

A Good Death in the Child with Life Shortening Illness: a multiple case study

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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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Abstract

Introduction: Understanding what a ‘good death’ in children might look like is important, as it impacts all stakeholders and promotes tailored support. Existing research indicates that opportunities for play, peer support and assent may be crucial. Our integrative review found meeting needs and managing control instrumental. The influence of disease type, location of death and access to palliative care is still unclear.

Aim: To explore how a good death in a child with life shortening illness can be achieved in the real-world context and the key factors that shape it.

Method: A qualitative multiple-case study design. The case was defined as family and professional caregivers of children who died. Cases were identified from a single institution in Singapore, stratified according to disease categories (cancer or non-cancer) and whether specialist palliative care was received. Participants included parents, and healthcare providers from a hospital and a community palliative care service. Data collection included (1) interviews, (2) artefacts, (3) clinical notes, focusing on the month before death. Framework Analysis was used to facilitate within and across case analysis, involving pattern matching and theoretical replication.

Results: Five cases were formed, with eight parents and fourteen professionals as respondents. Eight common and five contingent themes were identified. Common themes are universal in salience; contingent themes, though equally relevant, apply in a subset. Based on their relationship with a child’s death, all themes are sub-categorised under three headings. (1) Antecedents: Common – Letting go, Acknowledging the child, Closure; Contingent – Doing everything possible, Miracle hope, Different levels of awareness. (2) Determinants: Common – Suffering, Control, Systems and processes; Contingent – Being home, Palliative care. (3) Attributes: Common – Comfort, Dying not prolonged. An ecologically sound and holistic conceptual framework is represented.

Conclusion: Elements critical to a good death in a child are revealed, particularly around personal attitudes and service at a systemic level.

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Chapter 1. Introduction

1.1 Focus of interest

The research question behind this entire scholastic inquiry is: *How and why can a good death be achieved in a child with life shortening illness, from the perspectives of family and professional caregivers?*

Given how palliative care as a broad concept and clinical approach is now a standard in almost all patients who die from life limiting conditions, I shall begin by charting its evolution over time in light of the study question posed above. In contrast to the early days of the ‘modern’ hospice movement in the 1960s (Clark, 1998; Saunders, 1996), contemporary palliative care in the adult setting has moved upstream, from solely rendering end-of-life care to encompass comprehensive support of a patient who is receiving active treatment for a critical illness (Casarett & Teno, 2016; McGrew, 2003; Stajduhar & Tayler, 2014; Twaddle, 2003). This evolution in philosophy and practice has similarly unfolded in the field of paediatrics, with palliative care developing beyond children hospices into paediatric hospitals (Kang & Feudtner, 2012; Klick & Hauer, 2010; Knapp et al., 2011), including the paediatric intensive care ward almost exclusively in some cases (Gupta et al., 2013; Nelson et al., 2010). It is precisely in these new settings that dying has become increasingly problematic (Hinds et al., 2005; Institute of Medicine, 2015). Death now occurs in very complex young patients receiving highly complicated treatments, within a societal culture that has unrealistic expectations of what medicine can do (McCallum, Byrne, & Bruera, 2000; Ramnarayan et al., 2007; Wolfe et al., 2014). In the age of rapid medical advancements and new technology,

there is a need to review existing perceptions of death and dying in a child who is medically ill, from the angle of the family and wider society (Cox, 2018).

When the underlying illness proves refractory to treatments, and the sick child is anticipated to die, delivering a good death often becomes the next goal for stakeholders involved (Hinds et al., 2005; Mak & Clinton, 1999). As a paediatric palliative care clinician, a longstanding conundrum I noted in both practice and research has been around explicating the attributes of the proverbial good death.

1.2 Background

In 2017, the World Health Organisation reported that 6.3 million children across the world— younger than 15 years of age—had died (World Health Organisation, 2017). It was estimated that more than half of these children had serious medical conditions that directly or indirectly resulted in their premature death, either from overwhelming disease or treatment complications (Sidebotham et al., 2014). In Singapore, a small city state where this study was conducted, it translates to consistently more than a hundred children that die from life shortening illness annually, almost always in the hospital and predominantly under paediatric intensive care. This group, like the rest of the world constitutes about half the yearly mortality figures in children below nineteen years of age locally. To put in context, mortality in this paediatric age group forms around 0.01 percent of all cause total population deaths in Singapore (Chong, 2014; Chong, Chan, & Yusri, 2012). Caregivers, wherever they reside, whether parental or professional, have likely expected or at least been forewarned of these children's premature deaths as outcomes. Unless death came suddenly, it also implies a trajectory that the individual child had traversed, journeyed

alongside by his/her caregivers, both informal and formal. This is exactly where and when the study outlined in these pages is situated, aiming to understand: on the dying trajectory of a child with life shortening illness, how (and whether) a good death may be perceived by different stakeholders, and the underlying factors that shape it.

There has been considerable debate on the notion of what may be meant by a good death in the medically ill and the ramifications this has for care. There are six major components thought to constitute a good death in adults (Steinhauser et al., 2000). They include: 1. Pain and symptom management, 2. Clear decision making, 3. Preparation for death, 4. Completion, 5. Contribution to others, 6. Affirmation of the whole person. Although others have identified similar themes (Granda-Cameron & Houldin, 2012; Kehl, 2006), perspectives can differ between stakeholders; for example, between hospice staff and patients (Payne, Langley-Evans, & Hillier, 1996) and among individual patient groups, like between those with heart failure (Gott et al., 2008) and lung cancer (Hughes et al., 2008). Some studies have indicated a gradual departure from the homogeneous good death expectation that promotes open communication and acceptance of dying, as shaped by the conventional hospice philosophy. Hart (1998, p.65) describes this emerging tension as “a new form of social control within which socially approved dying and death are characterised by proscribed and normalised behaviour and choices”. This deviation or ambivalence about what makes a good death is also observed in other cultural contexts. In a Japanese population for instance, instead of passive adherence to universal practices, Long (2001, p.271) interprets the experience of dying as a “negotiation of social roles and relationships”. These findings highlight the need to continue exploring evolving attitudes on a good death, and also the underlying motivations for different end-of-life choices (Vig, Davenport, & Pearlman, 2002).

Notwithstanding commonalities like associated physical suffering and impact on family, there remain fundamental differences in the clinical and social contexts between the dying child and adult (Hynson & Sawyer, 2001). One example is the emotional impact on multiple stakeholders, like parents, siblings, grandparents and friends, not forgetting the professional caregivers, who are all part of the intimate social network around a dying child (Meier & Beresford, 2007). Arguably, ideas gleaned from adult literature may not fully match the circumstances of the dying child. The attributes of a good death in children have not been well described, but there are some indications that narratives indeed differ from those in adults. Ito (2015) identified 13 characteristics of a good death for Japanese children with cancer. Although most are similar to those in adults, unique themes specific to children include safeguarding opportunities for play, peer support, and assent. Most of all, in contrast to the adult good death concept, it also includes the child not being aware of impending death. Given the evidence gap and difference in perspectives, in-depth exploration through empirical research within the setting of children with life shortening illness is clearly warranted.

Other aspects related to the dying trajectory of a seriously ill child are of interest here. There are prevailing assumptions and mixed evidence on terminally ill children dying at home, and the impact of paediatric palliative care (Bluebond-Langner et al., 2013; Dussel et al., 2009). Despite expanding outreach of paediatric palliative care in the past decade both in the hospital and community settings, the majority of seriously ill children are still dying in the hospital (Brandon, Docherty, & Thorpe, 2007; Lee, Tieves, & Scanlon, 2010). While receiving paediatric palliative care and dying at home are often recognised as 'ideal' in the context of life shortening illness, during the period as the young patient lays dying, it is unclear if palliative care and being home still remain pivotal to stakeholders. In addition, along the dying trajectory, needs and experiences of the

family with a child suffering from cancer and that of a non-cancer condition can differ, even if themes of grief and loss may be common (Feudtner et al., 2011; Inglin, Hornung, & Bergstraesser, 2011). That said, both similarly involve children suffering from life shortening conditions, diagnosed and treated by specialist physicians, albeit for varying periods of time. These questions are all posed as the empirical study is conceived.

Looking more broadly, it is observed in practice that events and experiences are often influenced by contextual factors unique to each setting—in this instance other participating social agents like the wider family and service providers, including the supporting healthcare system, with its own structures, workflows and even culture (Hales, Zimmermann, & Rodin, 2008). To appreciate the intricate nuances surrounding perceptions of a good death, set in the worlds of stakeholders as they are lived, these intervening factors are also taken into consideration within the study design for in-depth interrogation.

1.3 Definitions of key terms

Caregivers

For the purpose of this study, caregivers are divided into two groups. First, informal caregivers: someone who provides physical, emotional or practical support needs to the sick child based on a social connection or kinship (Jaffray et al., 2016). Second, the formal caregivers: multi-disciplinary healthcare professionals that provide direct medical or social care, either in the hospital or community setting.

Child

In view of their short and different trajectories, infants below one year of age at the time of death are not the focus here. In this study, a child is defined as the young patient who is between the age of one and eighteen years. Developmentally, they can be normal according to age or delayed as a result of underlying illness.

Life shortening illness

This refers specifically to a medical condition that may result in premature death before the child becomes an adult, acknowledging that the latter can be variably defined in different jurisdictions. The medical conditions classified under four categories by the Association for Children's Palliative Care are referenced for this purpose (Wood et al., 2010). Type 1 are life threatening conditions with a chance of cure; examples include childhood cancer and some cardiac conditions. Type 2 are ultimately fatal conditions with early periods of normality; examples include many forms of muscular dystrophy. Type 3 are devastating progressive conditions where treatment is mostly supportive; examples include metabolic or neurodegenerative conditions. Type 4 are irreversible but non-progressive conditions that cause premature death through complications; examples include various types of severe traumatic brain injury (Hain et al., 2013).

Good death

Although the use of this phrase is common in the adult setting (Ellershaw, Neuberger, & Ward, 2003; Goldsteen et al., 2006; Smith, 2000), application within paediatrics can be problematic. Some perceive a child's death as 'unnatural' and could never be good (Welch, 2008). A child's death in this study applies to the situation when dying occurs, after active medical treatment has

failed or becomes futile. The quality of death is not objectively defined a priori, intentionally allowing research participants to interpret its nature and dimensions.

Palliative care (including the Singapore context)

In this study, palliative care refers specifically to specialist-level care from providers dedicated to supporting seriously ill children (Hain, Heckford, & McCulloch, 2012; Harrop & Edwards, 2013; Nevin, Smith, & Hynes, 2019), whether in the institutional or community setting. There are two state-run hospitals with paediatric departments in Singapore, and one has a consult-based palliative care service for admitted patients. Expertise in this new subspecialty is currently not available in any of our private hospitals. Like all other government hospitals, the financial model in both centres is that of fee for service, with subsidies at different levels (determined by household income) allocated by the government. Within the community setting, the country has a single centre that provides paediatric palliative care at home. There were no dedicated inpatient children hospice resources in Singapore at the time this study was conducted. All the multi-disciplinary healthcare professionals involved are anticipated to follow broad principles and quality considerations outlined in definitions and standards of paediatric palliative care from key organisations (Abu-Saad et al., 2007; American Association of Pediatrics, 2013).

1.4 Study approach and rationale

The therapeutic relationship between paediatric healthcare practitioners and child/family is inherently different, in nature and dynamics, compared to that in the adult setting (Groh et al., 2014; Hynson & Sawyer, 2001; Meier & Beresford, 2007). Perhaps because a vulnerable minor is involved, strong and sometimes emotionally invested relationships are often forged between

stakeholders (Tutelman, Drake, & Urquhart, 2019). This phenomenon is particularly apparent to me, having worked across both adult and paediatric disciplines in palliative care. The disparity in practice culture is also the same factor that makes transition into adult care problematic for a small group of children with life shortening conditions who outlive their prognoses (Joly, 2015; Kirk & Fraser, 2014). Likewise, medical decisions in paediatrics are made predominantly on the basis of best interest rather than patient autonomy, with parents or legal guardians where available as proxies (Rhodes & Holzman, 2014). Acknowledging the special ways paediatric providers and families work together in managing care for the very sick child, I decided in the context of this study that the attributes of a good death in a dying child should be co-constructed between both informal and formal caregivers.

The research question from the start indicated that only the caregivers' perspectives are sought. This was a deliberate decision, made after much consideration during early phases of study conceptualisation. The reasons for soliciting data exclusively from adult caregivers are both strategic and tactical. The paediatric population in question, ranging in age just between one to nineteen years, actually vary widely in neuro-cognitive development from diverse life shortening conditions described before. This has implications on the ability to verbalise or communicate, particularly within a study. Owing to these challenges and conditioned by inherently unique caregiver relationships mentioned above, perspectives from the children are obtained by proxy from their adult caregivers as a pragmatic compromise.

The influence of external factors where stakeholders are situated and the impact of the ecosystem where sentinel events occur have been mentioned (last paragraph in section 1.2 on page 13). These considerations were incorporated in planning the overall research design. The decision to explore the attributes of a good death in a medically ill child in this way stems from the assumption

that actions, events or experiences surrounding a phenomenon of interest are ultimately conditioned (Mitchell et al., 1998). To appreciate the true nature and dimensions of a good death deeply, it is believed that all the above considerations must be studied in confluence. These same arguments ultimately determined the underpinning philosophy and research methodology chosen for this study, elaborated in chapter 2 and 4 respectively.

1.5 My goals and aspirations

Two major goals provided me impetus to conceive and complete this study. First, the search for missing evidence, not just to fill a critical research gap but also to guide my own practice. While principles for good palliative care have been clearly defined, the construct of a good death in medically ill children has not been explicitly characterised. This is problematic for colleagues of mine that refer patients to me. As their patients traverse the dying trajectory, these paediatric specialists appear to feel helpless, struggling emotionally and sometimes even spiritually, when every intervention within their domain expertise proves futile. In my opinion, even if treatment fails and a young person is to die, care must never falter. With a better understanding of how and why different elements contribute to a good death, aspects like communication, care planning and service delivery can be much better executed. Guided by insights gleaned from those who have lived through the experience, there is assurance to all stakeholders that supportive management which follows, is both family-focused and evidence-based—with potentially favourable outcomes that include emotional healing from inherent losses and accompanying grief.

The second goal relates to advocacy for better care of dying children, beyond clinical practice to policy making. The point made earlier about *conditions* cannot be overemphasised (last paragraph

in section 1.4, previous page). A good death construct developed using a system's perspective illuminates gaps that exist in infrastructure and milieu within healthcare (Kang & Feudtner, 2012). Findings from the study are anticipated to inform or validate current processes and provide strategic directions for healthcare planning where appropriate (Kendall et al., 2007). Like another project completed before (Chong et al., 2018), findings from this study can become key drivers as I continue to engage administrators in the local Health Ministry, who are busy managing issues associated with a rapidly aging population, to highlight peculiar yet equally concerning needs of a comparatively smaller group of beneficiaries. While there may be contextual differences between geographical regions with dissimilar jurisdictions or even cultures that limit generalisation of study findings, there are bound to be elements that can still be adapted elsewhere. And I hope colleagues in the region who face similar challenges, whether in clinical practice or healthcare advocacy, would also benefit from the study results.

1.6 Thesis structure

Including this introductory chapter, there are six chapters and one appendix section in this thesis. The latter contains documentation that supported data collection and analysis. A case study database (appendix 10) is collated within the same appendix section, containing collected data and output from early phases of analysis (single-case analysis). Citations according to the American Psychological Association (APA) convention throughout the text in all chapters are listed at the end of the thesis.

In chapter 2, the philosophical orientations adopted for the entire study (including the literature review in chapter 3) are discussed. Chapter 4 opens with an exposition on methodology, before

elaborating study procedures under method. The study findings (chapter 5) and discussion sections (chapter 6) are kept separate in this thesis. Engagement of extant literature and mid-range theories at the level of broad thematic categories arising from empirical data is detailed in chapter 6. In addition, the goals and objectives outlined in this introductory chapter are revisited in light of new findings, before closing with study implications on evidence, policy and practice.

Chapter 2. Underpinning philosophical perspectives

2.1 Ontology

The philosophy of *critical realism* (Bhaskar, 2014) frames the entire research (including the literature review reported in chapter 3), from design, data collection and analysis, to reporting of findings. Critical realism provides the means to explore and understand a social phenomenon holistically and contextually, focusing not only on the structural elements and hidden forces that drive events, but also exchanges and experiences within a particular system at the individual stakeholder level (Blaikie, 2007). The decision to choose critical realism is argued in the next section, showing how its concepts are compatible with research objectives here, while contrasting with alternative perspectives from other paradigms. This is followed by a discourse on epistemological considerations that supported the choice of study procedures.

2.1.1 Paradigmatic options

Drawing perspectives from family and professional caregivers of children who died from life shortening conditions, the research question addresses a multi-dimensional and value-laden entity, that of a good death in a predefined context. Throughout a child's dying trajectory, multiple parties interact within different systems (family, community, healthcare), each with its own workflows, drivers and barriers. Every party brings its own influences to bear in attitudes, beliefs and values, and departs carrying memories of experiences perceived on a personal level. Findings from extant literature on end-of-life in children reveal these experiences to straddle multiple domains, including physical, psycho-emotional and spiritual (Hendrickson & McCorkle, 2008). Further, given its rarity compared to mortalities from medical illness in the adult setting, dying in

childhood from life shortening illness proves to be unique life episodes, shaped by local circumstances within the period that death occurred, and peculiar to each 'family' and 'professional' caregiver dyad (Welch, 2008). Given these considerations, a *multiple-case study design* is chosen as the overall research strategy (Luck, Jackson, & Usher, 2006; Yin, 2017). Its many strengths, including an inherent methodological flexibility to produce rich and in-depth findings (Andrade, 2009; Rosenberg & Yates, 2007), are detailed in chapter 4.

Healy and Perry (2000) listed four scientific paradigms that may be used to describe and explain complex social phenomena: positivism, constructivism, critical theory and realism. Perceptions of a good death as mentioned cross multiple dimensions and domains. Their individual properties are neither concrete nor readily measurable. Fusion of multiple realities resulting from both structural and personal conditions that dynamically evolve over time is anticipated. In light of these considerations, assumptions like a controlled environment and the deductive approach intrinsic to *positivism* are evidently problematic (Bryman, 2016). Besides, there is no place for subjective constructs like values or meaning in positivism's quest for a definitive universal reality. Conceptual ideations in *constructivism* were explored during the research planning phase, but also found to be unsatisfactory in addressing study objectives. Even though constructivism accepts that reality is value-based or even driven, being fully subjective in orientation, its underlying assumptions posit multiple realities that exist only in the minds of individual social actors (Robson, 2011; Silverman, 2013). Cultural and organisational elements (Bryman, 2016) in the empirical setting, like social and systemic barriers (Hales, Zimmermann, & Rodin, 2008) to service access, and various drivers that can impact outcomes are not taken into consideration.

Theoretical concepts where *critical theory and realism* converge propounded by Bhaskar (2014) to interrogate complex and dynamic systems with many interacting parts appear to be most

appropriate in locating the 'reality' related to good death sought here. The framework of critical realism offers strategies to achieve comprehensive real-world interpretations of phenomena, at both systems and experiential levels. Concepts in critical realism germane to this study are discussed next.

2.1.2 Critical realism

In terms of orientation, critical realism sits somewhere between naturalism and idealism (Porter, 1998). It posits a stratified view of reality that exists at three different levels: real, actual and empirical (Mingers, 2004). The *real* domain is the whole of reality, within which there are complex interactions between dynamic and open 'structures' that produce all events and experiences. These structures may be material or non-material. In the context of this study, examples of material structures include models like hospitals and services, while non-material structures refer to entrenched culture or practices like norms, workflows, and relationships between stakeholders. Each structure is dynamic in that it displays what is described as tendencies or generative mechanisms (Smith, 2006). Latent effects of these interacting causal mechanisms influence the appearances of events in the *actual* domain, regardless of whether they are observed or experienced. Up to this point, concepts raised are predominantly congruent with assumptions in naturalism. Where structures are described as 'open', it refers to how each unit whether it is about policies, services or rules of engagement, can evolve over time through interactions within the system, in this case healthcare for dying children. The *empirical* domain as expected consists of the world observed or experienced by social actors, where the effects of generative mechanisms are manifested. It is within these latter two levels of reality where social reality is co-constructed that assumptions in idealism are lived out.

2.1.3 Summary

To summarise, critical realism asserts a reality that does not arise entirely from the mind (Kant's transcendental idealism) but also in the structure of reality (McDonnell et al., 2009) which in itself is neither strictly universal (instead peculiar to each setting) nor ahistorical (acknowledges and accommodates its evolution over time) (Mingers, 2004). A contextually sensitive, yet deep understanding of a phenomenon over the course of time may be achieved. That is exactly the outcome that this study aims to achieve.

2.2 Epistemology

Current understanding from empirical evidence and clinical practice reveal the construct of a good death whether in the adult or children setting to be intricate and multi-dimensional. Many inter-related factors across different domains contribute to its complex nature. These attributes and their relationships are explicated in the next chapter on literature review. Above all, not only is context contingent and primal in shaping the death and dying experience, complete characterisation of any good death is also axiomatically dependent on the social agent/s who had lived through the experience.

Given the objectives to elicit the experience and meaning of caring for dying children to uncover the attributes of a good death, it becomes evident that a qualitative approach is indicated (Bryman, 2016). Ideal for the study of a social phenomenon in its natural setting, it involves 'rich' description and explanation that target holistic representation. In addition, the qualitative approach offers insight from the point of view of those who lived it (Andrade, 2009). The lived experience and sense making from stakeholders involved address the 'how' and 'why' in the

research question. Conceptually, reality (at least in the empirical domain) is accepted as being socially constructed. Besides, to characterise death using dichotomous or multiple discrete variables like good, satisfactory or bad can be problematic. With these study goals in mind, the philosophical assumptions behind *hermeneutic phenomenology* are applied to guide the process of data collection and analysis, within an overarching case study strategy mentioned before (in section 2.1.1 on page 20).

2.2.1 Hermeneutic phenomenology

Scholars have often classified hermeneutic phenomenology under social interaction theory (McDonnell et al., 2009). Hermeneutic or 'interpretive' phenomenology developed by Heidegger went beyond the study of experience (contrast Husserl's 'descriptive' phenomenology) to expose hidden meanings behind them. Schutz expanded beyond these two German philosophers' ideas to describe *lifeworlds* (everyday common-sense world) where humans as social agents make meaning through understanding based on a 'stock of knowledge' that is often taken for granted (McDonnell et al., 2009). He qualified that humans do not attach meaning to the world individually, rather our phenomenological understandings are shared with and reinforced by other members of society within a specific time and space. His hermeneutic school of thought promulgates this *intersubjective* orientation, which in essence echoes some of the distinctive features of social interaction theory (Porter, 1998). The 'stock of knowledge' effectively constitutes a conceptual framework that one subconsciously uses to make sense of the world around us, assuming that everyone else does the same. The researcher's role here is to discover how and why a specific conceptual framework is formulated and applied by social agents or actors. It is exactly this conceptual framework which shapes perceptions of a good death that this study aims to define.

This philosophical position is anticipated to give insights into the world of childhood illness and death by exposing underlying attitudes, values or beliefs among stakeholders, possibly even power relations, when intersubjective perspectives are mutually forged within the healthcare system, in itself an example of a unique lifeworld. Coupling this awareness with critical realism as the paradigmatic framework, it would be illuminating to observe how effects of larger policies and practice are played out at the micro level. Prospects to improve policy and practice become possible with in-depth understanding, toward improving the experience of caring for a sick and dying child (McDonnell et al., 2009). This hidden motivation for positive transformation brings the discourse on theory to another branch of hermeneutics, *dialectic or critical hermeneutics*.

2.2.2 Dialectic hermeneutics

Dialectic or critical hermeneutics combines the interpretive and critical research traditions. The focus is on *conditions* through which meaning is created, acknowledging the political dimensions of power and justice that may influence social phenomena and their interpretation (Lutz, Jones, & Kendall, 1997). There is an implicit assumption that not all social actors in the context of inquiry are equal or are able to get heard, which is fundamental in the purist interpretivist tradition. The assumption is analogous with what is seen in reality. It is not difficult to appreciate how navigating a healthcare system and interacting with different professionals while caring for a dying child can overwhelm the informal caregiver. Or alternatively, how a professional caregiver like a ward nurse who may be struggling with moral distress (Wilkinson, 1987) while caring for a dying child would perceive the situation. In the context of this study, differential political dimensions relate to more than just those between individuals as social actors. Barriers intrinsic to structures, systems and processes are also inferred. All these factors can ultimately influence overall experience and meaning making.

The concept of *praxis* is also represented in critical hermeneutics. This is when beliefs and values are made visible through deliberate actions to transform a particular situation. It is posed as a normal response to the complex and multi-faceted human experience (Weaver & Olson, 2006). Recognising the concept of *praxis* thus renders the respective stakeholder's perspectives apparent, as stakeholders' outcomes-driven actions in study findings are analysed and interpreted in context.

Considerations to unify concepts in critical theory and hermeneutics are not new (Bernstein, 2011; Hoy, 1988). They have arisen to address weaknesses in pure hermeneutics, summarised below (Orlikowski & Baroudi, 1991; Radnitzky & Giorgi, 1973):

1. Conditions (often external) that influence experience and meaning not examined
2. Historical changes and their effects neglected
3. Structural conflicts within society or organisations not addressed

Dialectic or critical hermeneutics (Myers, 1995) mitigate these gaps and their conceivable impact on research findings through a process of integration, emphasising both subjective meanings of individual actors and the social structures which condition and enable such meanings (Darke, Shanks, & Broadbent, 1998). With an intricate and layered theoretical approach to study design as outlined in sections before, a congruence between epistemological considerations (dialectic hermeneutics) and ontological foundations (critical realism) is attained. There remains however the need to accommodate findings in the 'real' domain (in Bhaskar's three stratified realities: real, actual and empirical) that is grounded philosophically in naturalism, while hermeneutics covers interactions within the 'empirical' domain. This is where a method of inquiry with realist orientations—case study design—can amalgamate these multiple streams of data inputs. More details will be given in chapter 4 (methodology and method).

