific challenges Any other challenges? Why do you think they are challenges?
3	Can we please talk about your views on the scope or role of palliative care in a child with advanced cancer	Role of palliative care for the child Role of palliative care for the families Role of palliative care for the oncologists/hospital
4	Can you please describe your experience of accessing palliative care services?	How easy or difficult it was to access the palliative care service? What were the virtues or shortcomings of accessing the palliative care services?
5	Can you please describe your experience of working with palliative care team?	What were the highlights? What were the challenges? How has the experience of working with palliative care service influence your practice?
6	Can you please discuss your views about referring a child with advanced cancer to palliative care?	What may be the benefits? What may be the disadvantages? What would facilitate a referral? What would hinder a referral?
7	Can you please describe the situation when you will consider referring a child with advanced cancer to palliative care?	Why? What may be the potential benefits of referral in these conditions?
8	Can you please describe the situations when you will not consider referring a child with advanced cancer to palliative care?	Why not? What may be the disadvantages of referral in these conditions?
9	Can you please narrate a memorable experience of making a palliative care referral?	Why was it memorable? What aspects made it memorable?
10	Can you please narrate a negative experience of palliative care referral?	Why was it negative? What aspects made it negative?
11	Is there anything else you would like to add or discuss that has not been covered in this interview	Probes based on the participant remarks

Interview Topic Guide v 1.0 Dated 16/4/2018

Appendix 4.6. Distress Protocol

Distress
- A participant indicates they are experiencing a high level of stress or emotional distress
- Exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Stage 1 Response
- Stop the discussion/interview
- One of the researchers (who is a health professional) will offer immediate support
- Assess mental status e.g. Do you feel safe? Tell me what you are feeling right now?

Review
- If participant feels able to carry on; resume interview/discussion
- If participant is unable to carry on Go to stage 2

Stage 2 Response
- Remove participant from discussion and accompany to quiet area or discontinue interview
- Encourage the participant to contact their GP or mental health provider

Follow up
- Follow participant up with courtesy call (if participant consents)
- Encourage the participant to call either if he/she experiences increased distress in the hours/days following the focus group

Appendix 4.7. Sample of Recording Initial Observations during the Familiarisation Phase
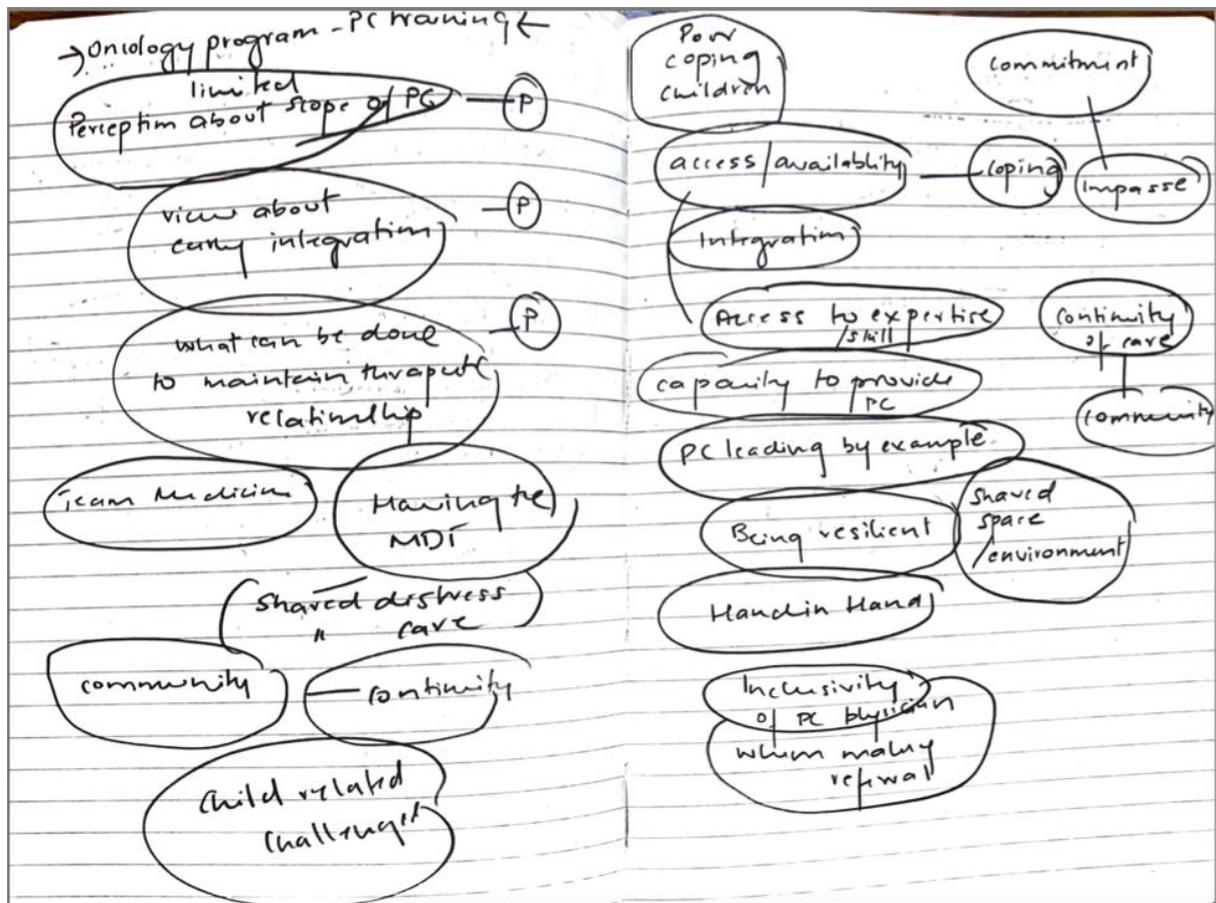
Appendix 4.8. Sample Transcript with Initial Coding

-Start of recording-

Today is XX of XXXX - XXXX. I am interviewing the participant XXX. The participant has consented for

audio recording.

Can we please talk about your work that involves managing children with cancer?

I'm a paediatric oncologist. So, I see children with cancer. Most common is leukaemia and the second one is lymphomas and brain tumours. So, I come every day and do the rounds sit in the OPD and go home.

So, what exactly happens when the child comes to you?