2.2.3 Summary

Critical or dialectic hermeneutics is the lens that this case study research uses in constructing a conceptual framework, to understand what a good death in a child may look like, in the eyes of all adult stakeholders who have been through the experience. The conditions (both social and structural) that facilitate or constrain, specific to a lifeworld (system) and period within which they interact and influence, where actions, events and experiences manifest, are all acknowledged.

2.3 Summary of philosophical perspectives

This chapter on underpinning philosophical perspectives justifies critical realism for ontological orientation. Its ability to accommodate macro and micro perspectives in a complex and evolving environment provides an overarching backdrop, to paint a holistic and situated narrative of a good death in a child with life shortening illness.

To achieve this task, theoretical propositions in the qualitative research tradition are referenced, particularly to answer the how and why questions in the quest for attributes of this good death. This thread will be picked up again in chapter 4 as the case study methodology is described. With aforementioned ontological orientation in mind, and inherent motivations to advocate for excellent care in this group of patients and families, choosing dialectic hermeneutics as the epistemological lens is argued as most appropriate in achieving the study objectives.

By recognising how events and experiences in the lifeworlds of stakeholders are intersubjectively and conditionally co-constructed, a real-life instead of an 'experimental' narrative for a good death that is aspirational, yet authentic may be drawn.

Chapter 3. Literature review

This literature review was published in the Journal of Palliative Medicine (Chong, Walshe, & Hughes, 2018), and is reproduced in full in appendix 1. The review is expanded and presented here, with more contextual detail on review design and methodology.

3.1 Introduction

The primary objective of the literature review is to gain early understanding of what makes a good death for a child with life shortening illness, from the perspective of everyone involved. Secondary objectives include uncovering the gaps that remain, in the interpretation of what is perceived from corresponding adult literature of a complex and multi-dimensional construct, while at the same time, seeking strategic recommendations for empirical research approaches where possible.

The review question is:

What is perceived as a 'good death' in a child with a life shortening condition, by different stakeholders, in all settings?

3.2 Method

This review follows the integrative review design of Whitemore and Knafel (2005). An integrative review is a robust, systematically constructed approach to synthesis of literature which strives to

be inclusive with its 'open methodological stance' (Welstand, Carson, & Rutherford, 2009). It enables data from diverse sources to be synthesised, to render a more holistic understanding of a topic (Virdun et al., 2015). Methods of synthesis that are unable to handle varied literature with different study designs anticipated, like meta-ethnography (Britten et al., 2002) would therefore not be suitable. Similarly, review methods like thematic synthesis (Thomas & Harden, 2008) that aims to reveal patterns or commonalities across literature, rather than seek a wider or deeper understanding of social phenomena may not attain review objectives needed here. An integrative review can either be aggregative or interpretive (Kylmä et al., 2009). To build a thematic framework that informs the empirical study to follow, the target is to achieve both. Perspectives from many different stakeholders are assembled and synthesised, to obtain a composite understanding of a good death. Heterogeneity of studies is a means to an end, instead of an end in itself. This is where approaches like narrative synthesis differ. While adequately flexible in managing mixed literature, narrative synthesis investigates heterogeneity across research to evaluate how they relate to study characteristics or other attributes (Popay et al., 2006). The ontological position adopted throughout synthesis of evidence matches that of the original study—critical realism. The review report here follows the recommendations of the ENTREQ statement (Tong et al., 2012).

3.2.1 Literature search and selection

The search was broad, as to my knowledge the topic of good death in children has not been extensively reported. Keywords or MeSH headings were supplemented by 'free-text' strategies to widen retrieval of relevant studies (Boland, Cherry, & Dickson, 2013). Since the subject of good death straddles academic domains, general as well as discipline specific databases were chosen to maximise data capture. Searches were performed across five databases in December 2016 (and

updated in May 2018): EMBASE, Web of Science, Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO, from database inception to search date. Search strings combined variations of “patients”, OR “next of kin”, OR “healthcare providers” (population), AND “death” (exposure) AND “perspectives” (outcomes). Detailed search strings for the Medline database are presented in appendix 2.

The inclusion criteria were:

1. Empirical research on experiences around death and dying in children with life shortening conditions.
2. Study samples that included either patients, family caregivers, and/or healthcare professionals.
3. Reported perceptions from those who were directly involved in caring for dying children.
4. The children referred to in the study were above one year of age (neonatal or infantile deaths were not a focus of this review), adolescents, teenagers or young adults (below 19 years old).

Papers were excluded if studies were:

1. Not empirical research (qualitative, quantitative or mixed) published in a peer-reviewed journal.
2. Reported in a language other than English.

No date limits were set. EndNote X7 software was used to manage citations, while NVivo 11 programme supported the management of included studies.

3.2.2 Appraisal of selected studies

While keeping validity of findings a priority, quality assessment in an integrative review (Whittemore & Knafelz, 2005) of primary studies with diverse research designs is inherently problematic. Hence, with the review question as focus, quality assessment is often achieved in the “broadest of terms” (Spenceley et al., 2008, p. 957). Only when discrepant findings are encountered is closer examination of factors like methodological rigour and data relevance warranted (Whittemore, 2005). The Australian Palliative Residential Aged Care (APRAC) Guidelines: Evidence Evaluation Tool was used to assess quality and relevance of selected studies (Kristjanson, 2006). Although not previously used in the paediatric setting, the tool had been customised based on Cochrane and Campbell Collaboration guidelines (Campbell Collaboration, 2002; Cochrane Collaboration, 2002) and was effectively applied to appraise both quantitative and qualitative studies by the Australian workgroup. Quality was addressed using eight questions, each requiring a yes or no answer (scoring one or zero respectively). Sum total range between zero to eight points, with score of eight implying best quality. In this review, papers with quality score of four and below were rejected before final synthesis (see results section). Relevance was rated by assessing the applicability of individual research findings to the review question, with scores that can range from low of one to highest of four. If any conceptual conflict had arisen at data synthesis (none in this instance), findings from studies with greater relevance were planned to be given higher weightage for consideration.

3.2.3 Data synthesis

For dependability of findings, a protocol for the integrative review was set up in advance (Ross & Estabrooks, 2008). The steps in data synthesis (Whittemore & Knafelz, 2005) involved:

1. Data reduction—extracting relevant sections from selected articles for an organised handling of data;
2. Data display—grouping excerpts from primary sources around meaningful variables in tables;
3. Data comparison—iteratively studying the displayed data, variables of interest are put into conceptual maps that show patterns, variations or relationships;
4. Drawing conclusions—moving beyond describing patterns to higher levels of abstractions.

To achieve what Whitemore and Knafl (2005) refer to as an innovative synthesis of evidence, primary analytic approaches developed for qualitative and mixed method designs were adopted. One such technique, the constant comparison method (Miles & Huberman, 1994; Quinn, 2002) was applied throughout. It entails categorising for example an action, event or participant into a general 'class', conceptually or theoretically, through multiple iterations during data analysis. Additionally, in the process of coding, second order findings that are often interpretations of primary data by authors were also extracted. These were predominantly obtained from discussion sections of the papers (reported in section 3.3.3, pages 51–52). By this stage, newly formed ideas and concepts were verified with primary sources (individual studies) for contextual accuracy. Conclusions were then drawn to complete the entire integrative review as specified by the review protocol.

3.3 Results

3.3.1 PRISMA diagram

A total of 29 papers met the inclusion criteria. The review process is illustrated in figure 3.1 below.

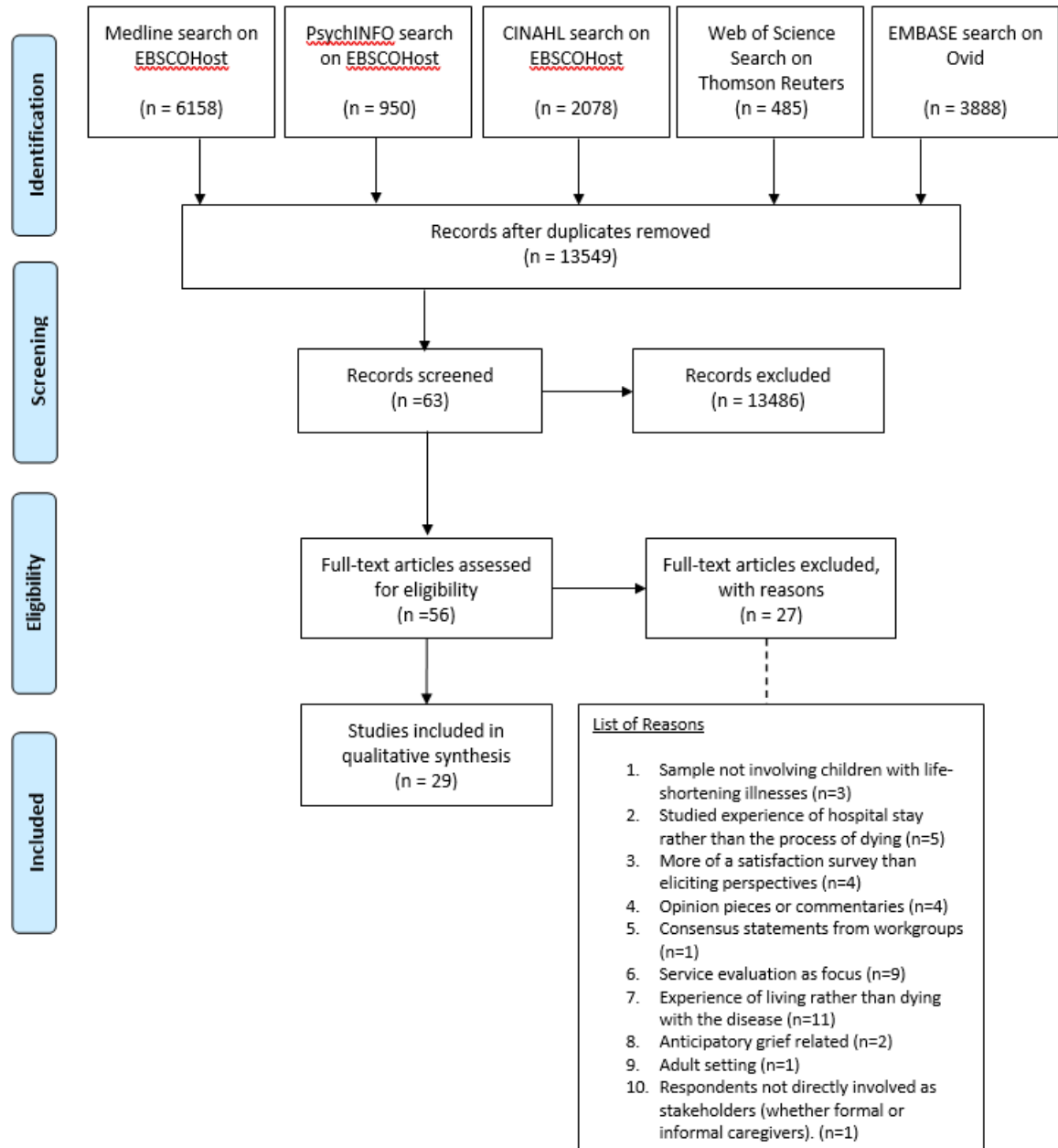


Figure 3.1. PRISMA flow diagram showing literature search and selection

3.3.2 Appraisal of studies

Relevant details of all 29 papers that initially met inclusion criteria are summarised in table 3.1. Five studies (Latha et al., 2016; Midson & Carter, 2010; Muskat, Brownstone, & Greenblatt, 2017; Nafratilova, Allenidekania, & Wanda, 2018; Suryani, Allenidekania, & Rachmawati, 2018) that did not reach the threshold set for quality (above score of four) and relevance (above score of 1) were not included in the final synthesis.

Table 3.1. Details (including appraisal outcomes) of all 29 selected papers

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
Balkin et al. (2015)/ United States	Compare physician and parent perspectives regarding prognosis and end-of-life experience of children with advanced heart disease	Mixed/ Cross sectional survey	Cardiologists and bereaved parents/ Non cancer/ Tertiary paediatric hospital	Nearly half of parents and physicians felt that patients suffered ‘a great deal,’ ‘a lot,’ or ‘somewhat’ at end of life. In 43% of cases, physicians reported that the parents were prepared for the way in which their child died, while the parents reported feeling unprepared.	8	2
Björk et al. (2016)/ Sweden	Illuminate parents' experience of losing a child to cancer	Qualitative/ Interviews and written narrative	Families with a child diagnosed with cancer/ Cancer/ Tertiary paediatric hospital	One essential theme emerged: Like being covered in a wet and dark blanket. Six related themes: (1) Feeling conflicting emotions, (2) Preparing for the moment of death, (3) Continuing parenting after death, (4) Recollecting and sharing memories, (5) Working through the sorrow, (6) New perspectives in life.	7	3
(Cataudella & Zelcer, 2012)/ Canada	Experience of children with brain tumour in their last month of life	Qualitative/ Focus group interviews	Bereaved parents of children/ Cancer/ Tertiary	Three domains identified that described child’s psychological experiences: (1) intrapsychic—internal aspects of a person such as cognitive and emotional variables, (2) interpersonal—interactions	8	3

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
			paediatric institutions in a region of country	between oneself and others, including being treated like their healthy peers and maintaining relationships with others, (3) posttraumatic growth—positive personal changes as the result of a significant struggle or hardship.		
Davies et al. (1998)/ 5 different countries	Explore the experience of mothers from different countries who each had a child die of cancer	Qualitative/ Semi- structured interviews	Bereaved mothers/ Cancer/ Tertiary paediatric centres, related home care programmes, bereavement support programmes	No culturally related differences were noted, and the mothers' recall of their experiences more similar than different. All mothers, irrespective of country, described similar reactions to the diagnosis, management of the end-stage illness, and challenge of coping with bereavement.	8	3
Davies (2005)/ United Kingdom	Uncover the experience (and needs) of mothers whose children died in different settings (hospital,	Qualitative/ Semi- structured interviews	Bereaved mothers/ Mixed/ Local hospitals and children hospices	Comparisons made between care and support received in hospital, at home and in a children's hospice. Identified their need for time, space and privacy with dying child and their body after death. Memories of these events continued to affect them.	7	4

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
	home and hospice)					
Eskola et al. (2017)/ Switzerland	Obtain parents' experience and needs during their children's end-of-life care at home	Mixed/ Patient medical charts, surveys, and interviews	Bereaved parents/ Mixed/ Part of a multi-centre national study	Parents created a sense of normality for the child at home, constantly balancing the family's lifeworld with requirements and challenges posed by the outside world. Parental 'readiness' and social support drove end-of-life care for children at home. In only 34.8% of cases was a child's end-of-life home care supported by paediatric palliative care.	8	4
Flavelle (2011)/ Canada	Case study of an adolescent's experience of living and dying of cancer	Qualitative/ Analysis of written journal	Teenage boy/ Cancer/ Local health centre	Five main themes: (1) Adolescent development, (2) Escape from illness, (3) Changing relationships, (4) Symptoms, (5) Spirituality.	5	2
Granek et al. (2015)/ Canada	Explore what makes patient deaths challenging for paediatric oncologists	Qualitative/ Semi- structured interviews	Paediatric oncologists/ Cancer/ Two paediatric hospitals	Challenging factors: First, relational, including dealing with families perceived as challenging; identifying with parents; and having long-term relationships. Second domain captured the process of death and dying, including death after curative treatment was stopped; death caused by complications; and unexpected deaths. The third domain encompassed patient factors that included suffering of the child, and the sense that no child should die.	8	3

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
Higgs et al. (2016)/ Australia	Solicit perspectives of parents with children diagnosed with Spinal Muscular Atrophy (SMA) Type 1 from diagnosis to bereavement	Qualitative/ In- depth interviews	Bereaved parents/ Non cancer/ A regional clinical genetics service	While individual experiences were unique, common themes emerged: shock and anticipatory grief, feelings of responsibility and helplessness, multiple losses including the loss of future reproductive freedom, feeling supported, regaining a sense of control by making decisions about the child's life and death, and finding peace in the dying process.	8	3
James and Johnson (1997)/ Canada	Locate parental needs while their child was dying of cancer	Qualitative/ Semi- structured interviews	Bereaved parents/ Cancer/ Palliative care service in a region of the country	Three needs were identified: (1) The need to have the child recognised as special while retaining as much normality within the child's and family's lives as possible, (2) The need for caring and connectedness with health care professionals, (3) The need to retain responsibility of parenting their dying child.	8	3
Kars et al. (2011)/ Holland	Reveal parental experience at the end of life in children with cancer	Qualitative/ In- depth interviews	Parents/ Cancer/ Paediatric oncology centres covering 80% of country	Feelings of loss play a prominent role during the end-of-life phase. Loss is a process of stepwise relinquishing—an internal struggle between preservation and letting go. Preservation means trying to maintain the child's status quo. Letting go means giving up resistance to loss for child's well-being.	8	4

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
Kars, Grypdonck, and van Delden (2011)/ Holland	Reveal parental experience (and meaning- making) when caring at home for their child with incurable cancer	Qualitative/ In- depth interviews	Parents/ Cancer/ Five paediatric academic oncology centres	Four end-of-life stages identified: becoming aware of the inevitable death, making the child's life enjoyable, managing the change for the worse, and being with the dying child.	8	4
Lamiani et al. (2013)/ Italy	Explore parental experience of end-of-life care in a paediatric intensive care unit (PICU)	Qualitative/ Semi- structured interviews	Bereaved parents/ Mixed/ University affiliated hospital PICU	Four themes described the parents' experience: (1) Loss of parental role, (2) Lack of physical intimacy with the child, (3) Ambivalence about end-of-life decisions, (4) Reclaiming the dying process	8	4
Lan and Yun (2015)/ Malaysia	Uncover parental experience in the end-of-life care of children with life limiting conditions	Qualitative/ Focus group discussions and in-depth interviews	Bereaved parents/ Mixed/ Paediatric department of a regional hospital	Weaknesses in the healthcare system, including processes within palliative care: like symptom control, closed communication, lack of support and anticipatory guidance as death approached.	5	2
Latha et al. (2016)/ India	Elicit perspectives of parents on	Mixed/ Questionnaire	Bereaved parents/ Cancer/	Toward death, dullness (30%), irritability (30%), and withdrawal from surroundings (10%) were the most common symptoms	4	2

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
	their child's end-of-life care	survey and interview	Tertiary paediatric haemato- oncology unit	encountered. About 30% of the children had fear to be alone. About 50% of the children had the fear of death.		
Lovgren et al. (2016)/ Sweden	Examine siblings' experience of brother's or sister's cancer death	Mixed/ Questionnaire survey	Siblings who are bereaved/ Cancer/ Part of a nationwide survey with data obtained from cancer registry and population register	Poor knowledge and lack of communication about their siblings' death. 70% reported that they witnessed their brother/sister suffering in the last hours in life. Many of those who were not present during the illness period and at the time of death expressed regret.	8	2
Lovgren, Sejersen, and Kreichbergs (2016)/ Sweden	Elicit parental experience (and wishes) at end-of-life in children with SMA Type 1 & 2	Mixed/ Survey questionnaire	Bereaved parents/ Non cancer/ Part of a nationwide survey with data obtained from National Board of Health & Welfare and Tax agency	Communication with physicians about their wishes and concerns regarding child's end-of-life care and preferred location of death contributed to their wishes being fulfilled. A vast majority of siblings did not receive psychological support after death of their brother or sister.	6	2
McConnell and Porter (2017)/	Elicit experiences of	Qualitative/ Semi-	Care team staff/ Mixed/	Despite the sadness of the circumstances, staff found many aspects of the work	8	2

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
United Kingdom	care team providing end- of-life care in a children hospice	structured interviews and a focus group discussion	One children hospice	rewarding. Challenging experiences included finding the right combination of medications to alleviate end-of-life symptoms.		
Midson and Carter (2010)/ United Kingdom	Develop an end-of-life care pathway through identifying parental needs and experiences	Qualitative/ Questionnaire survey	Bereaved families/ Mixed/ Tertiary paediatric hospital	Geography of the hospital could be disruptive and dislocating, and they often had no place to be alone or in private. Communication was identified as a core issue, with many parents being positive about the quality and timing of communication. Other parents expressed a preference for more preparation about the possibility that their child might die.	3	2
Muskat, Brownstone, and Greenblatt (2017)/ Canada	Experiences of social workers who work with dying children and their families	Mixed/ Semi- structured interviews	Acute care paediatric social workers/ Mixed/ Paediatric acute care hospital	Themes included the role of social work with dying children, the impact of their work and coping strategies.	8	1
Nafratilova, Allenidekania, and Wanda (2018)/ Indonesia	Explore experiences of parents with children suffering from cancer	Qualitative/ In- depth interviews	Parental caregivers/ Cancer/ One paediatric palliative home care service	Particularly during palliative care, parents cannot be separated from their relationship with God. Nurses are vital to the continuous assessment of parents' spiritual needs.	4	1

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
	receiving palliative care					
Price et al. (2011)/ United Kingdom	Uncover parental experience of caring for children with terminal conditions	Qualitative/ Semi- structured interviews	Bereaved parents/ Mixed/ Children's hospital and hospices in a region of the country	Four distinct processes identified in the responses of parents to the death of a child. These are referred to as 'piloting', 'providing', 'protecting' and 'preserving'. Facilitating capacity of parents to 'do' is central to coping with the stress and uncertainty of living through the death of a child.	8	3
Price, Jordan, and Prior (2013)/ United Kingdom	Compare priorities between healthcare providers and parents in the care of children at the end-of-life	Qualitative/ Nominal group technique in focus groups	Health and social care professionals/ Mixed/ Regional children's cancer unit and a children's hospice	Caring for a dying child is a multi-dimensional experience. Three implications for service development. Firstly, the need for "joined up" palliative care services, particularly concerning timely referral. Secondly, more structured bereavement services. Third, within an ethos of family centred care, needs of siblings should be addressed.	8	2
Russell et al. (2018)/ Canada	Understand perspectives of siblings with a brother or sister dying at home or in hospital	Qualitative/ Semi- structured interviews	Siblings/ Mixed/ Tertiary children hospital	The insights from the siblings revealed complex experiences, both personal and with the ill child, their families, and peers. These experiences were paradoxically sources of strain and of support, revealing the importance of validation and	8	4

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
				normalisation in assisting siblings to successfully navigate the experience.		
Suryani, Allenidekania, and Rachmawati (2018)/ Indonesia	Explore nurses' understanding of what comfort means to dying children	Qualitative/ In-depth interviews	Nurses who had cared for a dying child/ Cancer/ One paediatric palliative home care service	Nurses should provide information to the family in facilitating acceptance. Children died well when they did not experience suffering, and had their wishes granted.	4	1
Vickers and Carlisle (2000)/ United Kingdom	Gain perspectives of parents caring for a dying child at home	Qualitative/ Semi-structured interviews	Bereaved parents/ Cancer/ One paediatric hospital	Choice and control appeared to be fundamental to parental coping. Most parents were willing to take responsibility for the nursing care of their child. Home was the overwhelming choice of parents for delivery of terminal care, with most parents perceiving it as their child's choice also.	8	3
von Lutzau et al. (2012)/ Germany	Investigate the experience of children dying of cancer from the perspectives of parents	Qualitative/ Semi-structured interviews	Bereaved parents/ Cancer/ Paediatric oncology departments in the state	Nearly all children suffered from at least one distressing symptom. Symptoms successfully treated 65% of the time. 64% received home care, with 50% of these children eventually dying at home and 10% in the intensive care unit.	8	2
Zelcer et al. (2010)/ Canada	Explore the experience of children with brain tumours	Qualitative/ Focus group discussion	Bereaved parents/ Cancer/ One	(1) Dying trajectory characterised by progressive neurologic deterioration. Parental coping included striving to maintain normality and finding spiritual strength	8	2

Author(date)/ Country	Research question or aims	Study design/ Data collection	Participants/ Disease groups/ Setting	Main findings	Quality (0-8 points)	Relevance (1-4 points)
	and their families at the end-of-life		paediatric hospital	through maintaining hope and in the resilience of their child. (2) Parental struggles during this phase included balancing competing responsibilities and speaking with their child about death. (3) Barriers to achieving a home death included suboptimal symptom management, financial and practical hardships, and inadequate community support.		
Zimmermann et al. (2016)/ Switzerland	Understand perspectives of parents facing the death of their child (four diagnostic groups)	Qualitative/ Questionnaire survey	Bereaved parents/ Mixed/ All children's hospitals, general hospitals with paediatric units, long term institutions and paediatric community care services	Parents of a child with cancer rated their experiences highest and reported the highest satisfaction with care. The lowest scores were mainly reported by parents from the neurology group, with the exception of the shared decision-making domain, where parents of neonates reported significantly less positive experiences. The integration of specialised paediatric palliative care has the potential to minimise lost opportunities to support and assist parents.	8	2

Note: Studies (n=5) that are shaded above have not been included in the final synthesis

3.3.3 Themes

Three broad themes were identified; 'level of needs', 'the composite experience', and 'control'.

Level of needs

Needs were interpreted at two levels, that of day-to-day expectations and aspirational goals (table 3.2). On the first level, 'wish list or expectations' comprised practical needs that were often varied in nature. These can be organised into three aspects: structures related, for example provision for respite or a quiet location in the ward to grieve; process related, for example dedicated services for grief support or follow up after the child's death; stakeholder related, for example specifically attending to siblings or honouring parents' wishes to provide hands-on care. Conversely, on a higher level, aspirational needs like 'goals at the end of life' embody different types of longing frequently heard in practice, like doing everything possible, maintaining hope and minimising suffering.

Table 3.2. Level of Needs (met or unmet)

Wish list or expectations	Excerpts from the literature
Actively caring for the dying child	<i>The only answer to the child's vulnerability and dependency was for parents to transform their boundless love into unconditionally caring for their child and being present. (Kars et al., 2011b, p.E266)</i>
Follow up after the child's death	<i>The need for connectedness remained ... would have welcomed some formal follow up after their child died. (James and Johnson, 1997, p. 90)</i>
Involvement in end-of-life decisions	<i>Parents reported ambivalence about their involvement in end of life decisions. Some parents clearly expressed the importance of being informed and participating ... but they did not want to ultimately decide about withdrawal of life support treatment. (Lamiani et al., 2013, p. 1339)</i>

Respite care	<i>Whilst the provision of respite care gives parents a much-needed rest from caring for their ill child, of more importance was the fact that it enables them to focus on their other children/each other/other family members. (Price et al., 2011, p. 1389)</i>
Bereavement support service	<i>Awareness of families' manifest need for bereavement support and lack of relevant service. (Price et al., 2013b, p. 78)</i>
Talk openly with dying children	<i>Being able to talk openly with dying children is an important factor in facilitating a child's expression of choice and control over all aspects of care. (Vickers and Carlisle, 2000, p. 18)</i>
Special treatment	<i>Because of the severity of their child's illness compared with other children, they should not have to wait long to see a physician. (James and Johnson, 1997, p. 88)</i>
Goals at the end of life	Excerpts from the literature
Reduce patient's suffering	<i>The majority of both physicians and parents reported that their primary goal for the medical care provided to the patient once they realized there was no realistic chance of child survival was 'to lessen the patient's suffering as much as possible'. (Balkin et al., 2015, p. 320-321)</i>
Doing everything possible	<i>Parents expressed that they would never forgive themselves if they had not tried everything to save their child. (Kars et al., 2011b, p. E264)</i>
Stay home	<i>During the final stage of illness, nearly two thirds of the mothers were given a choice of caring for their children ... most chose home whether or not established home care services were available. (Davies et al., 1998, p. 305)</i>
Be with patient at point of death	<i>"I wanted to be with him when he died and that made me very nervous at the end because you do have to sleep and I just couldn't stand the thought that he would die alone or with a stranger and it was my worst nightmare." (James and Johnson, 1997, p. 92)</i>
Maintaining hope	<i>Maintaining hope for a cure was a prominent theme across all focus groups, even at the end stages of life. (Zelcer et al., 2010, p. 228)</i>
Unmet needs	Excerpts from the literature
Spiritual care	<i>Twelve (63%) mothers indicated that they were in need of spiritual care during the last month of the child's illness. None reported receiving spiritual care from either the hospital chaplain or the hospital staff. (Davies et al., 1998, p. 307)</i>

Coordination and continuity of care	<i>Experiences with continuity and coordination of care were rated lowest of all quality domains by parents from all diagnostic groups, and perceived satisfaction with care within this domain was lowest as well. (Zimmermann et al., 2016, p. 12)</i>
Access to respite	<i>The parents' need to be with and care for the dying child often presented conflicts when they had other responsibilities, such as parenting other children. (James and Johnson, 1997, p. 91)</i>
No point of reference to guide own experience	<i>Parents felt a deep lack of a model: "You've never been in this situation before." (Kars et al., 2011b, p. E264)</i>
Attending to the siblings	<i>During the last 24h before the loss, 43% of the siblings reported getting no information about the impending death of their brother/sister from a family member. (Lovgren et al., 2016a, p. 437)</i>
Meeting healthcare providers after the death	<i>After their child died, some parents felt abandoned by professionals, because professional support stopped and there was no further regular contact. (Eskola et al., 2017, p. 2469)</i>

Closer examination of these needs revealed a common thread, that of duality and ambivalence in and around them. For instance, most parents wanted to be personally involved in making critical decisions for their child. Yet this might not extend to decisions involving withdrawal of treatment:

"Some parents clearly expressed the importance of being informed and participating ... but they did not want to ultimately decide about withdrawal of life support treatment." (Lamiani et al., 2013, p. 1339)

Additionally, some wished that they could talk more openly with their own children when it became obvious that they were going to die, yet felt compelled to maintain hope for survival. Nevertheless, some did manage to keep both notions at the same time:

"Maintaining hope for a cure was a prominent theme across all focus groups, even at the end stages of life. Families described the ability to hold on to two dichotomous beliefs: the

realism that their child's prognosis was poor and the search for a miracle.” (Zelcer et al., 2010, p. 228)

Equally valid aspirations notwithstanding, the goals to reduce suffering while doing everything possible do seem to conflict, both conceptually and operationally.

Respondents in several studies said that their needs were never met. Although unclear if they were made explicit to providers, presumably, support by the paediatric palliative care team if available could have mitigated some of these unmet expectations like coordination and continuity of care and being able to stay home.

“The lack of a key worker 24/7 left parents to navigate the healthcare system on their own, with no support and anticipatory guidance, especially during the night and weekends.”
(Lan and Yun, 2015, p. 297)

A mismatch between needs and response from care providers could contribute to a perception of suffering. That would not make any death good.

The composite experience

Stakeholders faced other challenges as they navigated the healthcare system (table 3.3). These included negative experiences among healthcare providers themselves:

“Unexpected deaths were hardest on the families, and therefore, also hardest on the oncologists.” (Granek et al., 2015, p. 2353)

Here, the oncologists shared a common humanitarian perspective with many; the death of any child is against the order of nature. Another point made by the same group surrounded children

with cancer dying from medical complications, where frustration related to lack of mastery or control is evident.

Table 3.3. Perception of Suffering in relation to the Composite Experience

Negative experiences	Excerpts from the literature
Receiving conflicting information	<i>42% (13/31) of parents in this cohort felt they "sometimes" received conflicting information from members of the care team during their child's EOL care period. (Balkin et al., 2015, p. 321)</i>
Unprepared for the child's death	<i>55% (17) of parents reported feeling unprepared for the way the child died. (Balkin et al., 2015, p. 321)</i>
Not given 'time' & space' to be with dying child	<i>Within hours, he was taken to the mortuary and she had to leave. She described her anguish: "I've got to say, in everything, the hardest thing I ever had to do is walk away from the hospital." (Davies, 2005, p. 295)</i>
Suboptimal control of symptoms	<i>Parents in this study also reported feelings of helplessness, frustration, and lack of control in relation to alleviating the child's pain and suffering. (James and Johnson, 1997, p. 91)</i>
Sense of abandonment by healthcare providers	<i>"People do sort of disappear when the child's going to die. It's sort of like, they're all gone because they can't cope with it I guess..." (James and Johnson, 1997, p. 90)</i>
Loss of parental role and family intimacy in the hospital setting	<i>The parents who had the chance of experiencing their parenting role at home often felt that their knowledge of the child and their ability to provide care was disregarded by clinicians. (Lamiani et al., 2013, p. 1337)</i>
Inconsistent or change in healthcare providers near end of life	<i>There was a change in shift on the ward at the time of death. (Lovgren et al., 2016b, p. 204)</i>
Treatment withdrawal; complications related, sudden or unexpected deaths	<i>Paediatric oncologists noted that even though withdrawing treatment or support was necessary and agreed on by the health-care team and the child's family, it nonetheless posed an added difficulty when the child died. (Granek et al., 2015, p. 2353)</i>
Altogether, a most difficult journey	<i>The on-going disruption is characterized by an unfolding succession of events over which parents feel they have little or no control, sometimes</i>

	<i>little or no understanding and which invariably demands complex decision-making. (Price et al., 2011, p. 1386)</i>
Positive Experiences	Excerpts from the literature
Relationship between healthcare provider and child that facilitated death conversations	<i>Many parents reported that the relationships developed between staff and their children helped to facilitate discussions about death and dying when as parents they could not. (Cataudella and Zelcer, 2012, p. 1195)</i>
Special qualities of healthcare providers	<i>Parents felt cared for when they thought the healthcare professionals were respectful, sensitive, compassionate, empathic and consistent. (James and Johnson, 1997, p. 89)</i>
Given control over how or where child died	<i>Forty-three parents (90%) spent as much time as they wanted with their child after death and 44 of the 48 (92%) said goodbye in a way they wished. (Lovgren et al., 2016b, p. 202)</i>
Be there with child at point of death	<i>Although unable to ultimately protect their child (that is, from death), 'being there' at the point of death comforts parents. (Price et al., 2011, p. 1188)</i>
Actively rendering care on their own	<i>Parents were able to do something for their child, to become active participants and this was something that is perceived as "positive" and "good". (Vickers and Carlisle, 2000, p. 18)</i>
Access to healthcare providers day and night	<i>Reachability day and night (hospital and community care). (Zimmermann et al., 2016, p. 9)</i>
Supported both individually and as a family	<i>They supported by "just being there" or by connecting in some personal way such as through eye contact or with a smile. (Davies et al., 1998, p. 306)</i>
See death as "end to suffering"	<i>The moment after death was described by parents as the only time in which they could have the child back, free of medical aids and restraints, in a human way that was not possible before. (Lamiani et al., 2013, p. 1340)</i>
Perceptions of suffering	Excerpts from the literature
Loss of function and physical changes in dying child	<i>"Up until then he had adjusted quite well to the diagnosis, and most of the time his spirits were pretty good, but not in the last month." (Cataudella and Zelcer, 2012, p. 1193)</i>

Caregivers anticipating impending loss during the dying phase	<i>Knowing this all will end, together with the awareness of the excruciating pain his/her absence will cause in their future life, brings about unbearable feelings of loss. (Kars et al., 2011a, p. 30)</i>
Withdrawal from outside world commonly seen in dying child	<i>Many parents experienced moments where their child withdrew from them by turning inward or not wanting to be touched ... Parents realized that, in the end, their child inevitably would have to go through the process of deterioration and dying alone. (Kars et al., 2011b, p. E267)</i>
Whether 'preserving' or 'letting go', sense of suffering prevails	<i>"You are torn between these two things, that it would have been more comfortable and easier for her (to die) four weeks earlier, but at the same time you desperately wanted a little more time with her, that's the way it is." (Bjork et al., 2016, p. 42)</i>
Lack of support at home (especially after hours) causing helplessness and distress	<i>The lack of a key worker 24/7 left parents to navigate the healthcare system on their own, with no support and anticipatory guidance, especially during the night and weekends. (Lan and Yun, 2015, p. 297)</i>

There were also moments when people felt gratitude in crisis, validated for their selfless devotion or simply well supported by their providers. Summation of these encounters both good and bad produced the composite experience that coloured the perception of suffering for those involved. Most acknowledged that it was a difficult journey for everyone, though there appeared some ways to make the death 'better'. For the professionals, their attitude and supportive acts in sharing information consistently or giving bereavement support were mentioned. From the parents' perspective, directly rendering care themselves and being present at the time of death seemed critical. Lastly, systemic factors included a family-centred approach to care, access out of hours and adequate time and space in and around the death of the child.

Suffering was a given, and both the family and healthcare professionals perceived it. Death in itself could be recognised as an end to suffering:

“The moment after death was described by parents as the only time in which they could have the child back, free of medical aids and restraints, in a human way that was not possible before.” (Lamiani et al., 2013, p. 1340)

This way of rationalising may well be a way to cope for some.

Control (preservation and letting go)

A third theme identified mainly from second order findings (described earlier in section 3.2.3 on pages 30–31) was ‘control’. The imperative for control was pervasive and constant, and involved all stakeholders (patient, parents and professionals).

Patient’s perspective:

“Ed was trying to navigate through adolescence while fighting a serious illness ... Like most teens, Ed fought for independence from his parents, but this became difficult as his mobility worsened and he was forced to rely heavily on his family.” (Flavelle, 2011, p. 29)

Parent’s perspective:

“Feelings of loss threaten parental strength and in reaction, parents seek control.” (Kars et al., 2011a, p. 31)

Professional caregiver’s perspective:

“The unexpected, acute deaths from complications were described as especially difficult ... there was a sense of frustration and irritation over a death caused by a medical complication rather than the disease itself.” (Granek et al., 2015, p. 2353)

Control seemed to be a precondition for fulfilling fundamental parental tasks (Eskola et al., 2017).

Critically, it mediated the passage from ‘preservation’ to ‘letting go’ as the sick child entered the

dying phase. This process was not uni-directional but rather an oscillating one, not unlike the dual process model of grief (Schut, 1999). A swing in locus of control between parents and healthcare professionals was anticipated in the process of transition. Parental perception of suffering was reported to be influenced considerably by the entire experience (Kars et al., 2011).

The provision of informational, emotional and instrumental support by health and social care providers enhanced the sense of order and personal control for some, and sense of authority over the child's care and life with wider family for others. Overall, this aspect of control was inferred to have kept fear and uncertainty (contributing to a perception of suffering) that marked day-to-day living within limits of tolerability, particularly for parents involved (Price et al., 2011).

3.3.4 Synthesis of preliminary findings

Analysis and interpretation of all the findings, expressed as functions of distinct yet interconnected categories, brought synthesis to a different level of abstraction. It involved searching for patterns, variations and relationships among those three themes, within and across different variables (data comparison and drawing conclusions – steps 3 and 4 of data synthesis in an integrative review). A concept map was created to display and explain the conclusions that were drawn, in a delicate process of comprehensive data integration (figure 3.2).

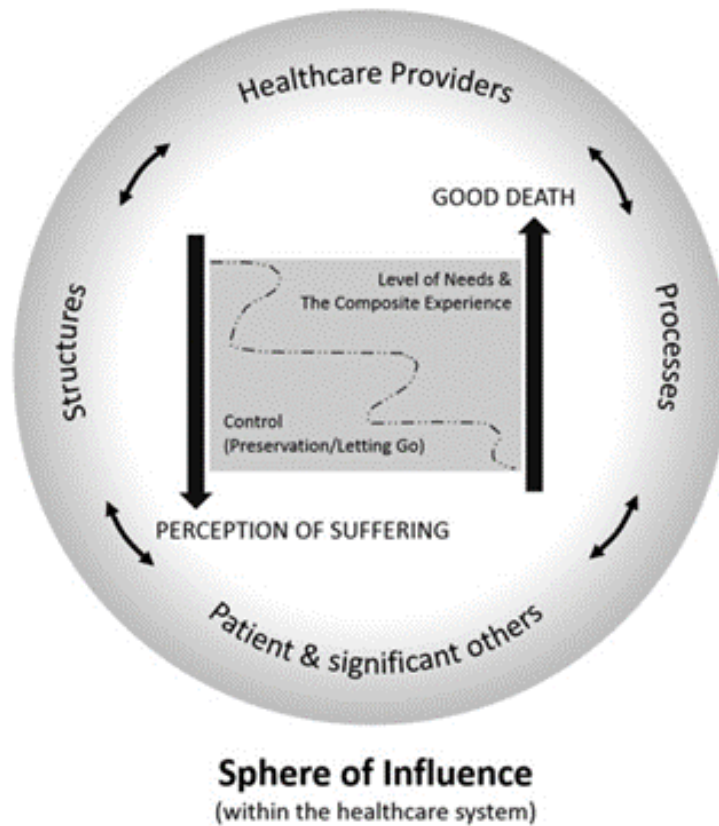


Figure 3.2. Sphere of Influence (overall construct of a good death)

The sphere of influence refers to the healthcare context within which stakeholders interact. Not only does the sphere cover relational experiences and meanings that result from their exchange, it also includes the structures and processes within the healthcare system that contain and drive these interactions. Whether it is the patient, family or healthcare providers, everyone would have their own intricate and dynamic balance of needs, experiences and sense of control. The shifting blend between these factors, depending on whether one is in preservation or letting go mode or even both concurrently, determines the extent (or the perception) of suffering at that point in time. It is postulated here that the measure of good death is inversely related to the perception

of suffering. Given how its putative attributes are interdependent and fluid, it is posited that the quality of death itself is never constant, at least in and around the dying phase.

3.4 Discussion

This review adds to knowledge through synthesising the scarce evidence related to good death in children with life shortening illnesses. Previous reviews either drew heavily on adult literature (Welch, 2008) or focused on a specific group like cancer (Hendrickson & McCorkle, 2008). Findings revealed a dynamic and multi-layered ecosystem that incorporates different elements (control, needs and experiences) and players (patient, family caregivers and professionals), within a space bounded by the healthcare setting. It is dynamic in that the predominance of different elements could change over time, between and within themselves. Yet they are also intimately layered, influencing how each element is expressed or experienced. In creating this concept map, the work of Corbin and Strauss on the Trajectory framework was referenced (Corbin & Strauss, 1991). The diversity, multiplicity and complexity of problems in chronic illness described in their Trajectory framework appear to be a similar journey that evolves over time. It involves interactions between various 'actors' and different 'schemes' (management goals and treatment plans), with associated trade-offs and impact, that ultimately ends in death.

These concepts resonate with that of Hendrickson and McCorkle (2008, p. 127), who stated that a good death in a child dying of cancer as "the final social process which involves many perspectives and is the sum of the interactions of multiple dimensions and their influences". However, the authors believed that each stakeholder brings their own definition of a good death. In contrast, this review postulates a singular unifying construct.

Not unlike what has been reported in adult literature (Hart, Sainsbury, & Short, 1998; Long, 2001), dying children (and their caregivers) similarly face social pressures to fit the norm of a good death, like open communication or acceptance of dying. That notwithstanding, departure from convention is common. For instance, the duality and ambivalence observed frequently define their unique experience. The implication for practice is a need for the professional caregiver to be free of assumptions, and to explore in-depth what may appear to be opposing or shifting positions.

Methodological design is one strength of this review. The protocol by Whitemore and Knaf (2005) facilitated identification of universal concepts from heterogeneous data. Following a stepwise approach that is outlined a priori, rigour is preserved and bias minimised (Weaver et al., 2016; Welstand, Carson, & Rutherford, 2009). The quality of all 24 studies synthesised eventually was appraised to be above average, and all were found to be relevant. Additionally, this review included studies performed across three continents (America, Europe and Asia), in multiple settings (nationwide and regional centres, institutions and community agencies, single hospital across departments, wards or individual services). A mix of studies in both cancer and non-cancer groups were evaluated. Different stakeholders were represented, including siblings.

Nevertheless, there are several limitations. Only one study reflected the child's perspective (single-person case study). The child's perspective is hence under-represented. The sampling frame restricted papers to only those published in peer-reviewed journals. Access to or availability of support was briefly mentioned but not explored in detail. Neither did socio-cultural attitudes or values surface in this review as significant contingent factors. Lastly, the impact from location of care and death, or support from palliative care were also not evaluated.

3.5 Summary

An integrative conceptual framework to the holistic and contextualised understanding of a good death in children with life shortening illnesses is presented. The 'sphere of influence' model can be verified and strengthened through further empirical inquiry. Concepts embedded within individual themes (level of needs, the composite experience, and control) and the premise that the overall perception of suffering predicts the quality of death and dying (indicator of a good death) are preliminary *theoretical propositions*, to be substantiated or further refined with empirical findings. In order to accommodate all experiences of multiple stakeholders and myriad 'structural' influences within a dying child's ecosystem, a flexible study design needs to be conceived.

Chapter 4. Methodology and Method

Research question:

How and why can a good death be achieved in a child with life shortening illness, from the perspectives of family and professional caregivers?

The research question is posed here again, as a roadmap to discuss methodology and method. To justify decisions in study design, ontological and epistemological considerations (chapter 2) and findings from integrated review of extant literature (chapter 3) are reviewed. The chapter concludes with a declaration of my own research perspectives, discussing tactics to maximise study rigour, while taking into account corresponding ethical considerations.

4.1 Methodology

The research question articulates the quest for in-depth understanding of a complex construct in context—good death in a child with life shortening illness. Rather than confirm a single theoretical proposition through hypothesis testing, a qualitative approach that can study an unquantifiable phenomenon that is subjected to multiple influences is indicated (Appleton, 2002). Inferred contingent factors, moreover, are impossible or even unethical to control experimentally. Given these considerations (also outlined previously in chapter 2, section 2.1.1 on page 20), methodologies within the positivistic paradigm (Bryman, 2016) are inadequate in addressing the research question. For generation of valid findings to impact clinical practice directly, that is with high ecological validity, the study needs to be rooted in the ‘messy’ real-life context (Jones &

Lyons, 2004). Adding to the centrality of context, the paradigm of critical realism assumes: with bounded 'structures' and 'mechanisms', context in itself can influence events and experiences as outcomes. The interactions (events and experiences) among social actors in turn can alter context, making boundaries unclear and conditions fluid (Keen & Packwood, 1995; Yin, 1999). With the phenomenon of a good death strongly context dependent as such, being intersubjectively and conditionally co-created between stakeholders operating within a 'living' system, research approaches with purely constructionist roots like ethnography or phenomenology (Bergen & While, 2000) would not be appropriate. The integrative review in Chapter 3 rendered a concept map for a good death in children with life shortening illness, to be verified and strengthened with empirical data. Hence, while other qualitative strategies like Grounded Theory are able to handle complexities related to conditions and context, and is aligned with critical realism philosophically (Bergen & While, 2000), its adherence to *de novo* concept development makes Grounded Theory unsuitable as study methodology here. Further, as perspectives of those who have lived through the experience are solicited, a 'rich and thick' account is anticipated (Guba & Lincoln, 1985). To that end, multiple perspectives from different stakeholders are expected to be analysed for deeper insights (Walshe, 2011). A robust yet flexible research design that can manage all these prerequisites is hence needed. As prefaced in chapter 2 (section 2.1.1 on page 20), a qualitative multiple-case study design (Luck, Jackson, & Usher, 2006; Yin, 2017), with its methodological flexibility to manage all considerations listed above (Andrade, 2009; Rosenberg & Yates, 2007), was selected as the overarching research strategy for the study conceived here.

A multiple-case study approach was chosen, both as a process of inquiry (methodology) and for delivering the product or report of findings (Luck, Jackson, & Usher, 2006). In this exploratory study, the case study design yields data and aids analysis (Jensen & Rodgers, 2001). Owing to its

focus on context in real-life situations, findings are produced with good ecological validity. Within the dynamic system of healthcare: rules, motivations and meanings among stakeholders that indirectly guide practices, interactions and aspirations, are progressively uncovered (Macpherson, Brooker, & Ainsworth, 2000). These findings should answer the 'how' and 'why' questions (archetypal of case study) embedded in the research question. Instead of drawing conclusions using statistical generalisation in a positivistic approach, a process of literal and theoretical replication (Jones & Lyons, 2004) achieve conceptual or 'analytical generalisation'. Operationally, preliminary theoretical propositions, in this instance drawn from the integrative review in chapter 3, are strengthened through iterations using findings from empirical data, first through within-case and then cross-case analyses (Yin, 1999). With critical realism the preferred paradigm for case study research (Easton, 2010), the philosophical backbone for the whole study is also safeguarded. Despite case study design's capabilities in handling both qualitative and quantitative data and even theory testing (Bergen & While, 2000), its versatility does not need to be tapped fully in the context of this study. Problems associated with positivistic approaches, coupled with the need to accommodate 'many moving parts' in deriving a conceptual rather than universal understanding of a complex phenomenon (good death) have been stated in chapter 2 and reiterated in passages before.

What makes a 'case' has been variably defined (Miles & Huberman, 1994; Stake, 1995; Yin, 2017). In essence, it consists of an integrated 'system' with a 'boundary' and 'working parts' (Appleton, 2002). In this study, it refers to a dying child with a life shortening illness in and around the last month of life, supported by caregivers (both professional and informal) within the health and social care system. The phenomenon in focus is the 'good death', or individual interpretations of it. The hallmarks of case study research include: a deliberate process in selecting cases,

triangulation of data from multiple sources, and search for disconfirming evidence during analysis (Baskarada, 2014). These will be referred to again in individual sections under methods.

4.2 Methods

4.2.1 Design strategy

The Case

The child who had an expected death at home or in a hospital from a life shortening condition, and primary caregivers (both formal and informal) who supported the child in the last month before death.

Setting for the study

In case study research, setting refers to the context with its boundaries defining the case. It includes all social actors and 'structures' (rules and relationships, system and processes) that surround a dying child. To maintain consistency in context across all cases, the study is conducted only among patients of one children's hospital in Singapore, which does not have an in-house specialist paediatric palliative care service. Assembling all cases from one institution in this way facilitates identification of contextual structures and conditioning mechanisms (ontological elements of critical realism) assumed to impact experience and meaning making. Although children can die in different settings, from the standpoint of available data, only those who had died in the hospital or at home are studied. Apart from unexpected deaths in the emergency room or those handled by the police, this in fact constitutes almost all instances during the study period.

Children with life shortening conditions who died in this hospital were mostly cared for either in the oncology or intensive care wards. The rest among this group of decedents were anticipated to die at home. They would have received specialist palliative care from the country’s only community paediatric palliative care service. Run by a charity, the community provider’s diverse services that include home visits, allied health inputs, in-home respite, out-of-hours support and bereavement care are provided free to beneficiaries.

Sampling multiple cases

Multiple cases facilitate analytic replication and generalisations (Luck, Jackson, & Usher, 2006) that ultimately maximise applicability of study findings (Lincoln & Guba, 2002). A range of four to eight cases was projected, sampled against key factors found empirically and in practice to influence the experience of dying (Donnelly, 2005): cancer or non-cancer diagnoses; received or did not receive specialist palliative care. These numbers were decided based on their potential to produce rich data relevant to the research question and practical factors, like feasibility for the single investigator and availability of eligible patients (Curtis et al., 2000). A purposive selection to achieve maximum variation was applied (Patton, 1990).

Selection of multiple cases

Tactically, a cross tabulation table (cancer/non-cancer versus received/did not receive palliative care) was set up to display the spread and frequency of cases shortlisted. See table 4.1 below.