When the child comes in for the first time, hmmm, they come with a suspicion of cancer or sometimes they are not expecting it and it's a surprise. (have a suspicion of cancer during the first visit) (surprised as not expecting to have cancer)

So first we do the relevant investigations which is a blood smear or scan or whatever is required and then… (conduct required investigations)

but initially we only tell them that we are suspecting malignancy and we are doing investigations towards that, (at first communicate as confirming the suspicion of malignancy)

so that a warning shot is already fired (smiles) (give an indication)

and they are prepared for the news (to prepare)

and ones we confirm the diagnosis, we will do a biopsy or bone marrow, whatever is required. Once the diagnosis is confirmed then we break the news that it is confirmed as a malignancy and what the treatment is what the prognosis is, what the cure rates are, what the side effects is and then the children start the treatment. (information about diagnosis communicated after thorough investigation) (information about prognosis, treatment and toxicities are communicated before commencing treatment)

You mentioned that they come with not expecting or usually it's a surprise, can we talk about it?

Okay. Sometimes they come with a different complaint where they have not suspected a malignancy. (sometimes present with a complaint not suspicious of malignancy)

And sometimes they are already picked up by somebody and then referred. (sometimes already diagnosed)

In children who are like where they have come with some complaint without a suspicion of malignancy, I think the first thing is once you get the first test which raises your doubt then only we start preparing them like, how this result has come back as abnormal and one of the reasons that is possible is because of this malignancy. (if initial tests points towards malignancy… start preparing the family)

See we need to do the test which would be most of the times…a particular test information, so that they are prepared initially itself that what we are investigating for the malignancy. (inform the family that tests are done to confirm the diagnosis) (helps them to be prepared)

If it doesn't turn out to be a malignancy, they are quite relieved (family is relieved if the tests do not show malignancy)

but most of the times in the suspected malignancy it turns out to be a malignancy. (often it turns out to be malignancy)

Sometimes the answer may be obvious, but we still want a confirmatory diagnosis if the count is very high like two lakh count and you know, there's not much of differential diagnosis is there but still we don't have a confirmatory diagnosis and although we are sure we say that, No, we are suspecting malignancy. We are going to run some tests. That gives them time to digest the information. (even when the diagnosis of malignancy is apparent confirmatory tests are done to prove it) (inform the family that tests are done to confirm the diagnosis) (helps them to be prepared)

Can we please talk about your experience of working in the field of paediatric cancer?

Well, it's actually quite rewarding because unlike adults we cure. (rewarding experience as children with cancer get cured)

Most of the children not all but majority of the children. So, it's much more rewarding doing a paediatric oncology. (most of the children get cured)

And also, you get to know the families because it's a long-drawn process not one consultation. Uh, so you get to know the families you get to know the children and so on. So, it's different from the other specialties. (get to know the families) (prolonged care)

You said it is a long-drawn process. Can you describe more about it?

For families it's always a bad thing, especially if they're coming from different places or where they have to travel. The long-drawn treatment makes it difficult because minimum they will have to stay here for six months or something. There is lot of traveling involved, that way it is bad for the patient. It is good in that you get time to know the family and have knowledge. So, there is much more better understanding between the doctor and the patient. (families have to travel a lot for treatment) (prolonged periods of living at a different place for treatment) (get to know the families) (prolonged care) (bonding between doctor and the patient)

You mentioned that knowing the families has been helpful, can you please elaborate on it further?

Definitely. I think you are at a much more personal level rather than I mean even if it is all professional, even then you know the family, (get to know the families)

you know the names, (know the names)

you know what they are doing and how it is affecting them. (know what they are doing and know how illness is impacting them)

Even where there are short treatment periods when they come for their complaints, you just do not manage the complaint and whatever the disease is. In oncology you get to know the full family and is

not just the mother and father, you know, some relatives initially, the people that come and go. So, by the end of the treatment you almost know everyone inside out. (treatment is not limited to managing complaints) (get to know the families)

It is really helpful when you are counselling and the first counselling is difficult then you later know, you know exactly what the issues are. (getting to know families and their issues helps in counselling)

Can we please talk about some challenges that you face in your practice?

Well managing a child with advanced cancer …I think in Indian setting like in any other setting first, the parents are very upset. (parents are very upset with cancer diagnosis)

I think it is even for the completely curable cancers. Once you tell them it's a cancer, they are in shock, denial and all those things… and convincing them… and then there is a phase of like…is there any point in treating… even for curable cancers… (even in curable cancers parents are upset) (react to the information in the form of shock and denial) (family unsure about benefit of treatment)

when you are looking at an advanced cancer with a poor prognosis and all of them becomes exaggerated and not only that they are upset and there is this element of what's the point of treating? (reactions are exaggerated in advanced cancer with poor prognosis) (family unsure about benefit of treatment)

Okay, and then and again the financial and economics comes into play. (family finances influence treatment decision making)

They ask for hundred percent guarantee when we say nothing has got hundred percent here. (family asks for guaranteed outcomes of treatment)

You are telling them it's bad prognosis when percentages are like very low 20% to 30% then it becomes very upsetting for them that they are going to put in a lot of effort, spend and still the prognosis may be bad and they are stuck between whether to do it or not do it. (communication of low treatment outcomes is upsetting for families) (families have to spend and put in effort for treatment) (family unsure about treatment decision making)

I think it is one of the challenges as a doctor you want to do it because even if there is a 10 percent chance you want to try it and see, (doctor would like to treat even when there are low outcomes)

but from the parent's point of view, even though they came around to that line of thinking initially. There's a lot of uh, which they have to think about whether to continue treatment or not. I think that's one of the biggest challenges. (parents find it challenging to make treatment decisions when outcomes of treatment are poor)

You mentioned parents become very upset. Can we talk about it?

The first thing is to acknowledge that they are upset, and I think showing them hope is okay. (acknowledge the emotions) (fine to give hope)

That means you have to tell that it is cancer, but there is treatment and it may be curable. (communicate the diagnosis of cancer also communicate that it is curable)

I think that's like channelling that upset into purposeful energy. So, I tell them, Yes, you have got upset but there's no point sitting upset, you will have to do this. Just let us start the treatment. So, I think that's what takes their mind of upset because they have got something to do. (channelling the upset emotions to positivity by assigning the task of treatment) (having something to do takes their mind away from negative emotions)

You mentioned parents ask you what's the point of treating. Can you please explain that?