Table 4.1. Four different profiles of cases (A – D)

	Cancer diagnosis	Non cancer diagnosis
Received palliative care	A	C
Did not receive palliative care	B	D

Based on the attributes bounding a *case* defined earlier, the following inclusion and exclusion criteria for case selection were conceived.

Inclusion criteria:

- i. Child's age between one to eighteen years at the time of death.
- ii. Suffered from a pre-diagnosed life shortening condition, either cancer or others in the four Association for Children's Palliative Care categories (Together for Short Lives, 2013).
- iii. Patient of the hospital.
- iv. Died more than six months before case selection.
- v. No further ongoing therapeutic relationship between family and healthcare staff from either the hospital or community palliative care team at time of enrolment.

Exclusion criteria:

- i. Sudden or unexpected death.
- ii. Child died outside of paediatric hospital ward or home.
- iii. Circumstances of death unknown or coroner's cases.
- iv. Died more than two years before case selection.
- v. Bereaved family members still receiving support from hospital or palliative care staff.

As outlined in the research ethics application, two collaborators (heads of oncology service and paediatric intensive care unit) sorted death lists (mortality data kept separately by the paediatric oncology service and intensive care) to impute patients into cells of the 'four profiles' table according to criteria above. Selection of the first case started from cell A with the most recent eligible case. This was followed by selection of a case for cell B and so on, till a minimum of four cases were chosen. In the event that more than four cases were needed, the cycle was repeated.

Sampling respondents within each case

Two categories of respondents were sampled within each case: formal and informal caregivers. At least one participant from each category was recruited, failing which another case (next in line) would be picked from the respective cell in the four profiles table. This requirement of at least two different types of respondents within each case allows 'pattern matching' during data analysis; congruent with the study's ontological position, where reality is assumed to be co-created.

Between one to four formal caregivers (e.g. hospital physician or primary nurse from the home palliative service) and one to four informal caregivers (e.g. parents, guardians or siblings etc.) were invited to participate for each case. In the event more than four caregivers (within either caregiver category) were found, priority was given to those that had spent the most time with the child in the last month of life. The intensive approach intrinsic to case study design had precluded enrolment of more than eight participants in each case. In fact, in-depth findings in the case study approach are not contingent on large sample sizes.

4.2.2 Inclusion and exclusion criteria (respondents)

Inclusion criteria:

- i. Healthcare providers (either from the hospital or the community palliative care team) who had provided care to the deceased child in the last month of life OR
- ii. Informal caregivers who had looked after the deceased child one month before death.

Exclusion criteria:

- i. Any of the two collaborators (as primary physicians) or principal investigator (PI).

- ii. Individuals under twenty-one years of age (cut-off for age of majority in Singapore).
- iii. Unable to give written consent due to mental capacity issues.
- iv. Not fluent in English.
- v. Still receiving support from any of the care teams e.g. for bereavement support.
- vi. Paid helpers at home.

4.2.3 Recruitment strategy

Recruiting respondents within each case

The primary physician was first contacted via email by me as principal investigator with information about the study, including its objectives and procedures (in a standard cover letter to professional caregivers—appendix 3). The participation information sheet and consent form (PIS-CF) (professional version) was also shared—appendix 4. The collaborators (head of paediatric oncology or paediatric intensive care) assisted in identifying the primary physician and providing their contact details.

The primary physician (if agreeable to support and participate in the study) then received an invitation pack through the department secretary containing the following:

- I. Standard cover letter to informal caregivers (appendix 5), inviting them to participate in this study.
- II. Participant information sheet and consent form (informal caregiver version)—appendix 6.

Each primary physician helped to send off the invitation pack to the respective bereaved family known to him/her. The informal caregiver/s contacted the PI by email or phone if he/she agreed to participate in the study or needed further information. A reminder (different version of the

cover letter with another set of PIS-CF) was sent through the primary physician if the family had not responded after two weeks. If they still did not make contact after another two weeks, it was assumed that they declined to participate and were not contacted again.

After completing their own interviews, the main family caregiver was asked to suggest up to three other informal caregivers (if available) to participate in the study as respondents. Interviews with them were completed afterwards on separate occasions.

Once data collection with one family caregiver was completed, the interview with the primary physician then followed. He/she was similarly asked afterwards to suggest up to three other healthcare providers that had rendered care to the deceased during the final admission, or within the last month of life if death had occurred at home. These other professional caregivers were invited to participate as respondents through email as per protocol. A diagram illustrating the series of recruitment procedures is shown below (figure 4.1).

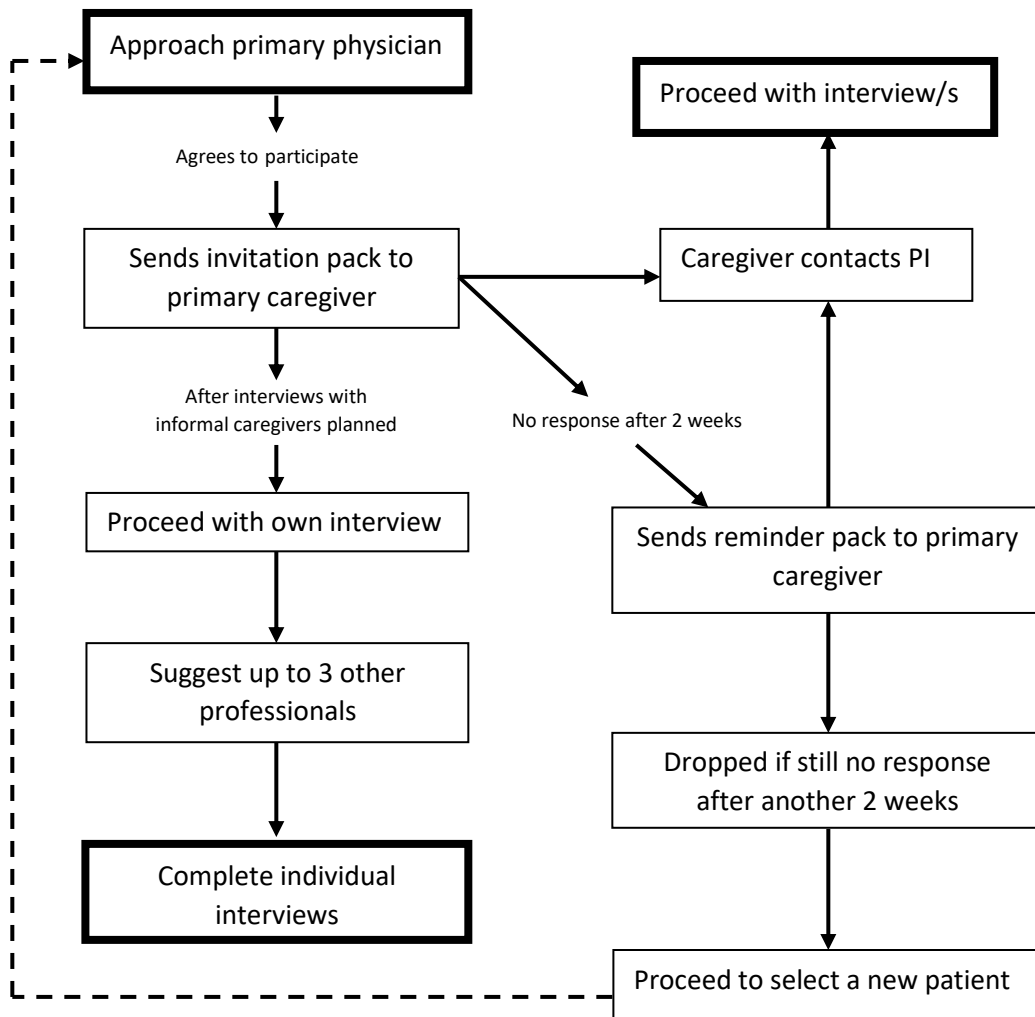


Figure 4.1. Sequence of respondent recruitment

4.2.4 Interviews

In-depth, semi-structured interviews were conducted by the PI with all respondents individually (although family caregivers like parents were interviewed together if they wished) at a location and time of their choice. This data collection interrogates the following preliminary *theoretical*

propositions (embedded within the sphere of influence model for a good death on page 54), while allowing perspectives outside of predetermined domains to emerge.

1. Needs at different levels (day-to-day expectations and aspirational goals) that are not met lead to perception of suffering.
2. The composite experience, both positive and negative, during the course of dying affects perception of suffering.
3. A sense of control, shaped by shifts between preservation and letting go, similarly influences perception of suffering.
4. The intricate blend of all three factors above indicates overall perception of suffering in individual cases.
5. The quality of dying (and death) relates inversely to the degree of suffering perceived in each case; perception of a good death is enhanced directly as the sense of suffering is minimised.

Each interview lasted between one to one half hours. Written consent was obtained just before the interview. No telephone interviews were allowed, to ensure adequate assessment of distress that could arise during the session. Only one interview was conducted with each respondent, as tracking perspectives longitudinally was not a study objective. A second interview was planned, only if a respondent became too distressed that an interview needed to terminate prematurely. A predesignated counsellor to provide oversight would be informed in that case.

All proceedings were digitally audio recorded (with consent) using an encrypted device for full verbatim transcription by the principal investigator. Transcripts were not returned to respondents for verification, but were randomly audited by the investigator's research supervisors for fidelity

in transcription. Field notes were maintained throughout interviews as one of multiple sources of data to be analysed later. A research journal was kept to document interesting observations or early thoughts.

In the beginning, an interview guide informed by study objectives and theoretical propositions listed above was used during the interviews. This underwent iterations as data collected was contemporaneously analysed (appendix 7). All interviews occurred within a 12-month period, between July 2017 and August 2018.

4.2.5 Other types of data

Documents like case notes, care plans and do not resuscitate (DNR) forms were accessed by the PI to support identification of sentinel events around the death of the child prior to the interviews. They also serve to anchor emerging findings in events and processes that actually occurred. A standardised data abstraction form was used (see appendix 8 on page 196). Memos documenting early thoughts were kept by the researcher in the research journal, to support narrative building and data triangulation during analysis (Bowen, 2009).

Family caregivers were asked before interviews to bring along artefacts like photographs, videos, letters and any other physical items in their possession that were created before the child's death or left behind as keepsakes. These were discussed during interviews to explore associated meanings and implications. Relevant observations about these artefacts whether in and of themselves or reactions they evoked in respondents were recorded in the research journal for reflective analysis.

4.2.6 A summary of data collection (refer to table 4.2)

Table 4.2. Composite data collection

Research objectives	Sources of data	Data collection method	Justification of method
1. Chart and review events before and around death of the child	Case notes, care plans and DNR orders	Peruse, summarise and collate without having to make copies of them. Supported by a data abstraction form (appendix 8).	Focuses on topic of interest, with potential for unanticipated data to emerge.
	Photographs, videos, letters and any other physical items	Semi-structured interviews to elicit meaning or implications behind each item. Detailed journaling of any observation in relation to each item.	Focuses on topic of interest, with potential for unanticipated data to emerge.
	Interviews with respondents	Semi-structured interviews	Focuses on topic of interest, with potential for unanticipated data to emerge.
2. Experiences of caring for the dying child	Interviews with respondents	Semi-structured interviews	Focuses on topic of interest. Allows comparison of views across stakeholders.
3. Thoughts and perceptions on a good death	Interviews with respondents	Semi-structured interviews	Focuses on topic of interest. Allows comparison of views across stakeholders.

4.2.7 Analysis of data

To record the entire process of recruitment, data collection and analysis, an audit trail was maintained in a research journal. Data collection and analysis were concurrent. This provided

flexibility to modify procedures in maximising data capture. The copious amount of varied data collected were managed using NVivo (version 11).

A blend of two strategies was adopted as empirical data were analysed: Framework Analysis (Spencer et al., 2014) supported by graphical data displays (Miles & Huberman, 1994). Framework Analysis reduces extensive qualitative data through summarisation and synthesis, while retaining links to original data. Following a sequence of data management and data interpretation, the process is systematic and comprehensive, at the same time transparent (Gale et al., 2013). Critically, compatible to the needs of this study and in contrast with other methods (Braun & Clarke, 2006), data analysis was performed using both a case and theme-based approach. What this means is that thematic categories can be interrogated with ease *within* as well as *across* cases (Gale et al., 2013). Ontologically, Miles and Huberman describe themselves as pragmatic realists, believing that fairly stable relationships in the form of ‘regularities’ that link social phenomena can be found among the “idiosyncratic messiness of life” (Miles, Huberman, & Saldaña, 2014, p. 7). In practice, over successive single-case data analysis within a multiple-case study design, regularities identified within each case is anticipated to strengthen an evolving conceptual framework. Processes and outcomes that are qualified by local conditions and gleaned across multiple cases purportedly leads to “more sophisticated descriptions and more powerful explanations” (Miles, Huberman, & Saldaña, 2014, p. 101), with implications on generalisability of findings.

In terms of application, these two strategies for data analysis are similar in that both promote the configuration of matrices in search of patterns, variation and relationships, yet also complementary, as each brings its own strengths. These are explained in more detail (with reference to this case study research) next. Framework Analysis itself involves five operational steps:

- I. Familiarisation: identify issues of interest recurrent across dataset and relevant to the research question. This commenced from the point the first recording was repeatedly listened to, through actual interview transcriptions and frequent review of transcripts during analysis.
- II. Construct initial thematic framework: from empirical data or prior theory. In this study, the literature review in chapter 3 with its model for a good death provided *theoretical propositions* (as listed in section 4.2.4 on page 68) for building the initial framework.
- III. Use the constructed framework to index and sort data: labelling the data (indexing) and organising into thematic sets (sorting). Coding of transcripts was performed, referencing the a priori thematic framework. In vivo codes that arise directly from empirical data were also formed in the process. Eventually the first framework matrix table containing selected data abstracts was created—comparing narratives across respondents within each case.
- IV. Review data abstracts to evaluate coherence with framework and to refine it inductively: by reading through the ‘piles’ of indexed data and examining remaining data that are not indexed. A colour scheme was applied across the array of codes to highlight those expressed by all or most respondents and those only expressed by specific groups, for example professional caregivers. This is where Miles and Huberman’s (1994) network displays aid further analysis. Network displays of each of these highlighted codes show connections between events, processes and experiences (main storyline in oval nodes connected by links; analytic narratives in rectangular nodes within those links). An

example of a coloured matrix and its related network displays (for one case) is available in appendix 9 (pages 190–193).

- V. Data summary and display: navigating through the whole dataset (theme by theme or transcript by transcript). This gradually moves towards case by case comparison in cross-case analysis, discussed in the next section on case study methodology. Event-State Networks constructed as per Miles and Huberman (1994) are heuristics that facilitate this part of data analysis. Each of these networks (one for each case) is an assembly of all their respective network displays, to show multiple overlapping events happening within—and driven by—context specific conditions over time (actions of stakeholders as ‘events’ in boxes; conflicts/rationales as ‘states’ in bubbles). Illustrations of these Event-State Networks for all cases are found in appendix 10 (pages 194–198). The process finally ends with data abstraction and interpretation. Specific procedures and outcomes involved are shown in table 4.3 below.

Table 4.3. Stage of abstraction and interpretation in Framework Analysis

Descriptions	Detecting ‘elements’ and ‘dimensions’	Devising ‘categories’ (different types of responses that discriminates between different manifestations of the data) or ‘classes’ (summative categories)
	Identify ‘linkages’	Linkages between phenomena AND their particular attachment to different subgroups
Explanations	Accounting for patterns	

Methodologically, in case study research a case-oriented analysis (in contrast to variable-oriented analysis in other qualitative research methodologies) examines the relationships among variables *within* a single case as an initial step, and then makes comparisons *across* cases looking for similarities and patterns (Kohn, 1997; Ragin, 2014). This horizontal logic is supported by triangulation or convergence of data from multiple sources.

Yin (2017) details a two-stage process that is used here. *Pattern matching* involves first making associations between findings in one case to theoretical propositions or conceptual framework (Miles & Huberman, 1994) drawn from prior literature review or theory (Yazan, 2015). This corresponds to steps I to IV in Framework Analysis. *Replication logic* compares composite findings from one case with another case, again guided by the same theoretical framework, which is now developed further. Two types of replication logic are described: literal and theoretical. The former confirms a finding when everything aligns, while the latter adds new dimensions when different explanations are found (Luck, Jackson, & Usher, 2006). This process of cross-case analysis is performed in step V of Framework Analysis. Comparing across cases, a second framework matrix table was developed using second order findings (particularly the Event-State Networks). Patterns, associations and gaps in the data were interrogated to produce overarching themes that were iterated further, by going back to first order findings (transcripts) to confirm salience, while at the same time, evaluating their individual qualities as independent themes. Finally, further interpretation and re-organisation of all findings produced the empirical framework for a good death. From an ontological perspective, this treatment recognises that each case represents one level of reality, with its own context, actors and conditions. Fusion of multiple realities through cross-case analysis results in emergence of yet another level of reality with greater depth and clarity, which is the goal of this study.

All findings obtained in the first stage (within-case analysis) illustrated as individual Event-State Networks are posted in appendix 10 as stated before. They offer opportunities for idiographic generalisation (Ayres, Kavanaugh, & Knafel, 2003), reconstituting experiences and meanings that can become decontextualised in the process of coding and matrix tabulation. Detailed findings in the second of Yin's (2017) two-stage process (cross-case analysis) are discussed in chapter 5.

4.3 Perspective of the researcher (including considerations around insider research)

Half the families and all the healthcare professionals (most are lower in seniority) participating in the study are known to me. I was the first and still the only specialist in palliative medicine who received dedicated training in paediatric palliative care, and lead the single community paediatric palliative care service in the city state of Singapore. This study is set in one of two tertiary government hospitals with paediatric departments where the care of critically ill children is centred. Given all the above, the community of study-eligible patient and families together with their healthcare providers is not only small but occasionally also intimately familiar to me. It is likely that some respondents could have felt obliged to participate in the study, or their perspectives might show "social desirability bias" (Darra, 2008, p 253) as a consequence. Inherent risks for the latter are recognised, while a considered and ethical approach to consent-taking was taken to manage the former.

An insider is defined as someone with intimate a priori knowledge of the community and its members. Bias as a consequence of missing the obvious or being 'too close' are concerns (Hellawell, 2006). The merits and pitfalls of the insider/outsider dichotomy has been widely debated. Most argue it is a continuum with multiple dimensions that all researchers navigate,

depending on time and place of research, power dynamics or topic under discussion (Dwyer & Buckle, 2009; Hockey, 1993; Mercer, 2007). Conversely, there are inherent advantages being an insider, such as understanding the culture, promoting telling and judging of the truth, knowledge of formal and informal power structures, obtaining permission to conduct research, and access to records, documents and interviews (Unluer, 2012). Brannick and Coglán (2007) summarised that we are all 'insiders' of many systems (families, communities and organisations), holding rich and complex knowledge of them. The position in fact enables tacit knowledge to be articulated, reframing it as theoretical knowledge. I am mindfully aware that I stand on privileged yet delicate ground, and am always reminded that a process of reflexive awareness is ultimately critical.

Reflexivity is an active engagement of the self in questioning assumptions, exposing their contextualised and power driven nature (Van Heugten, 2004). It is indicated across the entire research endeavour, from sampling and data collection to analysis and reporting. One aspect of this is my awareness of conflicts around role duality. See appendix 11 for an example of one of these reflections documented in the course of data collection. To minimise role-related tensions for example, all patients that make up the case studies have not been directly under my care as palliative care provider.

4.4 The ethical issues

4.4.1 Institutional review board (IRB) related

Local IRB approval in Singapore was first obtained on 1 Sep 2016 (NHG DSRB Ref: 2016/00720). Follow-on ethics approval was sought at Faculty of Health and Medicine Research Ethics Committee (FHMREC) in Lancaster University. Approval was obtained on 7 Nov 2016 after having

addressed minor queries and suggestions (reference: FHMREC16012). As a result, approval for necessary amendments made to the protocol and related documentation was obtained from IRB in Singapore before commencement of data collection (NHG DSRB Ref: 2016/00720). Copies of these three approval documents, together with the latest versions of all research documentation are enclosed in appendix 12.

4.4.2 Vulnerable participants

Vulnerability of bereaved persons as study respondents always generates concerns, even though they are legitimate research participants in their own right (Dyregrov, 2004). The contention that participation in research by bereaved parents puts them through undue risks has not been supported (Hynson et al., 2006). Timing, approach and interviewer skills are crucial (Butler, Hall, & Copnell, 2018). Most families interviewed in Hynson et al's (2006) study with bereaved parents felt participation six months after the child's death was appropriate. Letter invitations rather than phone calls were appreciated. It gave respondents time to think about it, including discussing it with others. Sharing of this nature nonetheless can evoke distressing emotions. As a clinician in paediatric palliative care with more than ten years' experience, I ensured that all interviews were carefully and sensitively conducted. Provision was also made for respondents to get support from a bereavement counsellor if needed. Notwithstanding the benefits in pre-empting distress during interviews, undue influence arising from power differentials between the physician-investigator and respondents (whether they are informal caregivers or junior healthcare providers) was acknowledged. This was mitigated as appropriate through various means, for example, reminding respondents during data collection that I was approaching them as a researcher with specific study goals, and would be prepared to address other concerns outside of the research if needed, afterwards. No incentives were planned for participation in this study.

4.4.3 Informed consent

Interviews proceeded only after written consents were obtained. Every new member of the family or professional caregiver that participated gave their own consent. For the former, a minimum of 24 hours lapsed between information sharing (e.g. receiving the PIS-CF as shown in appendix 6 on page 183) and actual interviews. Similarly, healthcare providers were recruited in succession without coercion or prejudice, particularly if it involved someone of junior grade. They were specifically informed that participation is entirely non-obligatory, and given up to two weeks (before reminders were sent) to respond afterwards.

Participants were able to withdraw from the study at any time before interviews were completed. A grace period of two weeks was given if the respondent wished to withdraw totally (including his/her views shared) after the interview. The reason being once perspectives were incorporated during analysis, information shared could not be completely removed. This was made clear to all participants from the start.

4.4.4 Data management plan

In accordance to local ethics requirements, all text data (consent forms, field notes, research journal and transcripts) on paper are stored safely in a locked cabinet (accessible only by the main researcher) for 10 years. Audio (encrypted digital recordings of interviews) and electronic data (encrypted soft copies of transcripts) are stored in a dedicated hard drive locked away in the same cabinet between use.

All data files are saved as backup in Lancaster University's secure online data storage depository 'Microsoft OneDrive' (compliant with the UK Data Protection Act 2018). In case primary data collected here is used later in another study, consent has also been obtained.

4.4.5 Anonymity in case study research

A small number of cases are studied and reported in 'vivid' detail in this study. Issues with confidentiality is anticipated at thesis completion (submission, acceptance and archiving afterwards) and dissemination of research findings, for example, when published in peer-reviewed journals. Contextual identifiers in individual stories can be revealing, even with anonymisation. This phenomenon of deductive disclosure or "internal confidentiality" has been described (Tolich, 2004, p. 101). The issue is reflexively managed throughout report writing to safeguard confidentiality, yet not losing authenticity as rich narratives are constructed. The use of pseudonyms in individual case summaries is one example of several strategies adopted.

4.5 Rigour

Multiple issues have been considered to optimise rigour in this study. A brief summary is outlined in text, with more details tabulated at the end of this section.

Defining quality in interpretive inquiries have been problematic. Some methodologists have argued against applying concepts of validity and reliability that are default within the positivistic paradigm in the evaluation of qualitative research (Popay, Rogers, & Williams, 1998; Rolfe, 2006). 'Trustworthiness' became widely accepted after criteria (credibility, confirmability, dependability, and transferability) perceived to be congruent with constructivist/naturalistic traditions were proposed (Guba & Lincoln, 1985). Yet others have questioned evaluating qualitative research only post-hoc, when study reports are appraised using assessment tools, advocating instead to incorporate checks *during* the process of research itself (Morse et al., 2002). This ensures that timely corrective actions are taken, before a study is completed and closed. In line with this study's

goals to impact policy and practice, the recommendations from Boaz and Ashby (2003) are also referenced. Beyond methodological quality, they raise issues like appropriateness of the research method to study purpose, transparency in reporting, and whether the main message is compelling (that is relevant to policy and practice). The first point in particular has been addressed extensively within this chapter. Lastly, like others before, the authors comment that appraisal of research quality is also contingent on the underpinning paradigm.

For research rigour in this study, a customised framework for judging research in the realism paradigm is adapted (Healy & Perry, 2000), alongside quality considerations based on case study methodology. See table 4.4 below.

Table 4.4. Framework for evaluating case study research in the realism paradigm

Elements of paradigm	No	Criteria	Description	Tactics (within case study design)
Ontology	1	Ontological appropriateness	Study of a complex social phenomenon	- Research problem is congruent with the realism paradigm
	2	Contingent validity	Open systems, involving generative mechanisms rather than direct cause-and-effect relationships	- In-depth questioning with emphasis on 'how' and 'why' aspects - Fine description of all contexts in individual cases - Literal and theoretical replication (Riege, 2003)
Epistemology	3	Multiple perceptions of participants	Neither value-free or value-laden but value-aware	- Multiple interviews (and multiple cases) - Other sources of data (artefacts and document reviews)
Methodology	4	Methodological trustworthiness	Credibility, confirmability, dependability, and transferability	- Describe (and follow) procedures like sampling, recruitment and interviewing (including keeping an audit trail)

Elements of paradigm	No	Criteria	Description	Tactics (within case study design)
				<ul style="list-style-type: none"> - Identify key research issues to formulate interview schedule (collect useful data) - Build case study database (including matrices and quotations) (Yin, 1999)
	5	Analytical generalisation	Theory-building rather than theory-testing (statistical generalisation)	<ul style="list-style-type: none"> - Structure and strengthen theoretical propositions, including rival explanations (Yin, 1999) through within-case and cross-case pattern matching and explanation building - Think conceptually and reflexively (prevent premature closure and artificial coherence) (Thorne & Darbyshire, 2005) - Integration of other evidence (including literature review)
	6	Construct validity	How well constructs that make up the final theory are built	<ul style="list-style-type: none"> - Use of prior theory - Case study database (to show chain of evidence) (Riege, 2003) - Triangulation (Baskarada, 2014)

4.6 Summary

In seeking to uncover the attributes of a good death and the underlying factors that influence them, from the perspectives of interacting stakeholders within a specific ecosystem and predefined period, a multiple-case study design is adopted. The methodological merits for case study research are discussed and its operational procedures (including sampling multiple cases and sampling within cases) pertaining to this study are outlined under methods. Data is collected

mainly through face-to-face interviews, though two other informational sources are also sought alongside: clinical documents and family artefacts, where available. Framework Analysis and novel qualitative methods of analysis involving network displays facilitate management of voluminous data using a case-based approach—producing findings that are not only ecologically sound but broadly generalisable. Ethical considerations, especially around insider research that is particularly relevant in this instance and factors related to rigour in the conduct and completion of the entire study are discussed.

Chapter 5. Findings

5.1 Cases and Respondents

Seven families were approached to participate in the study. One family (of a child with cancer—who received palliative care and died in hospital) was uncontactable even after sending a second reminder. Another family (child with cancer—never received palliative care and died in hospital) acknowledged the invitation initially, but declined to participate later. As there was only that single eligible child during the period of recruitment under the category of ‘child with cancer and no palliative care’, another family whose child had a diagnosis of cancer but received palliative care was recruited sometime later. The consideration then was to facilitate the process of ‘replication logic’ during cross-case analysis, at least among the cases with children having cancer diagnoses. Though the family had met palliative care, contact was brief. Overall management centred predominantly within the oncology service, and the child finally died in hospital. In a way, the opportunity lost to recruit an oncology ‘case’ that had not received palliative care was hence partially fulfilled.

5.1.1 Characteristics of cases - child decedents and their respondents

Profiles of each ‘case’ are summarised in table 5.1.

Table 5.1. Case profiles: patients’ clinical information and respondents’ socio-demographic information

	Case 1	Case 2	Case 3	Case 4	Case 5
Patient					
Age at time of death	17	16	6	11	1.5
Gender	Female	Female	Male	Female	Male
Circumstances of child during study period	Local resident	Local resident	Parents are expatriates	Came to seek treatment locally	Mother is an expatriate
Diagnostic group	Non-cancer	Non-cancer	Non-cancer	Cancer	Cancer
Location of death	Home	Home	Hospital	Home	Hospital
Specialist palliative care received	Yes	Yes	No	Yes	Yes
Informal caregivers					
Age (n = 8): mean of 44 years (range of 36 – 57 years)					
Relationship to child / Religion	Mother / Christian	Mother / Buddhist	Mother / Christian	Mother / Muslim	Mother / Christian
	Father / Christian		Father / Christian	Father / Muslim	
Professional caregivers					
Age (n = 14): mean of 42 years (range 30 – 67 years). Professional experience: mean of 15 years (range 2 - 43 years)					
Gender (F or M) / Appointment	F / Specialist doctor	F / Palliative nurse	F / Specialist doctor	F / Specialist doctor	M / Specialist doctor
	F / Palliative doctor	F / Specialist doctor	F / Specialist doctor	F / Allied health specialist	F / Hospital social worker
	F / Palliative nurse			F / Palliative social worker	F / Hospital nurse
				F / Palliative nurse	

A total of eight informal caregivers were recruited across the five cases. They completed seven audio recorded semi-structured interviews in locations of their choice. Two parents (case 3) were interviewed together, otherwise the rest of the respondents shared their perspectives separately. Half of these interviews were held at their own homes, while the rest were completed mostly in other locations, including one in the investigator's office upon request. Each interview lasted a mean of 87 minutes (range of 57 to 111 minutes). None required breaks midway or second interviews as a result of emotional distress. None asked to meet with the study's designated counsellor for debrief afterwards.

The other group of participants that make up each case are the healthcare professionals. All except one were of female gender, which is consistent with the general profile of paediatric healthcare providers in this country. Between two to four professionals were recruited for each case. They are multi-disciplinary staff; either from different departments of the hospital where sampling was performed, or the community team that supports children and families referred for palliative care at home. 14 healthcare professionals were all interviewed individually, again in locations of their choice, mostly in their own offices except one that was done outside a university library. Interviews lasted a mean of 62 minutes in duration (range of 44–79 minutes). In line with the protocol, second interviews were not performed.

5.1.2 Case summaries

For considerations of confidentiality, all the patients have been given pseudonyms. To contextualise study findings shared later, brief summaries of each patient's clinical history, including their individual dying trajectories are provided next. Certain medical details and personal characteristics have been omitted to preserve anonymity.

Case 1

Freya had a rare neurodegenerative condition since infancy. It resulted in global developmental delay (not verbally communicative) and she became totally dependent on caregivers for activities of daily living (including tube feeding). Her condition deteriorated at 17, when she required frequent admissions for chest infections. At one point when she developed yet another new infection, her parents decided to keep her medical management at home, to be close with two other younger siblings. Support from palliative care was intensified. Freya finally died at home.

Case 2

Yi Lin was 16 years old and she was found to have hypoplastic left heart syndrome at birth. She was not expected to survive long without treatment. More than a decade later, when she presented in hospital for management of heart failure for the last time, various treatment options were offered and palliative care introduced. Her family brought her home instead. Yi Lin continued to live 'normally'—like other teenagers as she wished—for another three months, enjoying time with family, including her younger sister. She eventually died at home from worsening heart failure.

Case 3

Daniel was diagnosed with arteriovenous malformations in the brain at infancy. With abnormal blood vessels that were not surgically operable then and at risk of spontaneous rupture with devastating consequences, his parents were prepared for the worse. It happened at school one day when he reached six years of age. He never recovered from the deep coma that he was suddenly found in, despite two major surgeries and intensive supportive treatments. He died in

less than a week. His parents had pledged his organs, before artificial life support was finally withdrawn.

Case 4

Alina was 11 years old. She had a rare type of cancer and she received treatment at different centres in several countries. Her last stop was Singapore, where she received chemotherapy that unfortunately still failed to control tumour progression. She lost the ability to walk and soon became totally bedbound with persistent pain and lower limb weakness. The multi-disciplinary community palliative team, including an art therapist, provided support to the small family of three who stayed in a crowded rental apartment. Alina died one night during her sleep with parents lying next to her.

Case 5

Ivan had a malignant blood disorder that is widely known to be refractory to therapy. Together with grandparents, his mother (who was estranged with his father) cared for him throughout his entire stay in hospital, where he never quite left since he was first admitted just before his first birthday for work up and treatment. Stress from the bleak outlook was compounded for everyone involved owing to underlying tensions within the family that complicated treatment planning and ongoing care. Nevertheless, the immediate family's decisions prevailed and Ivan did receive several lines of chemotherapy. He eventually succumbed to the disease and died in hospital.

5.2 Description & Interpretation of findings

Outputs from 'pattern matching' comprise second order findings obtained through within-case analysis. They are documented in diagrammatic format as Event-State Networks, and posted in appendix 10 on pages 194– 198.

Following pattern matching, in 'replication logic', a framework matrix of third order findings is assembled through searching for patterns, associations and gaps across all five cases, resulting in identification of 13 themes. The research question seeks the 'how and why' behind a good death in children with life shortening illness—a heterogenous group. The prior integrative review reported in chapter 3 proffered a tentative conceptual framework (the 'sphere of influence' model) that encapsulates the holistic and contextualised experience among various stakeholders from different disease groups. This stage of the empirical study is where universal elements between case-centric perspectives are assembled, while acknowledging the clinical diversity across individual cases. Findings from the latter process of cross-case analysis form the main bulk of this chapter.

Eight common and five contingent thematic categories are identified as contributory to a good death in children with life shortening conditions. Common themes are universal across all cases in their salience; contingent themes, though equally relevant, apply in a subset.

All themes, whether common or contingent, have been grouped under three headings, based on their relationship with a child's death. An antecedent here refers to any event, object or phenomenon that precedes death. Drawing from the ontology of critical realism that underpins this study, it may be compared to 'structures' that are either material—like a private space in the ward, or non-material—like a medical treatment. Determinants refer here to factors or agents

that directly or indirectly influence the outcome of death and dying. Ontologically, they may be compared to ‘causal mechanisms’ associated with ‘structures’ that generate change in the course of social interactions within a specific context that is bounded by time. Attributes refer to the intrinsic nature of what is perceived as a good death. Ontologically, it pertains to the understanding or sense-making from an experience that is acquired within the ‘empirical’ domain of realism’s three stratified realities. For clarity and coherence, themes are discussed consecutively in groups to follow. Excerpts from transcripts are posted alongside findings, both to situate and give resonance. The source for each quote is identified by a label that specifies the case and corresponding respondent. For example, **C1.Cfa** refers to the child’s father in case 1; while **C1.Pdr** refers to the palliative doctor also in case 1. The full list of respondent labels is displayed in table 5.2 below.

Table 5.2. Respondent labels

Case 1	Case 2	Case 3	Case 4	Case 5
C1.Cmo: child’s mother	C2.Cmo: child’s mother	C3.Cmo: child’s mother	C4.Cmo: child’s mother	C5.Cmo: child’s mother
C1.Cfa: child’s father	C2.Pnr: palliative nurse	C3.Cfa: child’s father	C4.Cfa: child’s father	C5.Onc: oncologist
C1.Neu: neurologist	C2.Int: intensivist	C3.Neu: neurologist	C4.Onc: oncologist	C5.Osw: oncology social worker
C1.Pdr: palliative doctor		C3.Int: intensivist	C4.Ahs: allied health specialist	C5.Onr: oncology nurse
C1.Pnr: palliative nurse			C4.Psw: palliative social worker	
			C4.Pnr: palliative nurse	

5.2.1 Common themes

Three common thematic categories are grouped under the heading 'antecedents'; the individual narratives specific to each case are represented in table 5.3.

Table 5.3. Framework matrix – common thematic categories (antecedents)

	ANTECEDENTS		
	Letting go	Acknowledging the child	Closure
Case 1	A new state of being reached, as a consequence of 'increasing awareness'. This allows the family to run 'the last mile' and achieve what they perceive as a good death.	To make the child feel treasured and loved, performing hands-on care, spending time and realising wishes.	Whole family come together to give blessings for child to go in peace.
Case 2	Same. A new state of being reached, after different 'conflicts' are resolved or overcome, and realisation of short prognosis. This leads to 'actions' that facilitate a good death.	Giving autonomy to the teenager to make choices, from treatment options, living life normally, to details around end-of-life care (like refusing injections).	Open conversations between child and family about her imminent death, her fears and wishes.
Case 3	Same. A state of being that arises as 'emerging reality', with time and when definite signs indicate that the child is dying. New goals are then set, in preparation for the child's demise.	Playing the child's favourite programmes (cartoons) for him throughout. Requesting for extra time just to say goodbye.	Family and friends coming together one last time to say goodbye.
Case 4	Same. State of being ('acceptance' level here) after seeing little hopes of recovery & worsening physical condition (losses). Bridge between doing everything possible to doing everything right. Impacts sense of suffering by reducing it. Compare similar in cases 1, 2, 5.	Affirmation of the child's virtues & bringing the right attitude during interactions and advocacy for the child's own needs throughout. It ultimately supports the child in coping with the adversities of illness.	Being able to speak openly about the child's imminent passing, drawing the family even closer together in spite of the grief.

	ANTECEDENTS		
	Letting go	Acknowledging the child	Closure
Case 5	Same. A new state of being when all treatments fail, obvious suffering manifest, and signs noticed. Goals of care shifts from curing to healing. Oncologist himself 'switched gears'.	Invoking the child in interpreting events and meaning making.	Memory-making activities like outings and photo taking, processing the loss with counsellor before child's death, and being able to say goodbye.

Letting go

The theme signifies a turning point in the journey of illness, where a new state of being is reached by stakeholders (family caregivers or healthcare professionals), through emerging insights from different sources that the child's condition is unquestionably worsening. This new frame of mind commonly develops over time, triggered by personal observations, as events like frequent admissions or signs of overt disease progression occur:

Every few months, she'd have a lapse ... So, we actually have to send her, every time in the hospital, one month, almost a month in hospital. She doing all the suction, and all the, all the ventilation support ... We see her suffering. (C1.Cfa)

For others, letting go results after assimilating information from doctors leading the care for the sick child. In another situation, letting go is eventually achieved once conflicts between various parties are resolved and a new goal consensually negotiated. The intensive care doctor who straddles between all parties involved in Yi Lin's care (young teenager with end-stage heart failure) shares:

I also recognised that the cardiologist, of course had done an excellent job over the last 14 years, keeping this girl alive, but I really didn't know, how much longer this was going to be the case, you see. (C2.Int)

Mum was, kind of, somewhat torn. Like, on one side, she wants to bring her home ... But she also wants to know, if there's really, any little thing ... that might have made her a little bit better, for a little while longer, so that she might last, that little bit. (C2.Int)

Sometimes, letting go happens only after everyone has tried hard enough, like seeking and exhausting alternative treatment options, after the initial course of treatment fails:

Now that we have tried already [second- and third-line treatments], and as we predicted, the response was poor, it's disappointing, but we have tried. Now, yes, we have missed the boat. But still, switching track, really, to comfort care - To me, it is not loss. (C5.Odr)

In all cases, once this new state of being is attained, different actions toward facilitating a good death can then follow. The oncology doctor in case 5 who 'missed the boat' proceeds to 'switch gears', shifting the goals of care from curing to healing, replacing aggressive treatments with oral chemotherapy for symptom control to improve quality of life:

I have to now change gear ... to move more on symptom control, low-dose chemotherapy, to control the disease, to make us co-exist with the disease for a while, until we can't control it further. (C5.Odr)

In another family whose child (Alina) also had a terminal malignancy, letting go is like a bridge between doing everything possible and doing everything right:

In his [father] shift to palliative care, although I offered it, it took some time. But I feel that this is a decision he subsequently made on his own ... He wants to be absolutely sure that he has explored everything, before he went down that road. (C4.Odr)

The focus of care is changed, and in some cases palliative care is introduced, leading to different streams of support that in the opinion of the parents led to considerably positive outcomes.

The family in case 1 for example reached the point of letting go, after having experienced increasing burden imposed on everyone with Freya's frequent hospital admissions. Once her parents let go, they proceed to run 'the last mile', achieving the best death and dying experience they can deliver for their teenage daughter with a neurodegenerative condition that has reached the end of her disease course. Her father proudly declares:

We give her, first-class service ... A very, very exclusive, healthcare for her, in the late period time ... So fantastic, that I think God know exactly what we want for Freya, and what Freya want before she go. Very beautiful. And this one, we will never forget. (C1.Cfa)

There is an inverse relationship observed between letting go and suffering. Given how suffering often connotes bad dying conventionally, appreciating any relationship (assuming that it is valid) between letting go and suffering is critical, if the construct of a good death is to be understood deeply. The sense of suffering that creeps into consciousness early in the dying trajectory triggers stakeholders to pause and reflect:

Maybe last half the year, when she has very frequent fever ... Most of the time, she's sleeping. Drowsy, because of medicine, fever ... I think she has quite frequent diarrhoea, which is like, almost, can be eight - nine times per day ... I think that's the max that, I think, she's [voice cracks] I mean as a child?... It's like, so much suffering. (C1.Cmo)

Alternatively, stakeholders decide to let go as they make plans to minimise further suffering that is anticipated, if they persist in the course that they are currently on:

Whatever they say, it's just shit only ... Instead of like, I have to everything worry ... So we just live as normal life. (C2.Cmo)

Letting go it seems, either occurs after suffering is experienced, or as prelude to reduce suffering. Adding yet another dimension, case 3 demonstrates a different perspective of letting go that occurs in the absence of explicit or anticipated suffering. Daniel, the boy who has a devastating bleed in the brain from a vascular anomaly is showing signs of brain death. He looks perfectly 'comfortable' in his lifeless form, even before life-sustaining treatments are later withdrawn:

So, fortunately in this case, the scans were very clear. The - prognosis was very clear. It made it very easy, as professionals, without any uncertainty. (C3.Neu)

The parents here confront only one outcome (death) that is foreseeably imminent and invariably defined by everyone involved, which contrasts with mostly uncertain trajectories in the other four cases, each with different implications that are dependent on choices that parents make.

Acknowledging the child

The intent behind this theme is consistent across respondents. It applies whether the child is verbally non-communicative (case 1), very young (case 5) or 'vegetative' (case 3) and even more so, if the dying child is older and self-determining:

Because throughout the treatment, the parents' wishes prevail. But in the end - that they should consider what the child wants. (C4.Odr)

Respondents argue that the child ought to be central in everything they do during this period, when it becomes clear that the prognosis is guarded (estimated in weeks to very short months). Acknowledgement may be achieved in several ways.

To feel treasured and loved:

Truly love and care the last period of time. I think that is, to me, is the most important. We have to put down whatever you need to do. You just have to spend time, the balanced time with them. (C1.Cfa)

Autonomy for the child to make choices:

Back to the baseline where I was quite clear that, she wasn't going to last much longer. That I do think that the locus of control should actually be, handed over to the family, and the child - Well, child first, if they're in a position to advocate for themselves. (C2.Int)

Giving the child a 'voice' that acknowledges deep bonding:

He kept on looking at me, in a way that - my son was actually like telling me, two weeks before he left, I hope - like telling me that - he can sense that I'm quite strong, and he can leave. (C5.Cmo)

It is believed that these gestures help the children who are cognitive in coping, as they face many personal losses at this time:

Yeah. So, only when we talk about these happy memories [child's achievements] - I think it took that time away. It created a bubble, I guess, for that - for that moment of being happy and being able to - talk about things. (C4.Psw)

In relation to acknowledging the child, this mother (case 4) sums it up powerfully:

One thing is very important - If this type of situation comes, make her understand, that she is the special one. It is very important because, maybe you cannot get another chance.

(C4.Cmo)

Closure

With almost the same ethos as acknowledging the child, achieving the act of closure is similarly raised by almost all stakeholders as critical to the perception of a good death. It is likened to a 'send-off' before departure that all families perform:

In fact, she hold out for one month. We tell her to go the next few day, but she didn't. There must something holding up ... We, as a family ... We have to be together, and wish her the best ... We actually, come closer together. We no more argue, we do not, we just do our good thing, we support. And we always come to say: "Freya, you need to go. You go."

(C1.Cfa)

Closure is completed through rituals like prayers, music and songs:

We had like Caucasians, Muslims, Chinese. Everybody in the room ... We had all these people that were in his life, and wanted to be there, and we could do it. Yeah. We had a; a Muslim Rabbi was doing a prayer there. A lady with a ukulele, singing. Everybody came and said goodbye to him ... Like a peaceful death. No pain. Surrounded by loved ones. Natural. I think that's, I think at least, that he had that, you know. I do. (C3.Cmo)

or via legacy-making activities that foster family intimacy, laced with implicit messages of 'bidding farewell':

It's when families have the chance to say goodbye to each other ... Spend the time they had wanted - It's always never enough, but having spent their time together, some parents would say that they have no regrets already. (C5.Osw)

In other instances, if the child is verbal and perceptive, where actions above may be inappropriate, closure is achieved tacitly through serious conversations about dying and death that will never happen otherwise:

Father was able to discuss with Alina about death and dying ... "You should feel lucky, because - when you are dying, your parents are beside you, and looking after you. You know, when baba - it's time for Baba to die, I'm not sure my parents will be there to hold my hand." ... So therefore, the last few weeks that she had gotten with the parents is no longer a very burdensome period, but it's more like - a gift. (C4.Pnr)

Particularly in this example, the act of closure draws the family together at a difficult time. It is observed in all cases. Rather than a sense of barrier or an act of separation that are widely associated with conventional notions of closure, stakeholders become closer at different levels—physically, emotionally and spiritually. Furthermore, the opportunity for closure appears to be supportive also in bereavement, as memories of related activities and conversations are reminisced.

The three themes grouped under the heading 'determinants' are discussed next (see table 5.4).

Table 5.4. Framework matrix – common thematic categories (determinants)

	DETERMINANTS		
	Control	System & processes	Suffering
Case 1	Management of conflicts between personal wishes for child and those of peers; care of other siblings at home; sense of ownership in terms of child's care in the home setting (including admission of visitors).	Palliative care support at home: advance care planning (ACP) that opens alternatives for family, affirming family's goals and plans for care when unsure, dedicated care 24/7.	Reduced quality of life with disease progression, and frequent hospital admissions that add burden to the child and family.
Case 2	Management of conflicts relating to choosing treatment options (between mother/patient and between doctors); putting final decisions ultimately to the sick child.	Giving the child and family the autonomy to make choices and honouring them; providing palliative care support at home, including end-of-life care.	To be subjected to aggressive treatments in hospital, whether to manage disease progression or prolong life. Not being able to live normally like other children, spending time with family and friends.
Case 3	Need for control associated with perceived sense of helplessness and trust in the healthcare providers. Acknowledges that little that can be controlled in this situation, till late.	Infrastructure, services available, and most importantly the attitude of the healthcare staff in the hospital, all bring stability and comfort to caregivers in a chaotic situation.	
Case 4	Awareness that not everything can be controlled. Hence a sense of helplessness can result, or conversely a shift in object of control is helpful. Both impact suffering, but in divergent ways.	Excellent healthcare (compared to elsewhere); palliative care at home; local burial approved.	Not having control over the situation (or making timely shifts to other objects of control) and unable to let go (come to acceptance) as stakeholders move forward along the dying trajectory.

	DETERMINANTS		
	Control	System & processes	Suffering
Case 5	Again, things like disease progression is beyond control, but is exercised in choosing appropriate treatment options and limiting futile interventions. At another level, there are other things that can easily be controlled, like external visitors or things at work. They can mitigate a sense of helplessness in these situations.	Chemotherapy with palliative intent (lesser side effects); parallel planning (memory making and processing anticipatory grief); nursed in single room within oncology ward till child died.	Physical distress that is not managed and being able to live 'normally' as a young child (to develop / play etc and be loved by everyone around him).

Control

This theme is lived or manifested, and perceived in several ways by different groups of stakeholders. It appears to be about mastery over conflicts. These conflicts occur between different groups, varying in magnitude and nature. Examples are drawn from findings in case 1 and 2 to illustrate the diversity found.

Conflicts in opinion between peers (other parents with children who are similarly ill) and their own like:

We, actually - Uh, in the mix of mind, actually ... Generally, a lot of people were saying that: "You have to send her for treatment." To prolong her ... To give her a chance to continue. You never know. To other people, another two months, three months, bonus. It's - it's her right to live another few months. (C1.Cfa)

Conflicts in goals of care between primary cardiologist and attending intensive care physician observed:

I also respect the cardiologist's saying ... Maybe she would live a few more years, if we don't stress her ... For myself, if I was facing this degree of illness - not that I would understand it to its entire extent - but I would rather have a life lived well for - a month or two, rather than - longer period of time being restricted at home, and tied to things, and not being able to do what I want. (C2.Int)

Not everything can be controlled unfortunately, despite the best of intentions, efforts or even power. The reality of a terminally ill child dying is a prime example. This fact, in itself sets up a conflict of its own that is unique to our stakeholders, whether they are family caregivers or healthcare professionals. With control slipping as the child deteriorates inexorably, it produces a sense of helplessness, especially among those who have not yet come to terms with the looming reality mentioned above. This helplessness leads to the kind of suffering commonly experienced by stakeholders with dying children under their charge:

I think control plays a very big part, mainly because being out of control puts us in a very vulnerable situation. Yeah. It's that sense of - helplessness. (C4.Psw)

[Her daughter's prayers to wake up being able to walk were not answered] *That time, I'm just feeling ... Most helpless person in the world. I couldn't do anything ... My one and only daughter, she just wanted some assurance from me. (C4.Cmo)*

When the futility of averting certain death is accepted instead of seeking to control or change it, the sense of helplessness is minimised, and the burden of suffering that is associated is concomitantly reduced:

I think the whole situation to me felt helpless. It didn't feel like at any stage, I, the only thing I felt we could control, and it didn't really - was when things were too late ... The day

where we basically had to - We basically took him off the machines, and we held him.

(C3.Cfa)

I find the families who are not wanting control a little bit more at peace. Not that they are not going through a difficult situation, and they are not struggling. But, they are just able to cope better, and they are a little bit more trusting. So they do not desire control over the situation. (C3.Int)

Acknowledging the futility of wielding control over the inevitable it seems may be achieved in two ways—either via passive ‘resignation’ in the early stages:

At the beginning ... They want things all out, and then up to a point, they see that, you know, even you do more, you don't get better benefits. And so they will withdraw. (C1.Neu)

or through ‘acceptance’ that involves deliberately working through difficult situations over time, at both cognitive and emotional levels.

At some point, there has to be a full stop. It's just where your full stop is. Uh, and whether you are willing to accept that. (C3.Neu)

In the span of a few days, the parents of Daniel who died suddenly from a lethal brain haemorrhage made that leap:

Then slowly it kind of, I guess from the next day, he almost looked different ... There was no more movement, there was no reflexes... (C3.Cfa)

And his head seemed to get worse... (C3.Cmo)

There was a sense, more than anything, the next day. (C3.Cfa)

Looking deeper, while acknowledgment is processed and embraced with time, helplessness and suffering are sometimes managed using two temporalising measures. First, shifting the object of control to something else. For Ivan's mother who is supported by the oncologist in case 5, she manages to limit aggressive life-sustaining interventions (if her son's condition turns worse suddenly) through a formal Do Not Resuscitate (DNR) order, effectively safeguarding his future comfort in a constructive way. She also manages to exert other forms of control in her office where she continues to report professionally, till shortly before her son died. The oncology nurse whom the family is very closed to remarks:

The child leaving and the child falling sick is nothing of your control. So, I imagine that there should be a replacement that they find outside of it. C5.Onr

Second, trusting doctors to do their best in every situation (as it happens in the case of Daniel) is another way to limit helplessness and suffering, while the work to achieve acknowledgement or acceptance is in progress.