The bottom line is painting the true picture, not very bad, not very good, but to tell them what the percentages are (providing the right information)

what it means because sometimes the most misunderstanding is when you tell the person is 30 percent or something. They think okay. The tumour will come down by 70% and 30% will remain. They don't understand that what I am meaning. So, I clearly telling them what I mean by 30% is like if I treat ten children completely only three will get well. (clear communications to clarify any misunderstandings)

And so that gives some hope that it is not completely lost. So then just let us let us pray and hope that my child is in one of those three. (fostering hope)

Even in the poor prognosis situation it is like all or none phenomenon, some children are completely cured. (even in poor prognosis situation children may be cured)

Okay. So, presenting that data is like explaining to them what prognosis means…not everybody is going to die. (poor prognosis means not everyone is going to die)

There is still hope that a small percentage will live. Yes. It is a small percentage, but there is a chance that your child may be in that small percentage. (small percentage that child may live) (hope that child might belong to the small percentage group)

You have mentioned few family specific challenges are there any child specific challenges that you would like to discuss?

The child specific are…one good thing is children cope much better than adults. (children cope better than adults)

They are not understanding what's happening. (children do not understand what is happening)

Whatever is happening cancer doesn't mean anything to them. (whatever is happening may not mean anything to children)

It's like they're more worried about the blood test that you are going to do or poking rather than what is going to happen in five years' time, they don't understand the gravity of the situation. They refuse medications or spit the medications out. (children are more worried about the immediate things happening to them rather than long term outcomes) (refuse medications)

So, there are age specific challenges but overall treating the child is much easier than adults. (treating children is easier than adults)

Less challenges because there is this whole lot of psychological components in adults that are not there. (psychological aspects of care are less in children when compared to adults)

Especially in children less than 5 years, they are just more worried about the immediate problem rather than the overall long-term. (younger children are more worried about the immediate things happening to them rather than long term outcomes)

Challenge is a disadvantage. They don't understand the gravity of the situation of taking medicine or uh, see they take it as like once they are better than there's no need to take any medicines. (children not able to understand the seriousness of illness can be challenging)

It is quite upsetting for them that they don't know why it is being done. Once they improve a little bit that they are actually well and feel that they are completely well. So is more difficult for them to accept that they are well, but something is being done to them. There's no explanation. Like we are saying we are trying to make you better. Like I'm already better isn't it. (children find it difficult to accept treatment not knowing why it is done and done when they are well)

In other situation like respiratory distress, they accept a little bit better because they are having a problem that is getting improved. And once the Improvement happens, whatever hurt is being done will stop. In oncology they come with some problems, symptoms improve and then they're actually well, but you're continuing the treatment. (children accept treatment when they are unwell) (children find it difficult to accept treatment when they are well)

The other extreme is the teenager. In the teenager because problem is again complex. (treating teenager is complicated)

Okay, uh, because the ones that are well, they understand everything, but do not want to do. (although teenagers understand they refuse)

The problem is once they have a hair loss then they don't want to go to school. They don't want to go to because the other children will make fun of them. (do not want to go to school when they lose hair) (fear ridicule from their peers)

Even if it doesn't happen, they are afraid that that is going to happen. Even though they are fit to go to school. They don't go to school. (fear of losing hair prevents from going to school)

There is an element of overprotection from the parents also that is adding to not going to school. I clearly tell them to send the child to school now but still the child is kept at home. (parental overprotection prevents children going to school)

It is because one the parents overprotect, and the other thing is the child doesn't want to go because there is no hair or there is line sticking out. (parents do not want child to be sent to school when there is an IV line)

This is especially in the school going children. In the older children like about 15 to 16, the main problem is the compliance. Um, they don't think I will get better. I don't like, oh I got cancer. I don't want to do anything. I don't care attitude. (compliance and attitudes of teenager towards cancer and treatment can be challenging)

Are there any other challenges apart from what you have mentioned that you would like to discuss?

I think the main problem…. Actually, in the Indian setting it is the finances it is the economic. (financial issues pose the major challenge)

Firstly, the treatment is costly, and it is not one of off treatment. (cost of treatment and prolonged treatment)

So, it is emotionally draining and physically draining for the family. (emotional and physical drain)

The other thing is the uncertainty, one complication can happen as everything goes well, so you tell them the plan and this one complication will throw the entire plan out of the window. (uncertainties due to complications)

I think that's where the families find it very difficult to cope. (families find it difficult to cope)

A child comes in with like leukaemia something then one severe infection, they are in the ICU, uh, not only the condition changes, the cost planning that they have planned goes for a toss. (development of a complication during treatment upsets the treatment cost planning)

You mentioned few financial challenges, can you please discuss it further?

I know but there's one thing good thing about this we can try to cut the costs. (treatment costs should be reduced)

Hospital will provide discounted treatment and the other way now is the crowdsourcing. I think the lot of patients are able to go on the crowdsourcing website and are able to raise funds for the treatment. (discounting treatment and crowd funding)

There are certain things that we can do where we can cut the antibiotics orally. Things like that can be done. And the other thing is the hospital giving some discounts and like that so that is how I think the financial parts are being managed. (minimizing antibiotic use) (hospital discounts) (managing finances)

Can you please describe your experience of referring or accessing palliative care?

I think I mean, I worked at setups where there was established palliative care. Even when I was in the setup where there was no palliative care in-house, there are always access to a palliative care, a good palliative care team. (worked with an established palliative care setup) (had access to a good palliative care team)

So, I don't think there was any major hurdles in accessing the palliative care. (no major hurdles to palliative care access)

When we are talking about access, I would like to know how easy or difficult it was to refer to palliative care?

I think it was quite easy because well, when I was in ****** there was a good palliative care team in place. (had easy access to a good palliative care team)

It was easy to refer and when I moved to the next hospital, there was no in-house palliative care team. (hospital palliative care team makes it easy to refer)

So, most of our advice was through the phone, but when the patient was discharged, and I handed over to the palliative care team. (received phone advice) (care transferred on discharge)

I see the palliative care team as like two things one is inpatient for immediate symptoms for the admitted patients and the second part is once I sent them home for ongoing care. (role of the palliative care team perceived as: symptom control and ongoing care after discharge)

In places where that is inhouse palliative care team, both parts are taken care of well.
(both the roles performed well by the hospital palliative care team)

Okay, palliative care teams will assess the child and put their plans, (assess and plan treatment)

symptom relief and everything else. (symptom control)

And then even after discharged home the palliative care takes over. (care at home transferred to palliative care on discharge)

Whereas working in a setup where there is no in-house palliative care team, Then the problem becomes when the patient is admitted under me (patients admitted under the oncologists when there is no hospital palliative care team)

and I am just taking palliative care advice on phone. (receives phone advice)

I just tell this the symptoms and everything that the quality becomes poor, a little bit because obviously, (quality of palliative care treatment compromised)

uh, I won't be able to do as good an assessment as a palliative care team would do from that point of view. (inability to conduct a good palliative care assessment)

But it still helps when I present them. They will tell something. (receives palliative care advise based on oncologist reporting)

Once discharged I just hand over completely to the palliative care team. (care transferred on discharge)

You just mentioned good palliative care team. Can you please elaborate what "good" means?

I said good. Good means proactive. (proactive care)

Not just I mean once you refer a patient, uh, you would come see the patient assess the patient. (patients are assessed by the palliative care provider on referral)

It is not like you give a problem, like pain, you come and give Morphine, not that kind of palliative care, but actually assess, check, look at all the aspects. Okay, and then come up with a full plan rather than telling patient has pain give Morphine. (not a problem check-list based approach) (assess all aspects of care)

It is quite easy to tell; we are not asking for the dose of Morphine. What you're looking for is the complete approach and package which is there in the palliative care. (expecting beyond problem check-list based approach)

They were always at the end of a Phone call, (always available on phone)

uh, maybe I uh, one thing was the only one thing was out of hours availability. (limited out of hours availability)

Otherwise within one working day all the patients used to be seen. (patients seen within a day)

Once you give a referral they will see on the same day or whatever the phone advice was given and by the next working day the patient was seen. (patients seen the same day or the next day)

At ***** actually as far as accessing the palliative services or getting hold of a palliative person was not difficult in the last few years. (accessing palliative care services was not difficult)

Can we please discuss about your experience of working with the palliative care?

When I returned from UK, I thought that there is no palliative care in India, (expected that palliative care was unavailable in India)

which was true to a certain extent, but I was just lucky (chance)

that I have to land in a place where there was a palliative care team in place. (joined a place where palliative care was available)

90% of the cases where I could have landed there may not have been a palliative care team in place. (high chance of joining a place where a palliative care team was not available)

I was just lucky enough to come to a place where there was an ongoing palliative care team, (considers himself lucky)

but I think most of the places they don't have access to palliative care team and there is lot of deficit. (feels that there are gaps in access to palliative care in most places)

My experience was very good (good experience)

to the extent now I just spread the word that this person is good, you can refer to him. (advocates for a particular provider)

For many other they don't even have it, (majority do not have palliative care services)

I mean they might have just heard about palliative care or it is something which they have read in the textbook, they have not actually accessed it. (majority have knowledge about palliative care from books not from experience)

I put lot of patients in touch with Dr. *****. You can refer to this person. He does a good job. (advocates for a particular provider)

Can you please narrate some of the highlights of your experience?

Parents of some of the children who died actually came and thanked us which is very unusual.

(parents thanking after the child's death is unusual)

When the child dies in the acute setting the parents are very upset,
(child's death in an acute setting is upsetting)

whereas children who have been referred to palliative care, some parents actually come and thank us, my child died, but still we thank you. (when referred to palliative care, bereaved parents thanked the referring oncologist)

You tried your best and the child was not in pain and was comfortable. And some of the patients were actually kept comfortable at home. (child was pain free, comfortable and at home)

I think that is one of the things which was really highlight as all these patients didn't die in the hospital. They died at home and (dying at home was the highlight of the experience)

I'm sure most of the palliative care teams would have been giving advice on the phone to these families. (providing phone advice to families)

Once I handover, I just roughly know what's happening but not actually involved in the actual care of what's happening? (knows somewhat about what's happening with the child even when actually not involved)

I know this is going this is happening and the child is comfortable. (knows that child is comfortable)

I get to know the information, but I am not like running the show of increasing decreasing the doses or responding to the phone calls. (not involved in the day today care of the child)

And so, whenever I handed over a patient to a palliative care, then I get an occasional phone call about the patient. (receives information through occasional phone call)

Most of the patients whether admitted or the treatment has started in the hospital or in the OPD. These patients also actually died at home (hospitalized patients referred to palliative care died at home)

and I am sure the palliative care consultant would have seen patient only once or twice physically, (patient seen only a couple of times by the palliative care consultant)

but the whole care was continued at home (care continued at home)

I think that was one of the good things about working with the palliative care team. (team approach)

You mentioned that it is good for children with terminal cancer to die at home. Can you explain it further?

I think it depends on the family. Some families can't cope. Okay. Some families just cannot cope. (some families find it difficult to cope)

They want to bring the child to the hospital and let the acute service take care when the child dies. (families want the child to die in the hospital)

Even though there is no point in treating they come to the hospital because they do not want it to happen at home. (families do not want the child to die at home)

They are actually afraid of what is going to happen when the child dies. (families scared of the events surrounding death)

They have accepted the fact that child will die (accepted child's death)

but the actually, what is going to practically happen they don't know (not aware of the events surrounding death)

so they bring the child to the hospital to die. (child brought to the hospital to die)

Where the palliative care team was involved and like there was time to develop rapport between the palliative care team and the family, none of them came back. (rapport with the palliative care team) (child did not return to the hospital)

They all accepted, knew what was going to happen and those children died at home. (accepted child's death) (knew the events surrounding death) (children died at home)

So, in a way that was good, but I think that depends… what decides that is one the family, and more than family how much time there was between the referral and the death. So, like where there were more than 15 days or one month or something a rapport actually developed between the family and the palliative care team. (early referral facilitated building rapport between families and palliative care team)

They have been much more comfortable to keep the child at home. (family comfortable with keeping the child at home because of previously developed rapport)

You just mentioned about duration of palliative care input and outcomes. Can you please elaborate it further?