Systems and Processes

This theme makes reference to material and non-material 'structures' (in the ontology of critical realism) and 'attitudes' displayed by healthcare providers. Examples of material structures in findings include the hospital emergency department, intensive care ward, and the community palliative care team. Non-material structures refer to various services provided, like good oncology care in hospital and 24/7 support at home from community palliative care. Attitudes sit exclusively within the empirical domain in critical realism, referring to experiences contained within interactions between social agents or actors. Examples of attitudinal experiences found in

the data include respect, empathy and compassion. In this study, they are bounded by the setting or context, and also involves temporality—close to the end of life.

Whether structural or attitudinal, some aspects of systems and processes have been found to bring stability and comfort. A sense of stability is particularly supportive at this time, when uncertainty and chaos are rife:

It's [palliative care] sort of giving stability, so, I mean - Because, it's a very emotional time for them, you know? Definitely, there will be ups and downs, and, there would be doubts ... Actually, in their heart, they know what they want. (C1.Pdr)

We were the people who cared for him, from the beginning until the end of his life ... So, in terms of the plan, it was always Dr T [intensivist] and myself, right. We did try to sit down with the family, for several family conferences, I mean, these were ... perhaps frequent enough. Uh, and the rest of the time - We sometimes met them separately, but we - we always touched base, and we knew what we were saying [consistent information shared between neurologist and intensivist], for the patient. (C3.Neu)

The positive influence that stability wields on the total experience along the dying trajectory for stakeholders like family caregivers is compelling justification of systems and processes as a determinant.

Similarly, 'comfort' (beyond that of the patient and more than the physical domain) is the top concern of all stakeholders when considering attributes for a good death (discussed in further detail later in pages 106-109):

Because Freya loves swimming ... And they [palliative care team] managed to bring her to the swimming pool, and Freya was really, very happy. Yeah. So mum takes comfort ... Mum actually said that, "At least before she died, she still do the things that she loved." (C1.Pnr)

*In a moment of difficulty in the last day, Dr A was ten-minutes phone call away. That matters to us ... But the *urge* I saw in her, in her expressions. That matters to us ... The very comfort it creates, at that second, for everybody. The way she held Alina's hand, the way she tried to talk to her. That matters ... So these are - there are many millions of moments like this. (C4.Cfa)*

Identifying specific features in systems and processes that ensure unfailing delivery of this aspect of comfort is therefore a priority for all support services.

Conversely, from the standpoints of stability and comfort, discovering areas that do not work well or exposing gaps by learning from stakeholder experiences are also important. Daniel's parents in case 3 share their own experience, highlighting where structures and attitudes can be improved:

The, stupid elevator ... He's just had a head injury ... The silly elevator got a "Ding". So every time it like [makes sound of the elevator bumping] ... Every time you go through. [Makes frustration noises]. Stop this elevator! (C3.Cfa)

They came in with a packet, and it was basically Daniel's skull ... And he said, "Do you want this?" And I asked, "What is it?" And he said, "It's the skull." And I was like, "Well. You know, what do I do with it?" I said, "Do I keep it for later, when we do the repair surgery?" ... And he kind of looked at me, like he didn't know what to say. And that's the thing. Those are all the bits of pieces that in hind - When you look back, you go, "He already knew that Daniel was not going to make it." (C3.Cmo)

Incidentally, this narrative behind that piece of skull bone contributed considerably to findings, particularly for this thematic category, even though Daniel's parents could not present any artefact like mementos at their interview.

Suffering

Respondents allude to suffering almost invariably near the end of each interview, when asked what a good death might look like. Yi Lin's mother imagines the outcome if her daughter with end-stage heart failure were to die in hospital instead of at home:

When she was in hospital, of course they will try to, like, put her in, everything, that kind of thing [intravenous medications and ventilatory support]. So, that time, we will think that - If she die at that time, we will find that it's, a suffer for her. (C2.Cmo)

An oncologist reflects on his experience managing distressing symptoms in Ivan, a toddler with leukaemia, where the child's father thwarted plans to start timely chemotherapy:

I think we provided good death in some way, but it could have been better in terms, at least, the duration, the treatment time, and all that. We needn't to let him suffer with ... even his eyes [invading tumour had caused blindness] - I think, was eventually affected. (C5.Odr)

Beyond commonly held notions of suffering that are often of a physical nature, study findings reveal nuances in the interpretation of suffering. To provide greater clarity and focus, each aspect is discussed in relation to the specific context within individual dying trajectories. Three interpretations of suffering are found: not living normally, having recurrent hospitalisations and not having control.

Not living normally

Findings from every case (other than case 3 where suffering has not come up as a theme) flag the need for the sick child to continue living normally in spite of terminal illness. To live normally means keeping the status quo, retaining the capacity to go about usual daily activities with minimal compromise on quality of life:

Maybe last half the year, when she has very frequent fever ... Most of the time, she's sleeping. Drowsy, because of medicine, fever ... I think that's the max that, I think, she's [voice cracks] I mean as a child?... It's like, so much suffering. (C1.Cmo)

It is also about having time with family and friends even while nursing an illness. A yearning for human connection often becomes more pronounced at this time:

The trip to [name of state in parents' home country] is like a family trip. So Yi Lin loved family gatherings, to be with people she is close too. So although she can't go on the cruise [forbidden by her cardiologist], but she's happy to go to [name of state], because she can be with her relatives, and I think that's what matters. (C2.Pnr)

Finally, peculiar to the paediatric setting, and as part of normal neuro-cognitive development growing up, the opportunities to participate in activities other children the same age engage in is important too. This is perceived by some respondents as empowering to the vulnerable child, not to be derailed by sickness:

For a one-and-a-half-year-old, what you really need is to walk and explore, and move around. That's where they reach their developmental milestones. That's, the innate nature to be able to do that. And despite his illness, he still had that. You know, he would walk around his cot, play, and all. C5.Osw

Having recurrent hospitalisations

Long and frequent hospitalisations, though medically indicated, are perceived to impose a tremendous burden on the child as well as the family. This is the hidden cost of keeping the much-weakened child alive for longer. The parents of three children, one of whom (Freya) suffered from a neurodegenerative condition at its late and advanced stages share:

Every few months, she'd have a lapse ... So, we actually have to send her, every time in the hospital, one month, almost a month in hospital. (C1.Cfa)

Can you imagine? I keep sending her in and out of hospital, I don't think I can cope lah. Because my son is still very young that time. (C1.Cmo)

The overall suffering involved is aggravated, as the child gets subjected to painful medical procedures while admitted, with the parents watching helplessly by the side:

She doing all the suction, and all the ventilation support ... Every time when she hospitalized ... we can see her, her face ... When you start doing suctioning ... It's very painful to see her look. (C1.Cfa)

This stream of thought on 'having recurrent hospitalisations' is exclusively articulated by respondents from case 1 and 2. The children in both instances suffer from non-cancer conditions. It is postulated that the journey (and experience) of illness and possibly death in these families may be different than those families with children suffering from cancer. The former lived through many previous admissions that have taken their toll. These families soon begin to develop new insights and now see past hospitalisation 'routines' as suffering.

Not having control

This narrative on the other hand is shared only by the families of children with cancer (case 4 and 5). The relationship between control and suffering has been discussed earlier. Briefly, suffering consequent to lack of control is that sense of helplessness, the result of an apparent conflict between expectations (like cure) and the reality (of dying) that lies ahead.

Characterising ‘attributes’ of what makes a good death are outlined next (see table 5.5). Since these last two themes are closely related, they are discussed together.

Table 5.5. Framework matrix – common thematic categories (attributes)

	ATTRIBUTES	
	Comfort	Dying not prolonged
Case 1	To be cared for by family caregivers who know the child well, at home (where child is most at ease), and hence not subject to advance technology that exists in hospital. Dying not prolonged unnecessarily.	Especially after family is prepared. Prevent further suffering as other signs of a weakening body manifest.
Case 2	Staying home and being surrounded by family; managed with healthcare interventions only when required; dying not prolonged.	To minimise further suffering that also impacts the caregivers.
Case 3	Caring and supportive environment for the family, including the siblings. No unnecessary prolongation of the dying process for the child.	
Case 4	Physical issues managed as a priority; trust and respect in a relationship always; dying not prolonged.	A prolonged battle adds to the suffering of everyone involved.
Case 5	Control of pain and other symptoms and creating an environment in the ward that is healing (moving away from watching ‘numbers’ to enjoying life’s daily moments) rather than focusing on curing.	Prevent prolongation of the process of dying that adds to the suffering through a prior Do Not Resuscitate (DNR) order.

Comfort

With a complex construct like a good death that is at the same time multi-dimensional, findings have yielded not only representations of comfort that are universal across all cases, but like in the theme for suffering also those that are stratified along disease categories. Each one of these representations is discussed with case examples, followed by comparisons between them to highlight underlying similarities, even as they appear superficially peculiar.

Close to family

The dying child being close to the whole family at home appears to bring comfort, even better if specialised care required at this time is rendered by the family themselves. In essence, despite the serious state of illness, the child continues to receive attentive care from dedicated family carers like before. It is perceived that any emergent distress at this stage would be more promptly and appropriately attended to than within an inpatient setting. This narrative comes from two of the cases (case 1 and 2) with children who suffered from non-cancer conditions:

We can correspond, by looking at her, her reaction, her sound-calling, her discomfort. We can sense, what is going on. So, by doing that, we know that, what is the next step to support her ... We know inside out about her. (C1.Cfa)

The exception is Daniel, the boy who was totally unresponsive from severe brain damage. He stayed in intensive care throughout the dying trajectory of less than a week, and his family was always at his bedside. The children in case 1 and 2 eventually died at home. The respondents in both cases also emphasise the importance of limiting aggressive technological interventions as the child receives supportive treatment, with a view to limit suffering and safeguard comfort:

She did tell her sister that, uh, she not scared about death. But she was scared about the journey to the death ... She don't like those, like, have to put the tube, the machine, the support, kind of thing. And she don't want to struggle life. (C2.Cmo)

Management of distressing symptoms

For two other children in case 4 and 5 who had suffered from terminal cancer, the priority from a comfort perspective is focused on ensuring active management of pain and other physical symptoms:

I think, if - to me at least, if the child is having a lot of pain, and then breathlessness is not well-controlled, then I think - we can hardly talk about a Good Death. I think the physical aspect is the priority. (C4.Pnr)

It is unclear from the data if differences observed between these two categories of cases are related to a preponderance of pain or other symptoms in cancer (from progression of disease or adverse effects of treatment) as compared to children dying with non-cancer diagnoses.

Caring and supportive environment

Yet another representation of comfort relates to the need for a 'caring and supportive environment' around the dying child. This comes up strongly from stakeholders (case 3, 4 and 5) that have not mentioned about staying close to family:

She [intensivist] was very good. Yeah. She was, she basically, I guess almost, in hindsight, I guess softened the blow but still managed to bring across the realisation that things are, you know - not good ... She inferred it without saying it ... And that almost felt, not worse, but it hit home more than, the outside, technical discussion which was more point-blank ... You felt like she really cared ... You could feel that she was doing everything she could

do ... She always spoke like she went through the thing - something similar herself.

(C3.Cmo)

The environment in question appears to be about staff attitude and a 'comfort zone' within which these families reside. Incidentally, the children in case 3 and 5 both died in hospital. In case 4, Alina's father qualifies that the exact location of care or death is not critical. Promoting a caring and supportive environment to him is more about trust and respect in relating to the dying child that generates comfort:

*It is very easy to fill up the child's mind ... Just being with her and respecting her. Negligence? They can sense it, [snaps fingers] ... And that *hurts* them a lot ... When a child is in that situation, right, the question should be, "What environment should be there around" ... So *create* home, wherever it is. (C4.Cfa)*

Dying not prolonged

Finally, arguments from every case are unanimous about not prolonging the process of dying. This is to minimise the suffering that each child and family needs to go through, particularly when the final outcome of death is defined and certain:

Towards the last stage ... it's very painful lah, to see her body start to sore ... Yeah, bruises ... It's not that I say: "Oh, I want her to die." But, it's like, it's very painful ah, to see them ... suffering so much, like, going through so much, but yet we can't help them ... I do not know why she dragged for one week. (C1.Cmo)

I wouldn't say her death had not been - peaceful, but I would say the prolonged - the prolonged battle with her illness was what was suffering. (C4.Psw)

This completes the discourse on the *common* thematic categories. In the next section, the remaining five *contingent* themes are discussed.

5.2.2 Contingent themes

Three contingent thematic categories are grouped under the heading ‘antecedents’; the individual narratives specific to each case (where available) are highlighted in table 5.6.

Table 5.6. Framework matrix – contingent thematic categories (antecedents)

	ANTECEDENTS		
	Doing everything possible	Miracle hope	Different levels of awareness
Case 1			
Case 2			Covert acknowledgement of dying (with open conversations and death preparations) that does not interrupt the process of living normally. This persists till the last day.
Case 3	Trusted doctors (and received clear and consistent information over time). A condition before letting go, and a precursor to the process of grieving.		
Case 4	Trusting doctors to do the best. Still continuously seeking alternative treatments. Same, a condition before letting go and thereafter palliative care introduced (almost like all-or-none situation).	A belief and yearning that sustains caregivers throughout the dying trajectory.	Here it is about continuing pursuit of treatments yet doing no harm, acknowledging the reality (that looms) yet believing in a miracle.
Case 5	A process to cope with the adverse situation, as hope gets created with every	Same. An enduring wish that keeps the family going till the end.	Overall, a flexibility to balance between doing enough and not too much

	ANTECEDENTS		
	Doing everything possible	Miracle hope	Different levels of awareness
	new therapeutic option. Same. Only then can letting go happen and supportive actions (palliative care or grief work) commenced.		in the midst of uncertainty and chaos. At one level, it's about holding multiple responsibilities like work (respite) and caregiving (acknowledging reality). Includes a readiness for change; at this level it's about adapting to new situations and being ready to change course anytime.

Doing everything possible and miracle hope

These two contingent themes are discussed together as they are closely related, though not invariably. It is apparent from the table above that findings come mainly from cases with children suffering from cancer (except case 3—where the well-functioning child died within a week after brain haemorrhage).

Among these three cases, doing everything possible seems a necessary precondition before letting go (discussed earlier in pages 88-92):

And a lot of families may not even be ready at the last moment. They would certainly still be grieving, and all that. But - I think the moment when they feel they've done everything, that makes it a lot easier. (C3.Neu)

Only then can restorative actions of various kinds proceed, like referrals to palliative care and commencement of grief or legacy related work. It feels almost like a responsibility or expectation that the parent is held against, to ensure all available therapeutic options have been exhausted:

In his shift to palliative care, although I offered it, it took some time. But I feel that this is a decision he subsequently made on his own ... He wants to be absolutely sure that he has explored everything, before he went down that road. (C4.Odr)

Doing everything possible is achieved by submitting to doctors within trusting relationships (case 3 and 5), or via a self-search for alternative therapies when doctors could offer no further curative treatment options:

*I always try that my daughter must get the best possible efforts, which will turn out to be successful. That's what I always expected ... "Okay. Maybe *this* drop of medicine will - make a miracle." I never gave up that hope. Not even in the last moment ... Expectations never end, you know? (C4.Cfa)*

In two cases (both children suffered from cancer), doing everything possible helps caregivers to cope. With every new or novel treatment proposed, a miracle hope is created. These hopes appear to sustain the desperate caregiver for the child who is fast running out of treatment options:

In patients where the outcomes would be very poor, parents do read and get second opinions, and third opinions, which we encourage. To make sure that we have dotted the I's and crossed the T's ... I think most parents, when faced with very little options of, eventual outcome of losing the child, would clutch at something. C5.Odr

It is worth considering why Daniel's parents in case 3 had not built their own miracle hope, despite starting like the rest (case 4 and 5) with doing everything possible. The child's future was unambiguous—clearly dire and irreversible. In addition, his parents trusted the doctors' assessment unquestionably. Alternatively, it is conceivable that the phenomenon of miracle hope may be exclusive to just the 'cancer' group.

Different levels of awareness

In three of the cases (consisting of children with both cancer and non-cancer conditions), it is noticed that stakeholders, in particular the parents, often adopt different dispositions or rationalities concurrently. This phenomenon is more prevalent early in the dying trajectory, although in some, multiple realities are embraced till the end:

I know that she was very ill, but I don't think that, it's the day. Even Nurse N and Dr A, kept on saying that, "We cannot go home, we have to stay here-" [Laughs]. And I keep on telling them, "You all go home." ... But, I think around, I think around seven o'clock, I find that, a bit like, like unusual lah ... When the SpO2 [oxygen level detector] cannot detect - Mmh. but I still don't think that she will, go on that day. (C2.Cmo)

The future states constructed by stakeholders can sometimes appear paradoxical juxtaposed. In other instances, they embody a delicate balancing act that social agents orchestrate between very different possibilities:

Whatever they say, it's just shit only ... Instead of like, I have to everything worry ... We make her like "She want go school. Go school. She want go out. We go out." (C2.Cmo)

She did tell her sister that, uh, she not scared about death. But she was scared about the journey to the death ... And she don't want to struggle life. (C2.Cmo)

A few motivations for doing this can be inferred from the data. In some situations, it allows stakeholders to 'do enough but not too much':

I think for him, he wants to be realistic, but I could see that he was still hopeful ... He wanted to explore options ... But he was not keen to do ... For any - any aggressive measure that will in the end be futile. (C4Odr)

In others, it is a reflection of their lived experience in the midst of pervasive uncertainty:

They get convinced by doctors telling them that, “Oh, actually there’s treatment available, and etcetera” ... But at the back of their minds, it’s always a scary thought [child dying] that they - it might not be at the forefront, but it’s there. C5.Osw

This may be why the phenomenon is not apparent in case 1 and 3. Individual stakeholders in those cases have either completely switched goals (case 1) or circumstances they face are better defined with little uncertainty (case 3). Lastly, holding different levels of awareness provides a flexibility to manage multiple realities or juggle different roles, within carefully nurtured realms of normality, manifesting a variety of tactics in coping with an ultimately dismal situation:

It is quite mixed ... Doctors were telling me ... And I also had some feeling inside, something will happen like that. After that also, I had another opinion in my mind. Maybe. You know, miracle is there ... So, both - both thinking - goes together. (C4.Cmo)

Two contingent thematic categories are grouped under the heading ‘determinants’ (see table 5.7).

Table 5.7. Framework matrix – contingent thematic categories (determinants)

	DETERMINANTS	
	Being home	Palliative care
Case 1	Keeps the family together. With care rendered by the family, comfort for the child is enhanced and suffering (from procedures) minimised. More likely that child dies surrounded by loved ones. Drawback is tension/stress created and intrusive visitors.	Supporting care at home 24/7: expertise, advice, and validation (caregiver training, trouble shooting, affirmation during dilemma). Utilised more effectively after awareness of palliative care changed. Perceived as part of the family at this special time.
Case 2	Place of child's choice (familiarity); with family around; and comfort maximised (no medical procedures).	Supported eventual dying at home. Introduced initially to support wish making (to attend a K-pop concert).

DETERMINANTS		
	Being home	Palliative care
Case 3		
Case 4	Rather than a specific location per se, it is more about an 'environment' that is deliberately created that contains intimacy, love and connection. It can also happen in hospital.	'Best possible treatment' that is first perceived as end-of-life care. Hence introduced late. Availability and attitude; guidance; and companionship. Again, referred to as part of 'family'. Ultimately enhancing comfort all round.
Case 5		Supports the primary oncology team in rendering comfort care in the ward. Same. Also introduced late in the course.

Being home and palliative care are two remaining contingent themes that are discussed before concluding this chapter on findings. They are classified as determinants (defined at the start of the chapter) for their impact on the perception of a good death, in situations where they apply. To qualify, some cases have not contributed findings in these two domains, as the sick child either spent most of the time in hospital, or the family had not received palliative care.

Being home

Most aspects related to this theme have been covered before in the exposition of other themes, hence only a brief summary of relevant points is provided here. In some cases, this reflects the patient's desire. Besides, being able to stay home (most of the time at least) before and during the dying phase keeps the family together. Otherwise, with visit restrictions in areas like intensive care units, siblings for example can be left out. This setup has also been shown in the section on comfort to benefit the dying child.

Given the living and caring arrangements thus made, there is a better chance that the family would be there at the time when the young person dies:

Because that time is there already. We want to have the family together ... But if she pass on in hospital, it might be the moment in time when, nobody's around. (C1.Cfa)

The same father acknowledges, much as there are benefits staying home, this comes at a cost of escalated care burden and family tension:

Because the stress level is so high. The anxious is there. The frustration is there. That time - Both of us trying to do the best for her, but, to each other, you are doing wrong. (C1.Cfa)

Finally, a variation on the theme of 'being home' centring around creation of a 'homely' environment anywhere (highlighted by Alina's father in case 4) has been discussed under the same section on comfort, that of a caring and supportive environment.

Palliative care

In the majority of cases, palliative care is perceived by both formal and informal caregivers as end-of-life care, leading to late referrals when the child is close to dying:

I think it was when she started deteriorating ... Because I feel like there's nothing, much I can offer. So I, I feel like she would need more care in terms of pain management, and psychosocial support for the family. (C4.Odr)

Service commencement is commonly tentative in the beginning, with beneficiaries often unsure about the role and nature of palliative support. Again, two narratives that are found here stratify along disease types. In children with cancer, stakeholders consistently credit palliative care for having optimised quality of life, particularly in relieving distress from physical symptoms:

I think in the end, we provided significant comfort care ... pain control was there. He had bleeding, he had discomfort, but I think he passed away quite peacefully. (C5.Odr)

For children with non-cancer conditions on the other hand, palliative care is perceived to offer comprehensive and holistic support across several domains that families appreciate, especially if dying at home is the preferred option:

Like, each time when she sick, I really do not know what to do. Even weekends, or even night time ... I can always approach the team for help, and they are all, I mean like very helpful, and patient. (C1.Cmo)

The palliative care ethos is nonetheless uniformly acknowledged by beneficiaries from both groups, who regularly cite palliative care providers as being part of the family:

It becomes an extended family, who are willing to come in and help. Not your real family, but somebody who just want to be part of it, and they come in, and give help. (C1.Cfa)

Lots - Lots for us. We cannot handle that situation without them. It is quite impressive ... We were just sharing everything with them ... They were not doctors; they were just like our family members. (C4.Cmo)

Such intimate expressions of gratitude from caregivers affirm the special contribution palliative care makes when they are involved, even if introduced late.

5.3 Summary of main findings

Eight themes are found to be consistently associated with perceptions of a good death in a child with life shortening illness from the perspectives of caregivers, both informal and professional. Other than revealing its intrinsic attributes, historical and contextual features have been incorporated in constructing a holistic and contextualised understanding, while recognising the

influence of systemic factors over time. These eight *common* themes are listed once again in table 5.8 below, classified under three different headings based on their relationship with a good death.

Table 5.8. Thematic categories contributory to perceptions of a good death

	Antecedents	Determinants	Attributes
Common themes	Letting go Acknowledging the child Closure	Suffering Control System and Processes	Comfort Dying not prolonged
Contingent themes	Doing everything possible Miracle hope Different levels of awareness	Being home Palliative care	

Five (contingent) themes are found to be critical in shaping perceptions of a good death, but in certain circumstances or disease groups. Appreciation of their individual impact to the good death construct adds depth and richness to the overall understanding of the death and dying experience for this heterogeneous group of young persons, their families and their supporting medical and social care professionals.

Chapter 6. Discussion

The multiple case study on perceptions of a good death in the child with life shortening illness found universal elements that influence the experience of stakeholders involved, above unique characteristics like age, diagnosis or care settings, with critical implications to practice and policy. In the process, the antecedents, determinants and attributes of a good death from perspectives of those who have lived through the experience of caring for a dying child are acknowledged. Eight elements were common to all stakeholders: letting go, acknowledging the child, closure, suffering, control, system and processes, comfort, and dying not prolonged. Five elements were applicable only in some circumstances: doing everything possible, miracle hope, different levels of awareness, being home, and palliative care.

Informed by the philosophy of critical realism, the complex and multi-dimensional construct of a good death in the context of a dying child is elucidated, recognising the confluence of causes, conditions and time, and involvement of multiple stakeholders and systems. When combined, these thirteen elements not only depict the rich and meaning-filled journey of illness and death but also more importantly answers the original research question: how and why a good death may be achieved in children with life shortening illness.

This study had aimed to close a specific evidence gap—a good death in the medically ill young person, given that current practice has been guided mostly by narratives from adult literature. After all, the clinical, social and cultural contexts between the dying child and adult are intrinsically different. For example, multiple stakeholders share special relationships with the dying child and are intimately involved or even invested as caregivers. The study also aimed to achieve another

goal—identify areas where things may be improved, to promote better care for everyone, in and around the dying child. These study outcomes are explicated further in this chapter.

In the next section, findings from the study are contextualised in light of previous evidence, highlighting where they converge and what may be novel. Following that is an exploration of the intersections between compatible theories and the latest good death construct, with a view to enriching current understanding further. An updated organic framework that consolidates all new inputs, both empirical and theoretical, is revealed at the end. Finally, implications on policy and practice of these emergent insights and suggestions for future research are discussed.

6.1 Empirical connections and contributions

6.1.1 Letting go

This is a major milestone along the dying trajectory, one which stakeholders cross if they feel they have tried hard enough, when suffering becomes unbearable, or the eventuality of probable death is confirmed. Critically, new goals are set thereafter and supportive care accessed, resulting in overall reduced suffering and improved quality of life (and death).