I think it is very important and when I was in **** it used to be introduced as symptom relief team and patients knew the palliative care team at diagnosis. (palliative care introduced as symptom relief service) (patients were referred at diagnosis)

It was not just the palliative care team, it was a palliative care team, but they were doing symptom relief and presented as yeah, we treat the cancer and these people treat the symptoms. So, the family already knew them. (oncologists treat cancer palliative care providers provide symptom relief)

It was not like from today you are palliative. There was no point where uh today you are palliative care… kind of switch over, it was continuous. (not switch over but continuous)

While working at ****that switch had to be done because there was no inhouse palliative care team to involve. (switch over happens when there is no hospital palliative care team)

So, the symptom control was being done by me only and it used to be like, (oncologist has to perform the symptom control role)

okay you are now palliative; this person will take more precedence over what I am doing. (switch over to palliative care)

It is a clear-cut transition here; there it was smooth. Actually, there was no transition at all. The palliative care continued to look after the symptoms, and we used to say now we will start treatment to cure your child. It was not like this is on that is off. It was like both is on and later one is off. (oncologists and palliative care providers performing their roles concurrently) (no transition issues when palliative care providers are working concurrently with the oncologists)

I was lucky enough to work with good people. (worked with good providers)

The only challenge was when I moved into the hospital that did not have palliative care. (changed jobs and had to work in a health care set up without access to palliative care)

I was so used to palliative care, which was looking after everything. (used to working in a set up with access to palliative care)

When I was working at **** that had an in-house palliative care, I did not have any challenges. At the other place it was the access to palliative care which was not there. (lack of access to palliative care was challenging)

You have stressed upon the need for an inhouse palliative care. Can you explain it further?

I think there is a need for inhouse palliative care. Yes, especially if you're dealing with uh, life limiting conditions. (hospitals caring for people with life limiting illness should have a hospital palliative care team)

In my previous workplace, it was the children's hospital and I was the only person treating cancer, the others were like respiratory physicians treating cystic fibrosis. People felt that there was no need for a palliative care team. (palliative care need is felt less among non-cancer providers in a general hospital)

When I was working at ****, it was a cancer hospital, so it was available. (palliative care need is better felt in a cancer hospital)

When you are working in a general children's hospital, very few people access the palliative care team. (fewer providers access palliative care in a general hospital)

Can we please discuss your views about referring a child with advanced cancer to palliative care?

I think when you are going down advanced cancer prognosis diseases…I think the quality of life becomes important. (quality of life is important in advanced cancer)

Okay, so, whatever we do. I think the palliative care team has got a better approach in providing the quality of life than an acute physician. (palliative care providers stand a better chance in improving quality of life than acute care providers)

I think it is important to refer to palliative care. (referral to palliative care is important)

You mentioned about few benefits, can we talk more about it?

I think benefits, one is child is more comfortable. (child is made comfortable)

Better symptom control (symptoms better controlled)

and number two there is less use of the hospital. (less access to hospital resources)

Okay, because just by training we are more used to see the patient, take history, do the clinical examination and then treat. When you are an acute physician you still treat the palliative patient with the same approach. (acute care physicians continue to treat a patient needing palliative care with acute care approach)

So, you are uncomfortable telling something on the phone without seeing the person. (acute care providers are uncomfortable in giving phone advice)

The palliative care person is much more comfortable on phone and managing at home doing that. (palliative care providers are comfortable in giving phone advice)

Okay, so actually place like**** where patients have to travel to see you, I feel that why they have to bring the child to the hospital for such a small complaint, but you are not confident enough to manage the child at home because your training is like that. Because you don't what to miss something. In acute medicine, you want to do a good physical examination, then you approach the problem. (by training acute care providers insist on bringing the child to the hospital for assessment) (bringing the child every time to the hospital for minor complaints can be an inconvenience)

And you even see the palliative care from that angle because that's what you're doing every day. The palliative care physician is comfortable answering over the phone and keeping the child at home. (palliative care providers are comfortable in giving phone advice and managing the care at home)

You mentioned about how palliative care is important to improve quality of life of the child. Can you please explain it further?

I think one is symptom relief. Okay, uh, no pain, no vomiting and wound care, (relief of symptoms)

Okay, and actually managing the patient at home, (home based care)

that actually will improve the quality of life that they are not carrying the child in **** where it will take half a day to come and go to the hospital. That itself improves the life. (logistics of travel and time taken to access hospital)

I'll tell you an example. I had a child with rhabdomyosarcoma, which was recurrent. And it's spread to the brain and all I referred the child to ****. Because this was admitted and operated in **** then discharged and palliative care was not there. Then after the surgery I did not see the patient at all because the child was too sick and bedridden to bring to the hospital. ****just saw the child once and I think he managed the palliative care for like three to four months and actually when the child died, they phoned me up and thanked me. (child referred to palliative care died at home) (family called the oncologist and thanked)

I thought **** was like actively seeing the child and managing the symptoms, but later I realized that **** has seen this patient once in the OPD. (child was seen at palliative care outpatients only once)

And everything was managed on the phone (phone advice and care was managed remotely)

and the family was really grateful because the child was bedridden, and it was not a very small child to carry. To bring them to the hospital even for symptom control would have been very difficult. (family expressed gratitude as it saved them the logistic challenges of transporting the child to the hospital)

I think that's the quality of life and that's like a real improvement in quality of life. If not anything else… not making them travel. (minimising logistic challenges of travel and transporting the child back to the hospital is a way of improving quality of life)

Can we talk about any disadvantages of palliative care referral?

The only disadvantage I can see is the naming (smiles). (the name palliative care is disadvantageous)

The Palliative, because the patient feels that you are already in the last stage. (patient feels palliative care means end stage)

Okay, so that's why it's better to get them as symptom control and introduce early. (introduce the service as symptom control and introduce early)

You talked about naming or branding somebody as palliative. Can you please explain it?

It has both advantage and disadvantages. When you brand as palliative then the realization happens to the parents. (naming someone as palliative can help the parents to realise)

Okay. This is now we are on a different territory, we are not trying to cure, that kind of realization it is good. (can help them to realise the change in treatment approach) (realisation is good)

But when parents have not accepted. Okay that there are some chances of cure etc. there will be resistance to go to palliative care. (parental resistance to accept palliative care when there are some chances of cure)

But that can be overcome by telling that this is for symptom relief. (introducing it as a symptom relief service helps in overcoming the barrier)

It does not matter that I am trying to cure you or keep you comfortable, keeping you comfortable is important. (child's comfort is important irrespective of treatment approach)

Even If I am trying to cure you, you need to see palliative care (palliative care is needed during the curative phase)

Not just rebranding, I think it should be from the beginning, right when you write the first dose of Tramadol or Morphine, the palliative care should be involved. (palliative care should be introduced early)

The patient sees you as not as palliative care, not like a switch on and off but a continuous service right from beginning for the symptom relief. This is the team which will come and give the relief. I think it is the introduction at the first stage rather than the last stage. (continued service from the beginning for the relief of symptoms)

At this point no. Once I moved to the**** it was always a switch on and off kind of thing. (switching over of the services)

It is because they understood that we cannot cure he's handing over to a person who will do the symptom control better. (when curative options are exhausted transfer to the provider who can control symptoms)

Can we please discuss what facilitates or may facilitate a palliative care referral?

I think in the India setting availability. Availability (availability of the services)
and knowing the right person. (right provider)

Even now I think that the service is patchy and not all hospitals have access to palliative care. (access to palliative care is limited)

You mention about the right person, can you please discuss what do you mean by that?

Because in settings where there is no actual palliative care team the job is taken over by a person who can manage pain, usually the anaesthetist. (when there are no palliative care services pain physician and anaesthetist fills in the role of the palliative care provider)

Okay, and their approach is entirely different. (pain physician and anaesthetist have a different approach)

Okay… The anaesthetist comes in because there is lack of service, you know, you want to refer to palliative care service but there is no palliative care service and what is the next best option? The next best option is the pain team which is usually run by the anaesthetist.
(anaesthetists and pain physicians are the next best option when there are no palliative care providers)

They get the control of the pain. very good, they do their job very well, but it doesn't cover the other things. (role limited to management of pain) (other aspects of palliative care are lacking)

When you say other things, what do you have in your mind?

When you say other things, I mean the not only the symptoms, but taking on social, emotional and psychological. Things that are completely untouched. (palliative care is not limited to managing physical symptoms) (Involves other health dimensions) (Other health dimensions not addressed)

Can we please discuss what hinders or may hinder a palliative care referral?

As far as I can see the main hindrance is only the availability. (non-availability of the service hinders)

Availability of the right person in the hospital. (right provider)

Once I decide, when I say an advanced cancer, the first thing I do is to counsel the family. (counselling the family about advanced cancer)

This is advanced cancer. These are the chances. Do you want to take the treatment or not take the treatment? These things are mentioned. (counselling about outcomes of the cancer and treatment decision making)

Most of them they will try to take treatment (majority opt for treatment in advanced cancer setting)

and once it fails, at that point the child is still asymptomatic. Okay, because we are going to pick it up early on the scan or a blood result or something, rather than the child being acutely symptomatic. (children with advanced cancer are often asymptomatic) (advanced cancer often picked up on investigations)

But you know, which way it is going to go. I usually refer to the palliative care team at that point before the child has got any symptoms. (refers the child to palliative care before appearance of symptoms)

When I say okay, this is now the time the child who is going to go from trying to cure to trying to keep the child comfortable. (discusses shifts in goal of treatment from cure to comfort)

Right now, completely comfortable but that is the time I introduce. I tell them I know your child has no symptoms now. Your child is likely to develop symptoms later. (asymptomatic now may develop symptoms later)

 You will need the help of this physician, please go ahead and see him now. (referred before symptoms appear)

You mentioned referral should be made before the child develops symptoms. Can you please discuss it further?

As I told you, first the rapport should develop. So that they know the physician. (referring early before symptoms develops builds rapport)

I think then it's much easier for the family also, to access palliative care, rather than wait for the symptoms to develop. (referring early when symptoms have not developed allows time for accessing the services)

All my references have been at that point, where I know that the child is palliative, but the child is fine. (always referred when there was a change in the course of illness)

So, they still go and see. He may say nothing, and everything is okay, if there are symptoms call me. (palliative care consultation in absence of symptoms may not yield much but important for future care)

You mentioned about referral when the treatment fails. What do mean by treatment failure?

The example, I was giving earlier, when I discharged, the child was fine. But it has recurred, and the surgeon told he cannot operate on it. That is the only time **** saw the child. There was no symptom actually and the child was well, okay. I'm not going to try to cure this child. There is no more aggressive chemotherapy radiotherapy or surgery. (child had advanced illness with no curative options) (child was asymptomatic)

We are not going to go down that route from now onwards and I know that this child is going to die but let me keep this child as comfortable as possible for as long as possible. (change in the treatment course, poor prognosis and the goal was comfort)

Are there any situations in your practice where you will refer the child to palliative care more often than other?

I think mostly, more often solid tumours tend to get referred than leukaemia, although leukaemia form the biggest number. (solid tumours are more often referred compared to leukaemia)

I think that is because leukaemia relapses are much more acute, and the child is going to die because of the low platelet count or something because of which the child is going to bleed. The time interval between stopping the treatment and the child actually dying is much shorter in the leukaemia (acute course and complications in children with leukaemia makes palliative care referral challenging)

compared to a solid so by default the solid tumors tend to get more referred that too extra cranial. (extracranial solid tumours are more often referred compared to brain tumours)

Because with the brain tumours what's happening most of the times is that the child gets seizures, unconscious or has drowsiness and all uh the patient brought to the hospital just because of the nature of the illness. (acute course and complications in brain tumours makes palliative care referral challenging)

Child having a solid tumour having pain or vomiting or other symptoms are more accepting of the palliative care physicians' approach. (symptomatic children accept palliative care more easily)

But in leukaemia it is very clear, they will need platelet transfusion or blood transfusion and by default end up in the hospital. The same thing is for the CNS tumours, because it will be a fit or the child becomes drowsy. Very rarely they may have hemiplegia and palliative care physician will be looking after them. But most of the time the child starts fitting, becomes drowsy, sleepy, abnormal breathing then they tend to bring the child to the hospital. (leukaemia and brain tumours present with complications and acute care needs needing hospitalization and care from an acute care provider)

So, by default more solid tumours end up with the you. (patients with solid tumours are more often seen by the palliative care provider)

It is because I think it's a more long-drawn process. (protracted course of cancer favors palliative care)

Because if the child is fitting or coning, or the child has a big intracranial bleed, or pulmonary bleed, we are not going to intubate, and the child is going to die very quickly. (cancers with acute complications can have a short course before death)
In solid tumours it is a long-drawn affair. So, there is more period which the child needs care (protracted course of illness in solid tumours favours palliative care)

Are there situation when you have not considered referring a child with advanced cancer to palliative care?