Murray Parkes (1998) refers to letting go as giving up on life itself, when the ‘appetite for life’ is reduced or lost in late stages of terminal illness. Instead of death that ensues, in this study letting go occurs much earlier in the course, with a series of restorative actions that follow, like accepting palliative care. In fact, this element of letting go only applies to caregivers here. In the findings, none of the young persons involved was observed by their respective stakeholders to express contemplations of surrender, whether directly or indirectly.

In this millennium, empirical evidence from predominantly adult literature (Bouchal et al., 2015; Kruse, 2004; Lowey, 2008; Sopcheck, 2015) posit letting go as a shift or even transformation that involves “emotional, transitional and decision-making processes” (Sopcheck, 2015, p. 71). To begin, the literature acknowledges existing physical and emotional attachments between the caregiver and the dying person. There is gradual realisation among significant others who are caregivers that change is inevitable, and that letting go is ultimately in the dying person’s best interest, as suffering is not prolonged unnecessarily just before death. Nonetheless, there still needs to be assurance that everything possible is done (Kruse, 2004; Lowey, 2008). The decision to finally let go is contingent on acceptance, a turning point as the caregiver come to terms with impending loss and relinquishes control of the situation (Sopcheck, 2015). Whether explored through related constructs like anticipatory mourning (Bouchal et al., 2015) or specifically at letting go (Kruse, 2004; Lowey, 2008; Sopcheck, 2015), these studies invariably report a state of paradox observed in the process of transition; it describes a tension that is lived and experienced between being present/holding on and letting go (Bouchal et al., 2015; Kruse, 2004). This same tension that precedes the transition to letting go is observed across all cases studied, albeit at different times along the dying trajectory. The point related to a state of paradox will be picked up again when the thematic category ‘different levels of awareness’ is discussed (section 6.1.7 on page 131).

In the face of incurable childhood cancer, the stage before finally letting go has been similarly described as a transition between preservation and letting go, mediated by parental ability to manage their feelings of loss, and the control that parents cede as a consequence (Kars et al., 2011). Owing to the success of programmes for the treatment of childhood cancers and the stakes involved in saving a child’s life, abandoning the curative approach is often unbearably difficult for

any parent (Morgan & Murphy, 2000). Factors found by others to have influenced parental decision-making include the existing and anticipated suffering in the child (noted in this study), and echoing Murray Parkes point (1998), albeit by proxy, the perceived will to live in the child (Zaal-Schuller et al., 2016). This tension between preservation and letting go is represented in chapter 3 within a concept map that shows its influence on the perception of suffering, and as a corollary the quality of dying and death. Any intervention by healthcare professionals to help parents cross this critical milestone become salient, particularly around support in managing ongoing loss. The same tension it seems also affects the healthcare professionals (Leung et al., 2012). Perspectives from two oncologists interviewed in this study indicate they learnt to 'let go' along the course, activating palliative care or 'switching gears' thereafter.

Study findings suggest a few other strategies that may be helpful when supporting family caregivers. First, parents need validation from healthcare professionals that they have indeed done their best. Second, when treatment interventions repeatedly fail to produce their desired outcomes, it may be appropriate at that juncture to explore with caregivers gently their perceptions of suffering. Lastly, 'bad news' that is sensitively but consistently and clearly delivered can trigger a turning point in conflicted family caregivers for letting go.

6.1.2 Closure

As the child moves closer to the end of the dying trajectory, findings show that the need for closure is compelling. The underlying message is saying goodbye, even though the ways closure is achieved can vary, like being there when the child dies or having 'serious' conversations prior. In the process, the family as a unit is drawn closer together during a difficult time. Yet, at another level, closure appears to have other meanings as well. Literally interpreted, it implies a sense of bringing to an end, but it can equally apply in special situations where continuity is yearned for

(Ralph et al., 2014). The intent behind organ donation after the death of a child exemplifies the latter.

With roots in Gestalt psychology, Gozzi argues that seeking closure is “a metaphor for an impossible state of affairs within the human condition” (2003, p. 297); it connotes the futile pursuit of relief or end to sorrow. Contemporarily, closure has found diverse applications, sometimes taking on opposing meanings—like ‘remembering’ and ‘forgetting’ (Berns, 2011a). It is described as a new language constructed in response to loss that is grounded in our culture and social experiences, hence its heterogeneity (Berns, 2011b). Much more than conventional notions of a parting ritual, whichever form it takes, closure is also a way to manage or make sense of traumatic loss or grief. Berns’ (2011b) point about closure being supportive in bereavement is supported by findings from this study.

What is even more salient in the data however, relates to how the family is intimately drawn together *before* the death. The majority of scarce literature on closure pertains to the period post bereavement, either of caregivers reconnecting again with healthcare providers (Back et al., 2009; Egly et al., 2013) or even resisting against closure during transitions through the death of a child (Woodgate, 2006). In the adult setting, the Life Closure Scale on the other hand, measures psychological adaptation in the *process of dying* within two existential dimensions—finding meaning and maintaining self-integrity (Dobratz, 2004). The pre-death context is similarly adopted by Emanuel, Bennett and Richardson (2007) as three domains within a dying ‘role’ are conceptualised. The role anticipates tasks like last goodbyes, giving permission and reaching closure (in this case, closure involves settling with people with whom the dying has meaningful relationships). Particularly among young persons who are perceptive, the emotional and spiritual

connections forged in closure through many candid conversations along the dying trajectory for example are immeasurable and most empowering.

6.1.3 Control

At the experiential or practical level, a sense of control is found in this study to be helpful for stakeholders in coping with uncertainty and living with terminal illness. In essence, findings indicate having control is about mastery over various types of conflicts—including that of ultimately overcoming death through reversing the course of dying, which is doomed to fail. Inability to reconcile with the latter, either through resignation or acceptance, results in helplessness and concomitant suffering.

Dimensional analysis of a good death for the child with cancer (Hendrickson & McCorkle, 2008) reveals that autonomy and self-determination are highly valued by the dying child, parents and healthcare providers when there is uncertainty in disease recurrence or prognosis during the process of making medical decisions, including that of choosing the location of death. Similar to findings from this study, ‘retaining control and taking decisions’ enhances overall coping within families (Eskola et al., 2017), allowing parents to maintain other household routines while rendering end-of-life care at home. Knowing that their child is likely to die can disrupt the parents’ assumptive world, which impacts the sense of order and ultimately control (Darlington, Korones, & Norton, 2018). In mitigation, they focus on immediate challenges instead of distant realities (Ullrich et al., 2016) or get involved practically themselves (Young et al., 2002). Those strategies have not been regularly observed in this study. In contrast, our stakeholders continue to keep control in perspective, but shift the object of control elsewhere or cede control to healthcare professionals that they trust.

Lastly, working alongside parents in fighting for a child's survival, healthcare professionals interviewed in this study face the same tensions surrounding control, albeit over other aspects like planning efficacious clinical treatments or estimating the prognosis accurately. Achieving a sense of mastery over various types of conflicts apply here too. They also learned to embrace passive resignation or come to final acceptance as ways to cope. This has been described previously as transitioning from a position of control—always doing something to solve a problem—to being a vulnerable witness during the dying trajectory (Kane & Primomo, 2001).

6.1.4 Suffering

Study cases universally raise 'living normally' as a priority—maintaining quality of life where feasible, the sick child doing things other children do and maximising time with family. This is similar to findings from a concept analysis of suffering in the context of children and adolescents with cancer (Fochtman, 2006), where it is observed that the contemporary understanding of suffering relates more to the multi-dimensional experience throughout the process of cancer treatment, rather than purely focusing on physical aspects or end-of-life concerns. As disease progresses and death is anticipated, restoring function through aggressive treatments becomes secondary to maintaining 'integrity' and 'wholeness' (Kane and Primomo, 2001). These emergent care goals are congruent with findings from this study around 'living normally'.

Two other narratives of suffering from this study appear to stratify along disease-specific lines. Repeated hospitalisations involving aggressive treatments that also burden the whole family are problematic for 'non-cancer' cases, while lack of control is the chief concern among 'cancer' cases. While the literature in the childhood cancer population have reported physical symptoms, dying in intensive care and absent Do-Not-Resuscitate (DNR) orders as proxies for suffering (Fujii et al., 2003, Wolfe et al., 2008, Heath et al., 2010), the issue of 'control' or the lack of it has not been

highlighted before. However, only one of these three studies included a qualitative design that may be more exhaustive in soliciting alternative perspectives. Given the understanding established in this study of letting go and control, and their associations with suffering, the stratification of suffering narratives noted here suggests that families of children with cancer lag behind those in the non-cancer group in 'coming to terms' (Smith, 2014). This is postulated to be related to comparatively shorter courses of illness and possibly more treatment options within the cancer group.

Lastly, in the 'sphere of influence' model for a good death described in chapter 3, the perception of suffering is conceived to impact the quality of death directly, with intervening factors that are a blend of needs, experiences and control. Empirical study findings here however posed additional elements that independently (and together) with suffering, influence perception of a good death. New entities like 'acknowledging the child' and 'closure' that did not appear before for instance have been added.

6.1.5 Comfort and dying not prolonged

Like the theme of suffering, there is similar stratification in perspectives along disease categories for the attribute 'comfort'. In fact, two typologies may be observed. Among non-cancer cases (except case 3 where suffering did not emerge as a theme), 'comfort' means being close to family, including receiving care directly from loved ones if possible. It also means not being subjected to technological interventions unnecessarily, even though these may have been acceptable in the past. Incidentally in both cases, the location of care and finally death happens to be the home. Among the cancer cases, instead of minimising aggressive treatments, management of pain or other physical complaints is paramount. Rather than being close to family, a 'caring and supportive environment' is perceived to bring comfort close to the time of death. When care needs to be

administered in hospital, in this case within the oncology ward, a homely environment can still be created (Gott et al., 2019; Robinson et al., 2015). One child with cancer eventually died in hospital while another died at home supported by palliative care. The father in the latter had remarked that regardless of location, the special environment created in trust and respect makes all the difference in safeguarding comfort till the end. Observations related to place of death here concur with those from a systematic review on preferred place of death for children and young people with life-limiting and life-threatening conditions (Bluebond-Langner et al., 2013)—current evidence does not favour dying in any specific location.

While preference for ‘dying not prolonged’ is unanimous in this study, in the review by Hendrickson and McCorkle (2008), a divide between child/family and healthcare providers was noted: The former tended to ask for more time while the latter cited brevity as ideal. This is an interesting proposition. Not totally dismissing actual contrasting perspectives, this variance from study findings here may result from differences in epistemology, study design and sample. For example, findings from dimensional analysis of existing literature that includes opinion pieces may reflect markedly different perspectives to this research that involves participants who have lived through the experience.

6.1.6 Doing everything possible and miracle hope

As related phenomena, both elements are observed almost exclusively within ‘cancer’ families in this study. Only after doing everything it seems, can the pivotal process of letting go take place. Before that, constantly seeking alternative treatment options or entrusting the sick child to the treating physician are enduring imperatives. To understand these behaviours, concepts like ‘parental resolution’ and ‘secure-base or safe haven’ in social attachment theory have been applied (Kearney & Byrne, 2015). Having come up *in vivo* and since respondents were not

specifically asked about these two elements, the reasons behind an apparent association with a cancer diagnosis can only be postulated. Comparing broadly with ‘non-cancer’ cases, much like in the theme of ‘suffering’, predominantly shorter durations of illness from first diagnosis to the dying phase may be contributory. Families of those with cancer might not have the same passage of time (and events or experiences) as non-cancer families in assimilating the ‘emerging reality’ of looming death and at the same time assuring themselves that they have already tried hard enough. Indications of parental responsibility within the ‘doing everything possible’ theme suggests difficulty ‘coming to terms’ (Hinds et al., 1996), particularly for a child who was well a short time before. Hence the need to do everything possible, building successive miracle hopes, with every new treatment that becomes available (Feudtner and Morrison, 2012). Perspectives of a ‘good parent’ in the context of decision-making from other studies (in paediatric oncology and intensive care populations) revealed other priorities however—child’s best interest and quality of life (Hinds et al., 2009; October et al., 2014). Although samples in those two studies are not comparable to ours in certainty of dying, the reasons for those alternative perspectives are unclear and deserve further interrogation.

Specific to hopes for a miracle, study findings here reflect deliberate efforts by patients and caregivers in coping with foreseeable loss, identical to ‘patterns’ of hope for a miracle described in the adult setting outside of religious worldviews (Shinall Jr, Stahl, & Bibler, 2018). In fact, a spectrum of hopes that change over time has been described previously (Clayton et al., 2005). This change in hopes is also reported in the paediatric literature, and similar to that found in this study, adds further that less common types like miracle hope tends to remain constant (Hill et al., 2018). No matter how far some hopes are from reality, parents often identify themselves as bearers of hope and see it as their role, whereas healthcare providers tend to view hope from the

perspective of solely positive outcomes (Reder & Serwint, 2009). This can set up unnecessary tensions between mutual stakeholders for the sick child. Although it had not surfaced as a key issue, the professional caregivers among respondents in particular have shared how they struggled at times with parental hopes for a miracle during the dying trajectory. This is discussed further in the next section.

6.1.7 Different levels of awareness

As one of several coping strategies, informal caregivers are observed to hold very different positions concurrently. A comparable situation is first described in adult literature as 'middle knowledge' (Weisman, 1972), where a patient vacillates momentarily between hoping for recovery and admitting its unlikelihood. Sometimes, denial and acceptance are even expressed simultaneously. It is mentioned again in the last decade as 'flexible realism' in the literature (Hales, Zimmermann, & Rodin, 2008; Masson, 2002), where contradictory or rapidly shifting attitudes to death and dying among patients and caregivers are noted in the face of unfolding realities. The same phenomenon is reported in contemporary paediatric literature as 'cognitive dissonance' (Kamihara et al., 2015), where parents who are aware that their children suffer from terminal cancer openly articulate expectations of cure, sometimes even as they are in the midst of preparing for their children's deaths (O'Brien, 2014).

It is observed in findings that when executed well, being able to adopt different levels of awareness enables family caregivers to operate almost 'normally' throughout the dying trajectory. This aspect in particular is analogous to 'mutual pretence' described in anthropological studies of children and their families within the hospital oncology setting (Bluebond-Langner, 1978). Similar to the American experience described in the latter, children who were dying with cancer in Greece were able to exchange silent goodbyes with parents without breaking the collusion (Papadatou,

Yfantopoulos, & Kosmidis, 1996). Unless there is little uncertainty in prospects or outcomes, like when the child is evidently dying, mutual pretence is frequently observed among parental respondents in this study, cutting across case characteristics like disease categories, location of death and palliative care access. Bearing the same label, elements of Glaser and Strauss' classic theory on different levels of awareness may initially seem to be manifested here (Andrews & Nathaniel, 2009; Glaser & Strauss, 1965). However, in contrast to largely discrete categories of knowing—four different types, as described in their very first Grounded Study—cognition and adoption of divergent realities in this study is almost always synchronous.

Yet another variation of this theme relates to the position of ambivalence seen among those with miracle hopes (Billig et al., 1988), like seeking to do everything but not too much. This fits closely to the last of three streams of consciousness that our stakeholders held. At a time when there is pervasive uncertainty, staying nimble to change with seeming ambivalence appears to be a rational position.

We return to the last point in the section on miracle hope (section 6.1.6 on page 127), that posited professional and parental caregivers have differential perspectives. Particularly during interactions with healthcare providers, every one of those three presentations discussed above on levels of awareness can lead to confusion or even conflict, with implications on the care rendered and its associated experience. It bears reiterating that in totality, these initially puzzling phenomena observed within 'different levels of awareness' are manifestations of caregivers' attempts at adapting and living with multiple challenges along the dying trajectory.

6.1.8 Summary

In closing this section, where some of the key elements that impact perceptions of a good death are discussed, the 'sphere of influence' concept map from chapter 3 is again referred to. Apart from suffering, empirical study findings have added other common and contingent elements that together contribute to a good death. At the same time, entities embedded within 'needs and experience' in the previous model identical to narratives elicited in this study have been made explicit, like staying home to be cared by the family under the theme of comfort. Lastly, even though a comprehensive overview of a good death was rendered, the sphere of influence model did not manage to capture the *journey* of illness that precedes death. It is a period that respondents spoke passionately about, which appears to strongly influence the perceptions of death and dying. Division of thematic categories into antecedents, determinants and attributes in reporting findings is a deliberate attempt to depict a final journey that involves conditions, processes and actions. This 'deconstructed' latest iteration of an intrinsically complex construct, contextualised and enriched with the evidence base from both adult and paediatric literature is anticipated to promote an even deeper understanding for all.

6.2 Theoretical congruence and comparisons

Two major theories have informed further iteration of findings at advanced stages of data interpretation: Ecological Systems theory and Trajectory framework. While the former is located and utilised in the process of appreciating the influence of context, culture, and setting on the perception of a good death, the latter was in fact first referenced at the phase of literature review

(cited in chapter 3). The reasons behind choosing these two mid-range theories to support deeper data interrogation and how new findings can in turn add to them are discussed in detail next.

6.2.1 Ecological Systems perspective

Actions, events and their associated experiences are generated as stakeholders interact. During data analysis, it became evident that in the real world these phenomena do not happen in a vacuum, but rather within dynamic overlapping systems or units of different sizes and levels of complexity. Each unit bears distinguishing features with the power to influence, often conditioned by history and culture entrenched over time. The dying trajectory in focus here appears to be a package of multiple units assembled. Despite seeming diversity among individual units and more broadly along 'assembly lines' of different subunits, some regularities or patterns are still discerned, even between case studies with disparate characteristics. This suggests underlying mechanisms or properties that may be common or even possibly universal. It is exactly these considerations that initiated a search for extant theories to interpret emergent findings.

For the purpose of discussion here, a brief outline of the framework located is provided as foreground. As a backdrop, attention is again drawn to critical realism, the ontological position anchoring this study. Ecological Systems framework has dual roots: Bertalanffy's Systems theory and Bronfenbrenner's Ecological environment (Friedman & Allen, 2011).

Bertalanffy adopts an *ecosystem* perspective to analyse the complex nature of human interactions within a social environment. The parallel in this study of an ecosystem is the 'case', bounded by the individual healthcare setting and end-of-life period in terms of time. 'Systems' are described as micro, mezzo or macro depending on their size and complexity. Here, the patient and caregiver dyad may be interpreted as a micro system; family and supporting services as mezzo systems; and

the community or hospital within which all stakeholders interact as macro systems. It is assumed that within an ecosystem, smaller systems interact, with activities or processes aiming to strike a balance—*equilibrium* (a delicate state that can be potentially disrupted with any change) or *homeostasis* (a dynamic state that is fluid and hence more resilient). This dual balancing act conceptually mirrors the phenomenon of ‘different levels of awareness’ in findings, or even the oscillation between ‘preservation and letting go’ discussed in chapter 3. The delicate state of equilibrium achieved within different levels of awareness, like in mutual pretence observed in this study, illustrates exactly those interactions between micro and mezzo or even the macro systems described in Systems theory. On the other hand, the dynamic state of homeostasis, embodied within the phenomenon of preservation and letting go, exemplify the fluid shift of control between stakeholders (parents and the healthcare providers) situated at different systemic levels.

Bronfenbrenner believes in other *environmental factors* within human social systems that can shape interactions, in contrast with unnatural scientific systems where everything external to the phenomenon under scrutiny is ‘controlled’. The impact of material and non-material structures, like a consistent care team in intensive care and access to 24/7 palliative care at home that brought stability and comfort respectively, have been discussed under the theme system and processes in chapter 5 (pages 100–102, above). These environmental factors define not only the ‘here and now’ circumstances, but also possess historical and cultural features. Entrenched practices or unquestioned conventions, like seeking to provide mementos to grieving parents regardless of context, is an example found in the study that had led to an adverse experience. On top of biological qualities like terminal illness that is the focus here, biopsychosocial perspectives which are unique to the environment under scrutiny are equally emphasised in this theory. Hence, for the purpose of this study, attitudes, beliefs and values that influence individual interactions

and experience are also recognised. Imperatives to acknowledge the child and the tensions around control in this setting are examples of biopsychosocial factors requiring consideration, as a phenomenon like good death is explored in depth. Smaller systems that are embedded within progressively larger systems are assumed to interact in this 'messy' way, both horizontally and vertically.

In combining both concepts, sociologist Carol Germain has been instrumental in applying the Ecological Systems framework within the social work arena, advocating using the 'person-in-environment' model to assess behaviour and plan interventions (Germain & Bloom, 1999). The 'person' in question (micro or mezzo systems) refers to either an individual, family or community. Two concepts were particularly cogent as data analysis was in progress. Firstly, the nature of relationships between systems is described as 'transactional', involving reciprocal exchanges between entities or elements, each changing or influencing the other over time in what is termed as 'circular' relationships. This concept has important study implications, in terms of opportunities presented for positive change, as various systemic units engage and evolve. This interdependent interactions between systems is consistently observed in this study across diverse stakeholder perspectives, for example, in reaching the point of letting go (pages 89–92 in chapter 5). Freya's family (in case 1) for instance gradually realised the futility of aggressive treatments after multiple hospital admissions that they eventually opted for palliative care at home. Secondly, Germain promotes five areas as key to understanding the nature of interactions between systems in the person-in-environment model: life stress, adaptation, coping, power and human relatedness. These dimensions are lived out most strikingly by stakeholders within the themes of doing everything and miracle hope (pages 111–112 in chapter 5). Ivan's mother from case 5 for example, submits in trust to the treating oncologist with successive treatments for the child, building

miracle hopes along the way to cope, before finally letting go as adaptation. In varying degrees, all five areas have substantial applications in other instances, as behaviours and events along the dying trajectory are analysed to reveal underlying motivations and meanings.

One conceptual element that empirical findings here can possibly add to the Ecological Systems perspective is an alternative supposition of one system concurrently nesting within two larger systems, outside of the single person-in-environment norm. This stems from the 'different levels of awareness' phenomenon discussed above.

6.2.2 Trajectory framework

The need to recognise a *course* or journey as the death and dying experience is reconstructed and understood has been emphasised. Corbin and Strauss (1991) believe chronic conditions have a course that varies and changes with time, bringing along with it a diversity, multiplicity and complexity of problems. It involves the combined efforts of affected individuals like family and healthcare professionals (who bring 'technology' or treatments) in shaping the course or trajectory. These efforts directly impact an eventual outcome (well-being, or death in this case) and indirectly that of two other entities: biographical fulfilment (aspects of the self, like a need for control for example) and performance of everyday activities (compare 'not living normally' in theme of suffering). A sudden change in the illness along the trajectory demands shifts and adjustments among these three factors: technology (hospitalisation or second-line oncology treatments with associated burden and adverse effects), biography (that mandates realignment of goals or trade-offs like missing school) and normality (possibly accepting some loss of function or becoming dependent on devices like non-invasive ventilator machines). This adds to the uncertainty and flux that is common at this time. Contextualised to this study, a few conclusions may be drawn. While death as an outcome cannot be changed with disease progression, there are

other factors within the system/s that can. More specifically, the balance between technology, normality and biography (as defined within this study) can still be carefully calibrated (operationalised as expectations of or exchange for something) along the dying trajectory by stakeholders. Ultimately, the quality of dying is hopefully optimised, even if death cannot be averted. Additionally, the model also posits other 'conditions' along the trajectory that may influence the experience. These include for example past experience, access to resources, and setting of care, very much like Bronfenbrenner's environmental factors.

Corbin and Strauss' theoretical framework (1991) is grounded in studies of chronic illness set in both hospital and the home that included dying patients young and old. Concepts like equilibrium and homeostasis in Ecological Systems theory are almost similar to the shifts and adjustments of those three factors in Trajectory framework in response to change. Power, an element in Carol Germain's (1999) interpretation of the nature of interactions is noted to be absent in the trajectory framework though. Nonetheless, in terms of setting and context, Trajectory framework is both 'systems' and 'ecologically' congruent, indicating good synergy with combined application of both theories during study data analysis.

Among many concepts nested within the original trajectory framework, one stands out as most relevant for this study, which is that of 'supportive assistance' (Corbin & Strauss, 1991, p. 167). This refers to the nurse in the original paper, whose role the framework was specifically conceived for, aiming to achieve dual goals of shaping the course of illness and maintaining the patient's quality of life (through biography fulfilment and maintaining functional performance). In this study, these overarching goals likewise guide all health and social care providers along the dying trajectory, particularly specialist palliative care, that in the end determine the quality of dying or death.

Similarities in concepts notwithstanding, this study does add its own dimension to the Trajectory framework. Comparatively, in this instance the 'journey' under focus is temporally compressed yet no less turbulent—one where actions, events and experiences unwind precipitously over a much shorter course of time, from days to short weeks rather than months to years. It is almost a microcosm of the Trajectory framework on display.

6.2.3 Synthesis of all insights

The 'sphere of influence' model for a good death presented in chapter 3 that is developed from existing literature is now strengthened. Gaps like impact of location of care (and death) and support from palliative care that were signposted in the integrative review have been addressed by new empirical findings. Likewise, a dynamic balance between needs, experiences and sense of control represented in the previous model which contribute to the degree of suffering (postulated to preclude a good death) is now superseded; in its place, the latest construct consists of definitive elements like antecedents, determinants and attributes that operate along what stakeholders perceive as an uncertain and fluctuating course. Enabled by findings from participants who have lived through the experience, deeper interrogation of preliminary theoretical propositions explicated specific needs and experiences in real life that are not immediately apparent in the earlier model conceived from literature. Importantly, the relationships and associations between different factors across three new domains are now made explicit. Not only are elements like 'control' and 'letting go' refined, new dimensions like 'acknowledging the child' and 'closure' have been revealed. The overarching concept within the sphere of influence model recognising the influence of physical and socio-cultural 'structures' on events, experience and meaning-making now has its own place as 'systems and processes' under the domain 'determinants'. At this stage

of the study, for a good death in the child who is dying from life shortening illness, new *theoretical propositions* are posited:

1. A good death is characterised by ‘comfort’ and dying that is not prolonged.
2. A good death is a function of interactions between different causes and conditions that apply in individual cases.
3. A good death is shaped through universal elements at the personal and systems level, above case heterogeneity.