So far, I have not thought of any. I think it has to do with the acceptance of the family, (family acceptance of palliative care key for referral)

I think if you have not referred because the family is in denial and don't want to see palliative care. (non-referral is due to non-acceptance of palliative care by family or denial)

Very rarely almost none that I have not offered. (seldom not referred)

If I see this as an advanced cancer with symptom needs which is beyond my first line of management I usually refer. (advanced cancer, symptoms, beyond first line of treatment triggers for referral)

I usually tell that this is a person who can take care of this problem better than me then it's up to the family to accept or reject. (decision to accept/reject rests with the family)

I don't use the word palliative care. I just say these kinds of symptom is looked after by this person. He will do a better job. (name palliative care not used) (introduced as symptom control service)

They are a bigger problem because they tend to end up more landing in the hospital. (families refusing palliative care more often access hospital resources)

That is why they just bring the child to the hospital and stay there till the child dies. (families refusing palliative care have higher chances of child dying in the hospital)

Then everything is taken control off, you put the canula, just keep going up on the painkillers. You control everything, everything is taken care of. (receive more intense acute care in the hospital)

It is exactly the type of parents who are not able to cope with the process of child dying at home. So, they will line up in the hospital, just come to die. (unable to cope with child dying at home) (accessing hospital resources and hospital death)

And you will have to keep the junior doctors away from acting on things. (have to resist junior doctors from acting upon things happening with the patient during the course of hospital stay)

You mentioned acting on things, what do you mean by that?

When I say acting on things, because some will ask for the blood sugar to be checked or CBC, where it is completely not required, and the child will be poked three times to take the blood which we are not going to act. (medical investigations not required, or no action will be taken on the investigation results)

Can you narrate a memorable experience of palliative care referral?

I've told you one that we have managed. This was a child who had a tumour in the paranasal sinuses operated. Given chemotherapy and radiotherapy, recurred, given second line, again tumour regressed, and then was sent for surgery, the second time surgery went wrong because they couldn't remove the entire thing. So, they did half as much excision as possible and came out and then they went in again to remove that tumour (child with a recurrent advanced cancer)

and the child had complications, intracranial bleed, hemiplegia and all those things. So, they abandoned the surgery then they wanted to operate on the child again. (severe complications)

But by that time, she was not fit for chemotherapy. (not suitable for disease modifying treatment)

She was waiting for the surgery and the disease progressed. Progressed means only on the scans. (progressive disease)

The child had no symptoms and that is when we decided that the child is progressing on second line chemotherapy. (progressed on treatment)

They went and saw ****. Finally, the patient died, the parents actually phoned and said I'm so sorry the child died, but you did everything and **** did everything and thanked us. (family called and thanked the oncologist after patient's death)

Why was this episode a memorable experience?

The fact that the child was managed at home without ever getting out of the home was like really unique. (continued care at home until the end)

Can you narrate a negative experience of palliative care referral?

As far as I can see, the team that I have worked with, I think no.

Is there anything else that we have not covered in the interview you would like to add?

The only thing I would like to add is more of you are required. Availability is the main issue. (availability of the services is the main issue)

Since this question of availability had come time and again why do you think palliative care services are not available to paediatric oncologists?

I think right now because there are more pressing needs. Okay. Now the biggest challenge is to actually convince the patients to get to take the treatment and not to abandon the treatment. Most of us now are focusing our efforts towards that. Until this issue is sorted nobody is going to ask for more palliative care. All the efforts are towards curing the children who can be cured. We are failing in that itself. That is seen as a bigger need. (not taking treatment or abandoning cancer treatment is a major challenge) (efforts focused towards enhancing cancer treatment takes precedence over palliative care)

Thank you very much for participating in this research interview and thank you for your time. I'll stop the recording now.

-End of Recording-

Appendix 4.9. Coding Process and Organising the Codes using NVivo Software
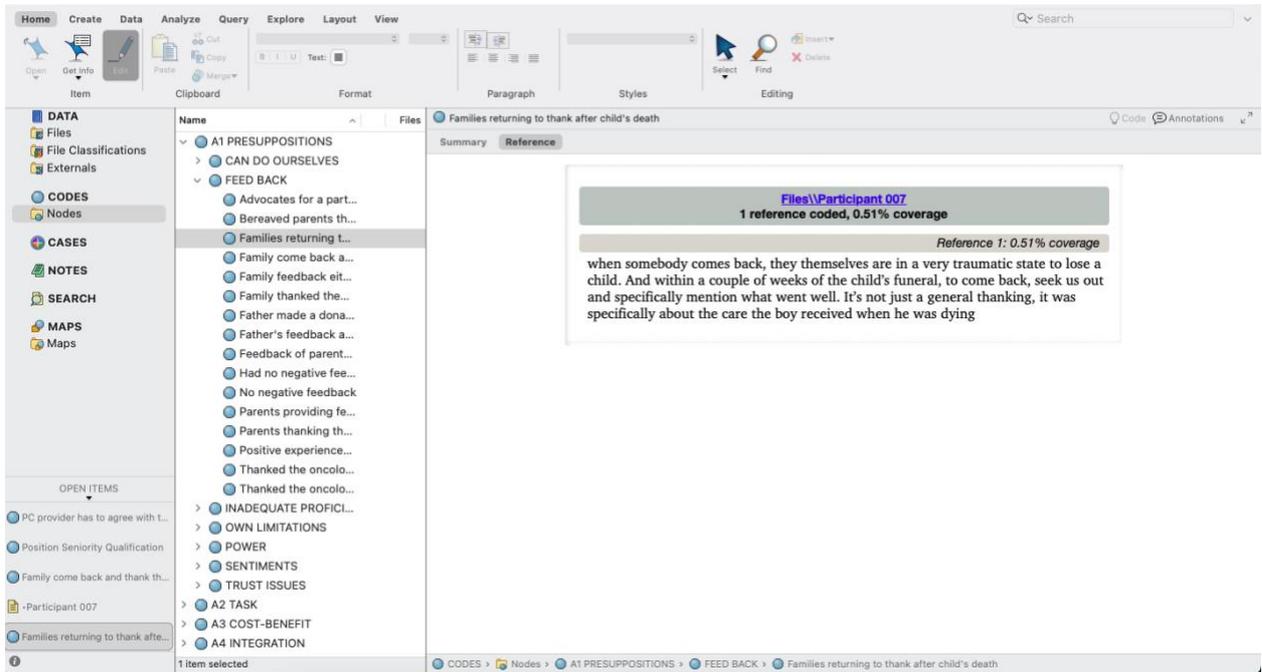
Appendix 4.10. Checklist of Criteria for Good Thematic Analysis

Transcription	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy.
		I transcribed the interviews myself, and the exercise of listening to the audiotapes and transcribing enabled accuracy. An example of a detailed transcription is provided in **Appendix 4.8**.
Coding	2.	Each data item has been given equal attention in the coding process.
		All interview transcripts were uploaded to the NVivo software version 12.6.0 for Mac, and the coding was done using the NVivo software. For each interview, the entire data set was coded **(Appendix 4.8)**. However, only those coded section of the data relevant to the research question was analysed.
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.
		Codes across the datasets were examined for broad patterns, and similar codes (called nodes in NVivo) were collapsed together to create a higher code (top-level node) in NVivo software. A set of these higher codes (top-level nodes) were further collapsed as a candidate theme. The candidate theme represented a central organising concept **(Appendix 4.9)**.
	4.	All relevant extracts for all each theme have been collated.
		Relevant extracts for each theme have been collated through NVivo software **(Appendix 4.9)**
	5.	Themes have been checked against each other and back to the original data set.
		Themes are checked against each other, and themes and subthemes are visually represented in **Figure 5.1.** It is traced back to the original data set using NVivo software **(Appendix 4.9).**
	6.	Themes are internally coherent, consistent, and distinctive.
		Each theme has a set of subthemes that are distinctive and are coherent with the main theme, as demonstrated in chapter five.
Analysis	7.	Data have been analysed rather than just paraphrased or described.
		The research findings were analysed and represented as themes/subthemes and interpreted using the social exchange theory and feedback intervention theory. The themes generated were coherent and satisfactorily answered the research findings. Philosophical approach

		and theoretical frameworks enabled interpretation of research findings
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.
		The analysis of views of oncologists and haematologists on palliative care referral matched the extracts coded and supported the claims made by the researcher. The coded excerpts are provided in the results sections alongside each subtheme in chapter 5.
	9.	Analysis tells a convincing and well-organised story about the data and topic.
		Various aspects relating to the phenomenon of palliative care referral in a paediatric oncology setting and what helps and hinders it was narrated and discussed.
	10.	A good balance between analytic narrative and illustrative extracts is provided.
		Study findings discussed in chapter 5 has a good balance of analytic description of the participant's views and relevant extracts to support them.
Overall	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
		The data collection and analysis happened over 18 months (July 2018 – Jan 2020). The writing up of the results and their interpretation occurred between April 2020 – March 2021.
Written report	12.	The assumptions about thematic analysis are clearly explicated.
		It is stated in detail in Chapter 4
	13.	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.
		Themes were organised to describe the phenomenon inductively and reflexively. The subthemes and themes are generated from coded extracts relevant to the phenomenon explored.
	14.	The language and concepts used in the report are consistent with the epistemological position of the analysis.
		Critical realist paradigm is the philosophical position that informs this research. The research interviews, analysis and interpretation of study findings were consistent with the philosophical position.
	15.	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.
		The reflexive thematic analysis allows the researcher to play an active role in knowledge creation. The researcher's subjectivity and reflexive interpretation are part of the data analysis.

Appendix 4.11. Institutional Ethics Committee Approval from India

KASTURBA HOSPITAL
MANIPAL
(An associate Hospital of MAHE, Manipal)

Kasturba Medical College and Kasturba Hospital
Institutional Ethics Committee
(Registration No. ECR/146/Inst/KA/2013/RR-16)

Communication of the decision of the Institutional Ethics Committee

Wednesday 09th May 2018   IEC : 292/2018

Project title	:	Oncologists and Haematologists views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.
Principal Investigator	:	Dr. Naveen Salins
Guide/ Co Guide/ Co Investigators	:	Nancy Preston, Sean Hughes
Name & Address of Institution	:	Department of Palliative Medicine, Kasturba Medical College, Manipal, Faculty of Health and Medicine, Lancaster University, UK.
Status of review	:	New
Date of review	:	08.05.2018
Decision of the IEC	:	Approved for the study period from 08.05.2018 to 07.05.2020 as mentioned in protocol.
Endorsement of continuation of approval : (due date 07.05.2019)	:	Signature and Seal

- The PI and all members of the project shall ensure compliance to current regulatory provisions (as per Schedule Y of Drugs and Cosmetics Act and ICH-GCP), Ethical Guidelines for Biomedical Research on Human Participants by ICMR, and the SOP of IEC including timely submission of Interim Annual Report and Final Closure Report
- Participant Information Sheet and a copy of signed Informed Consent shall be given to every research participant
- Inform IEC in case of any proposed amendments (change in protocol / procedure, site / Investigator etc)
- Inform IEC immediately in case of any Adverse Events and Serious Adverse Events.
- Members of IEC have the right to monitor any project with prior intimation.
- Ensure registration of this study at Clinical Trials Registry - India (CTRI) before the enrollment of the first participant (The registration number is to be forwarded to the IEC within 7 days of your successful registration).

Dr. Stanley Mathew
MEMBER SECRETARY - IEC

IEC Secretariat, Room No. 22, Ground Floor, Faculty Room Complex, Kasturba Medical College Premises, Kasturba Medical College, Manipal - 576104, Karnataka, India. Phone : +91 - 0820 - 2933522, Fax : +91 - 0820 - 2571927. Email : iec.kmc@manipal.edu

MR-798

Appendix 4.12. Clinical Trials Registry of India Approval

CTRI No	**CTRI/2018/06/014397** [Registered on: 04/06/2018] **Trial Registered Prospectively**
Acknowledgement Number	REF/2018/05/020110
Last Modified On:	01/06/2018
Post Graduate Thesis	No
Type of Trial	Observational
Type of Study	Qualitative Study
Study Design	Other
Public Title of Study Clarification(s) with Reply Modification(s)	Views of cancer specialists on referring a child with advanced cancer to palliative care
Scientific Title of Study	Oncologists' and Haematologists' views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India.
Trial Acronym	

	Secondary ID	Identifier
Secondary IDs if Any	NIL	NIL

	Name	Naveen Salins
	Designation	Professor
	Affliation	Kasturba Medical College Manipal
Details of Principal Investigator or overall Trial Coordinator (multi-center study)	**Address**	Department of Palliative Medicine and Supportive Care Kasturba Medical College, Manipal Madhavanagar, Udupi Dakshina Kannada KARNATAKA 576104 India
	Phone	9969683669
	Fax	
	Email	naveensalins@gmail.com

Appendix 4.13. Faculty of Health and Medicine Research Ethics Committee Approval

Lancaster University

Applicant: Naveen Salins
Supervisors: Nancy Preston and Sean Hughes
Department: Health Research
FHMREC Reference: FHMREC17089

05 June 2018

Dear Naveen

Re: Oncologists and haematologists views of what facilitates or hinders referral of a child with advanced cancer to palliative care in India

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

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.