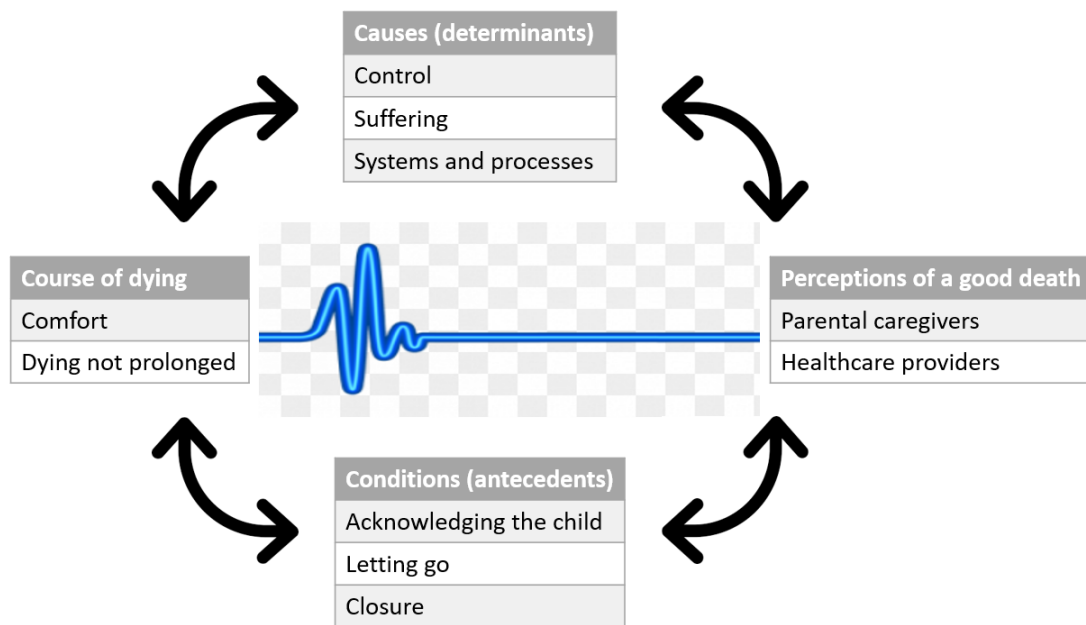


Figure 6.1. Good Death – a composite perspective from family and professional caregivers

To illustrate the confluence of factors that influence perceptions of a good death, a diagrammatic representation is created (see figure 6.1). It highlights the short and unpredictable trajectory that ends in death—one that is perceived to be ‘good’—for the child with a life shortening condition.

Key theories around systems-based circular relationships of the person-in-environment, balance between technology, biography and normality, and prevailing ecological factors have all been incorporated into its conception. This rendition adds to foundational understanding of a good death based on the 'sphere of influence' model in various ways described. Supported by empirical findings and underpinned by theory, this iteration of a conceptual framework for understanding perceptions of a good death is believed to add greater insight and clarity. Effectively attaining the other study goal mentioned at the beginning of this chapter, this final framework provides a structured roadmap as an advocacy tool to envision desired care for critically ill children and their families.

6.3 Implications for policy and practice

6.3.1 Clinical implications

In whatever age groups or disease categories among the medically ill, when cure is no longer possible and dying inevitable, delivering a good death often becomes the ensuing goal for caregivers, both formal and informal (Hinds et al., 2005; Smith, 2000). While intuitive, this may be emotionally difficult for caregivers and at the same time inherently problematic due to its complex nature.

In relation to the last point, an observation around 'needs' flagged in the findings chapter on systems and processes (pages 100–102) warrants comment. For families whose children died due to incurable medical illness, these myriad needs can be incidental and diverse. From the service providers' standpoint, absolute consideration of these needs has implications, particularly around feasibility and long-term sustainability (Donnelly et al., 2018; Koch & Jones, 2018). While still

fulfilling needs but on a different level, consistently adopting the right attitudes like respect, empathy and compassion at interfaces of service provision is however attainable.

Deconstructing a good death to expose intervening causes and conditions in this instance reveals areas within healthcare that professional caregivers can immediately intervene as critically ill children and their families are supported. The concept of 'supportive assistance' described in page 138 within the section on Trajectory framework outlines overarching goals and their implications. Healthcare providers will see different aspects in the good death model that resonate with their own settings and circumstances. Two thematic categories deserve elaboration here for their salience in clinical practice.

Acknowledging the child

During the course of dying, whether the patient is a young toddler, non-communicative child or a maturing teenager, almost all respondents indicated a priority in 'listening to' and 'respect of' the child. As new complications arise or when current treatment fails, professionals may inadvertently omit the needs of the child as they actively engage parents in making crisis management plans. Empirical findings show that the young person needs to continue feeling loved, if not more so, affirmed for their achievements both past and present and accorded a degree of autonomy that is manageable by them—if they request or whenever appropriate. They also need to be given the space to 'grow' and 'live' outside the illness, connecting with peers or just catching up with developmental milestones. These findings are similar to perspectives of a good death for children with cancer among Japanese childhood cancer survivors, bereaved family caregivers and medical professionals (Ito et al., 2015). Acknowledging the child is not so much about ceding control or changing its locus but rather a commitment to focus on the needs of the child at this time, whether

during reassessment or when making new goals, and staying together as a family as much as possible.

Different levels of awareness

This phenomenon, where seemingly conflicting frames of reference are concurrently held by family caregivers has been discussed. Clinicians will interact more effectively with families after having understood innate nuances surrounding this observation, as families cope or 'come to terms' with a forbidding reality (Hinds et al., 1996; Smith, 2014). Clear and consistent information should always be delivered, to minimise uncertainty wherever possible and to prevent creation of false hopes. Dichotomous or mutually exclusive options may not be as acceptable as open-ended ones when it comes to medical decision-making, even if they work better for clinicians routinely. In addition, professional caregivers must be prepared to accept last-minute turnarounds, as a parent may change course suddenly, to pursue another outcome that is perceived to be right for the child and family at the time.

6.3.2 Broad imperatives as drivers for better care

Study findings have flagged different issues related to systems and processes, with implications at a policy level. They cover three main areas: infrastructural issues, availability and access to services, and attitudes. Two entities are discussed in view of their considerable impact on a good death: dying at home and palliative care.

Dying at home

Notwithstanding commonly held assumptions on the benefits of dying at home, even in the adult setting, questions have been raised about using home deaths as a proxy for good death (Higginson et al., 2013). There is recognition of contemporaneous factors that can negatively impact the

overall experience (Benson et al., 2018), like caregiver uncertainty, or interference from other family/social networks. Some of these factors are also seen in this study. Attention should instead be paid to creating the 'caring and supportive environment' in the hospital setting for example, beyond that expected from a dedicated inpatient hospice (Gott et al., 2019; Robinson et al., 2015) which thus far has set the benchmark for a good place to die (American Association of Pediatrics, 2013). The life-stages of the young person should also be taken into consideration when structuring care outside of the home, like for instance allowing open access to friends or even pets where appropriate (Grinyer & Thomas, 2004).

Palliative care

Findings show how palliative care (in this case that provided by a community-based tertiary service) has shaped the experience for families who received it. Second opinions, caregiver affirmation and 24/7 support are some of the tangible benefits shared by respondents. Psycho-emotionally and spiritually, it soothes and brings comfort through an ethos that includes journeying alongside, with care staff consistently referred to as being part of a larger family. Given this, an imperative for policy makers to provide palliative care in different settings is represented, to maximise access and reduce barriers, for families and even healthcare providers. The latter may not yet have requisite knowledge or skills to render end-of-life care within their own specialty like paediatric oncology. As demonstrated in one of the cases, indirect support through consults is equally helpful. Whilst provision for paediatric palliative care varies across regions (Knapp et al., 2011), broad principles highlighted here may be adapted to suit individual circumstances, healthcare systems and jurisdictions.

6.4 Study strengths and limitations

6.4.1 Strengths

To date, there has not been any empirical study that specifically addresses the perception of a good death in children across both cancer and non-cancer groups. Even within individual disease categories, there is a dearth of robust evidence related to how different stakeholders perceive the quality of dying and death. The predominant focus on suffering, mostly of the physical dimension, as a proxy measure for good death has been discussed earlier. This study fills that gap.

Research findings are grounded within the real-life context, taking into consideration systemic factors, both social and structural, that influence and co-create events and experiences among stakeholders. Fidelity to its strong underpinning ontology and epistemology produced an understanding that is sensitive to prevailing culture, history and time, particularly as clinical circumstances evolve quite rapidly along the dying trajectory. This has implications on the ecological validity of data, presenting opportunities for vicarious knowing or service planning, for the practitioner or policy maker respectively (Kang & Feudtner, 2012).

Findings are produced using a robust, yet flexible case study methodology that has been rigorously adhered to throughout. Multiple perspectives were solicited, including triangulation of data sources, across five case studies that have been purposively selected, aiming to obtain data of considerable depth and detail. Apart from findings in chapter 5, most of the other research output are assembled in appendix 9 and 10. In combination, it is a chronicle of the entire research endeavour as well as a library of other primary data that offers additional insights, beyond those presented in the main thesis. The literature review for this study (Chong, Walshe, & Hughes, 2018) provided preliminary theoretical propositions, encapsulated within the 'sphere of influence'

model. These have now been enriched with empirical findings and strengthened with substantive theories. An updated organic framework is now accessible (figure 6.1 on page 140), signposting universal factors (including their relationships and associations) across three domains that influence perceptions of a good death. Their immediate implications for policy and practice have been discussed in previous sections.

6.4.2 Limitations and gaps

As understanding of a good death is deepened through integrating perspectives from all types of caregivers, questions will linger around the young person's voice in this. For practical reasons (the young persons' neurodevelopmental diversity and anticipated ethical challenges), the research question has not solicited the views of the child directly but rather through proxies. Findings uncovered in this study therefore ought to be seen in that light. There have been calls for greater inclusion of children's voices in healthcare, from standpoints of person-centred care and children as 'active consumers' of services (Dickinson, Wrapson, & Water, 2014; Hart & Chesson, 1998). The United Nations Convention on the Rights of the Child advocates that while their protection is widely accepted as prerogative, children also need opportunities to participate in matters affecting them (United Nations Human Rights, 1989). Different scholars have defended the right for children to represent themselves in areas like research, sharing health information and shaping healthcare delivery (Coyne, 2010; Dickinson, Wrapson, & Water, 2014; Gibson et al., 2010; Kerrane & Hogg, 2007; Koch, Marks, & Tooke, 2001). Amid debates around the child's voice versus that from their proxies in the domain of research, Nilsson et al (2015) believe each stands on separate ends of a spectrum—rendering a 'child's perspective' and the 'child perspective' respectively. Where any study rightfully situates could depend on three factors: 1. Research question, 2. Cognitive and experiential capacity of the child as participant, and 3. Level of

interpretation needed. On the last point, the authors argue that even in studies that purportedly take the child's perspective through interviews with children as direct respondents, a child perspective is still represented in some ways. While the child tells the story, the researcher ultimately interprets the script. In the same concept paper from narrative review of the literature (Nilsson et al., 2015), they add that the child expresses opinions more easily if asked questions related to everyday lives, like experience during a procedure; in research on abstract constructs in particular, concepts may need to be translated to the child's context in the present for manageability. This is where soliciting the good death narrative among children in the process of dying becomes problematic. Physical and mental disabilities of different degrees prevent some children from participating in research. Yet gaining their perspectives in terms of experience and hopes for desired care is crucial, if not more so than other children who can articulate their needs. Proxies who are often their caregivers can fill this gap. Investigators observed that in this population of children with disabilities, parental stress and socioeconomic circumstances affect concordance in reporting between the proxy and the child (Huus et al., 2015; White-Koning et al., 2007). Less disagreement interestingly was found in children with more severe intellectual or communication impairments (April et al., 2006; Britto et al., 2004). Additional proxy reports, for example from attending medical staff, have been suggested as complementary in augmenting study findings (White-Koning et al., 2007). In this study, seriously ill children who were close to the end of life grappled with neurocognitive and emotional issues, either from their primary conditions or adverse circumstances they were in. Parental proxies similarly faced challenging situations at the time. These factors precluded obtaining 'voices' from the children directly, and an approach that solicits perspectives from bereaved parental proxies was taken as a morally sound compromise. To strengthen overall findings however, perspectives from other proxies, like their healthcare providers, within a case study approach are obtained in this instance.

Owing to small samples available and change in clinical practice, it was not possible to field a case of a child with cancer that had *not* received palliative care. It is unclear how perspectives from this group (if available) would change the findings. Also acknowledged is the fact that while a retrospective review of end-of-life care is a valid methodology (Earle & Ayanian, 2006), perceptions of a child's death among the bereaved may be influenced by the degree of grief resolution over time (Addington-Hall & McPherson, 2001; Morgan & Murphy, 2000). While parental respondents are at least six months to two years into bereavement, this aspect of their psychological status was not specifically screened during study recruitment.

For a researcher pursuing this PhD as a distance-learner, the process of data collection, analysis and interpretation is conducted mostly alone, though supervisors are consulted at regular virtual meetings. Full triangulation by peer researchers as part of best practice is understandably imperfect. In mitigation, portions of de-identified data have been exchanged using secured channels for supervisor verification and feedback.

Given the impact of contextual features for a phenomenon contingent and consequent to interactions between systems, findings presented may not appear to be immediately transferable to other settings outside the one described here. However, with a research design underpinned by an ontological paradigm that sits between positivism and constructivism, and conclusions derived through strengthening a peer-reviewed conceptual framework with empirical data, case-to-case translation (or inferential generalisation) and analytic (or conceptual) generalisation can still occur (Firestone, 1993; Polit & Beck, 2010; Smith, 2018). Most of all, the multiple case study design and Yin's (2017) two stage process of pattern matching and replication logic (literal and theoretical) (Luck, Jackson, & Usher, 2006) ensure that the conceptual framework (or theoretical

propositions in Yin's terminology) is adequately robust, trustworthy (Guba & Lincoln, 1985) and transferable for the purpose of cross application in other settings.

6.5 Further research

With a focused research question to explore what makes a good death, several key conditions and attributes have been revealed. Whilst there are strong justifications for their inclusion as critical elements, there is a need to understand one particular theme even more—letting go. It seems an instrumental component, triggering a series of events that culminate and end in the death of the child that is largely well perceived. It also has strong associations with other themes like control and suffering that directly impact a good death. In this study, it stands between continuing suffering, transition to a better quality of life for everyone (before the child dies), or the introduction of palliative care. Passage of time, good communication and having tried hard enough appear to facilitate the process of letting go. Future research can unpick other factors that potentiate or block arrival at this essential milestone, as a sick child enters the dying phase. A qualitative approach, including observational approaches like ethnography, is most appropriate, for instance, examining and contrasting perspectives between the young person and parental caregivers when it comes to letting go, at the time when salvage treatments are declined or a DNR order is made.

Given myriad interpretations of 'closure' in both empirical literature and mainstream media, it is worth exploring specifically how different groups perceive and practice closure, including explicating underlying motivations and needs. This will provide an array of perspectives toward deeper understanding for what appears to be a necessary pre-death ritual, particularly if the

influence of sociological factors like culture, religion, values and beliefs are interrogated together. Theory that is grounded in the experience of participants who are recently bereaved may be constructed, again through qualitative inquiry.

The paediatric good death model constructed here can potentially inform conception and validation of a quality of dying and death measure for children that is equivalent to the adult version (Hales, Zimmermann, & Rodin, 2008, 2010). The latter has proven useful as an objective proxy measure for a good death among individual cases, programmes and policies. Similar benefits may be translated to the paediatric setting in that case.

Lastly, whilst dying at home and palliative care support are explored in the context of a good death, relevant findings have only been tangentially elicited from some respondents. Future research can address these topics deliberately in relation to end-of-life situations, through targeted research questions and using mixed methods on a larger sample, preferably including young persons themselves. Despite many challenges involved, rather than their proxies, children remain the key stakeholders with 'voices' that give the most authentic findings. Novel methods to engage seriously-ill children themselves in prospective data collection under controlled ethically-approved conditions may be explored in future studies (Gibson et al., 2010; Kerrane & Hogg, 2007).

6.6 Reflexivity and reflections

As a palliative care physician, I am passionate in improving the lives of the dying, especially if it is a child or young person navigating the end-of-life phase from medical illness. Having practiced in the field of paediatric palliative care for more than a decade, journeys with dying children and

their families in different states of distress or equanimity have long planted the seed for one specific scientific inquiry—to unveil the mystery behind a good death, if there ever is one, for this group. Apart from answering what superficially looks like a philosophical question, the driver behind this research is actually a fervent hope to improve the care of other children in the same predicament, particularly from a systems perspective (larger policy and practice angle—advocating universal access and consistency in quality), tapping on the wisdom of those who have lived through it.

As a clinician-researcher exploring a space that I inhabit daily in the professional arena, it has been a challenge ‘bracketing’ (Tufford & Newman, 2012), staying in the investigator role throughout participant recruitment, data collection and interpretation of findings. Here, I am reminded by an entry in my research journal of how tempted I was to render immediate bereavement support, as Alina’s mother (case 4) teared up at one point during her interview. She had brought along as instructed a Mother’s Day card Alina made, containing a handprint that her daughter said her mother could touch and be reconnected with her, if they were ever separated. My supervisors have been very helpful as a ‘third eye’ almost, signposting as I navigated those grey boundaries, while at the same time helping me to appreciate the hidden advantages of performing what is commonly called ‘insider research’ (Mercer, 2007; Taylor, 2011; Unluer, 2012). A fine balance is negotiated in every instance, like the one cited above, to produce this final report.

In what feels like an odyssey completing the entire project (including writing the thesis) as a part-time student, much is rewarded in terms of new perspectives to standard care as well as situating and adding to current evidence. Together with insights obtained from within the local community or ‘systems’, what comes out strongly for me in the end is a greater level of confidence and conviction, first as a practitioner and then an emerging researcher. Feeling energised might be a

way to describe the state that completing this study has evoked in me, though what comes next is as yet unclear.

6.7 Summary of discussion

Study findings and a new model constructed to understand the making of a good death are discussed in great depth, by locating them in current evidence and mid-range theories, substantiating their validity, relevance and applicability. Implications for practice and policy are suggested, with the hope to improve if not transform the lives of anyone who boards the oft-quoted 'roller-coaster ride' on the dying trajectory. Study strengths and limitations are also discussed. Reflexivity issues are posed, openly situating the clinician-researcher and making transparent unique challenges faced. Finally, research gaps and suggestions for future research are offered.

6.8 Final thesis conclusion

When all curative treatments fail and a sick child is going to die, every paediatric practitioner will now know what the child and the family invariably need, and also what the health system can offer, so as to facilitate the best and most meaningful dying experience for everyone involved.

Empirical findings have provided new understanding of what makes a good death for a child with life shortening illness in the existing health and social care setting within the Singapore context. Not only are its intrinsic *attributes* defined, intervening *antecedents* and *determinants* along the dying trajectory are also revealed. Between key stakeholders, thirteen elements across these

three domains have been found to be instrumental during the process, in the setting of a medically ill young person, days to weeks before anticipated death. Rather than promoting a specific manner that dying should be experienced, an interpretive framework that is instructive without being value-laden to the care of dying children and their families is rendered (Hales, Zimmermann, & Rodin, 2008). Otherwise, a “reductionist and restrictive force” (Goldsteen et al., 2006, p. 384) may inadvertently be imposed in delivering a paradigmatic normative good death.

In that short period of time, it is observed that many processes, actions and events occur, bringing a diversity of experiences and meanings to stakeholders involved. Phenomena narrated by respondents unfold within their individual systems (including both social and structural aspects) that intersect and interact, in turn influencing how the same phenomena are perpetuated and perceived. Messy as it may seem, this is how living and life is like in their own worlds. It is exactly those realities that this study aims to reveal. Evidence in palliative care has been described as “a complex constellation of constructed facts, propositions, experiences, biographies and histories, and is ultimately an exercise of judgement bounded by time and context” (Collier et al., 2019, p. 723). The proverbial good death in relation to children and young people has now become less of a mystery.

Entirely contextualised within paediatric practice, findings add to scarce evidence on the experience of death and dying in children, from the perspectives of both parental and professional caregivers. Contrasting narratives that deviate from adult literature are found, even though some elements may be similar. This has practice implications for healthcare providers who specialise in supporting children and families. With ‘thick’ contextual data (Ponterotto, 2006), and rich findings that are substantiated by extant literature and theory, there is ample potential for generalisation of findings outside this study’s specific clinical setting.

While attributes like *comfort* and *dying not prolonged* are universal to all cases, there are five thematic categories found applicable only in a subset. Two examples—*being home* and *palliative care* (as determinants) in fact have been deliberately interrogated as part of the study design. Even though in this study they have not been found to be uniformly compelling at the end of life, underlying concepts around creating a ‘homely’ environment wherever the patient is supported, and the imperative to provide palliative care at different sites to optimise the quality of dying are noted.

A question posed in the introduction chapter concerns the dying trajectories between different patient populations. Though some thematic categories—*doing everything possible* and *miracle hope*—are stratified along disease groups, both cancer and non-cancer patient groups have been found to share eight ‘common’ elements across all three domains. The composite experience of key stakeholders along the dying trajectory is hence more analogous than anecdotally perceived.

Uncovering systems and processes as a ‘common’ determinant in shaping a good death raised three potential areas for positive change: infra-structural issues, availability and access to services, and attitudes. They merit the attention of service providers, commissioners and policy makers. Though ‘infra-structure’ elicits ideations of huge proportions, study findings indicate immeasurable impact through just simple actions: like ensuring lifts that move smoothly or providing family rooms for dignified privacy. It is evident from caregivers’ perspectives that little things count. On this note, this report comes to an end.

In closing, it leaves me to make a brief and final statement. Addressing the research question led to detailed mapping of needs and experiences among stakeholders in different phases as a medically ill child is dying, delineating touchpoints where improvements may be made. While some may question if the death of a child can ever be good, this study has revealed specific

elements perceived by major stakeholders to be critical for a good death. If the death of a sick child ever becomes inevitable or anticipated, as direct service providers (and healthcare researchers), we now stand guided. It only leaves us to strive and deliver, aiming to render the best quality of death always.

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Perceptions of a Good Death in Children with Life-Shortening Conditions: An Integrative Review

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Abstract

Background: For children with life-shortening illness, achieving a “good death” can be a tacit goal. There is little understanding of how different stakeholders perceive what a “good death” might be.

Objective: To review empirical literature to construct an understanding of a “good death” for children with life-shortening conditions.

Design: An integrative review approach was followed. This involved searching across Embase, Web of Science, Medline, CINAHL, and PsycINFO (no date limits set), as well as identifying eligible studies tracking reference lists. Appraisal of shortlisted articles in full text was performed, followed by data extraction, synthesis, and interpretation.

Results: Analysis of articles ($n = 24$) yielded a dynamic and layered narrative about a good death that revolved around three themes. (1) Level of needs: includes both practical support and aspirational goals such as “do everything.” (2) The composite experience: whether positive or negative adds to produce a sense of suffering. (3) Control (preservation and letting go): moving from maintaining status quo to acceptance of the child’s death, the experience of which also contributes to suffering. Framed using a health care system perspective, a concept map that interprets a good death in children with life-shortening conditions is represented.

Conclusions: A single yet holistic understanding of a good death experienced in the “real world” is suggested. Pediatric health and social care providers, and even policy makers, can use this new understanding to conceive alternative approaches to enhance support to dying children and their families.

Keywords: children; death; life-shortening conditions; pediatric palliative care

Background

IN THE UNITED STATES, more than 50 children die a day. It is estimated that up to three-quarters of these children and their families could benefit from palliative care and hospice support, alongside condition-specific care by primary physicians.¹ Supportive care before these children die may be rendered in the institutional setting, or in the community including at home.^{2,3} Initiatives to improve end-of-life care in medically ill children must consider this care complexity that may involve different stakeholders in multiple settings.

Many pediatric palliative care programs have been established in the last decade.^{4,5} While laudable, it is critical to ensure that beyond access, the needs of dying children and their families are adequately met. Particularly in the context of pediatric end-of-life care, while “doing everything pos-

sible” seeking further life-prolonging treatments,⁶ facilitating what is often called a good death can be a parallel goal.^{7,8}

There has been considerable debate on the notion of what may be meant by a good death and the ramifications this has for care.^{9–16} Most literature discusses this concept in relation to adults, but the attributes of a good death in children have not been well described. The aim of this integrative review is to understand how a good death in children with life-shortening conditions is perceived, from the perspective of multiple stakeholders.

Design

This review follows the integrative review design of Whitemore and Knaff.¹⁷ It is a robust, systematically constructed approach that strives to be inclusive with its “open

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methodological stance,"¹⁸ enabling data from diverse sources to be synthesized for holistic understanding.¹⁹ Given the review objectives, critical realism²⁰ was adopted as the philosophical paradigm to underpin synthesis. It posits one social reality that exists at three levels²¹: *empirical* (where phenomena and meaning making are experienced or co-created), *actual* (naturally occurring events, whether perceived or not), and *causal* (where underlying structural mechanisms exist). Review reporting followed the ENTREQ statement.²²

Literature Search and Selection

Searches were performed across five databases in December 2016 (updated in May 2018): Embase, Web of Science, Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Search strings combined variations of "patients," OR "next of kin," OR "healthcare providers" (population), AND "death" (exposure) AND "perspectives" (outcomes). The search strategy for Medline database is available in Supplementary Table S1 (Supplementary Data are available online at www.liebertpub.com/jpm).

The inclusion criteria were as follows:

- (1) Empirical research on experiences around death and dying in children with life-shortening conditions.
- (2) Study samples that included patients, family caregivers, and/or health care professionals.
- (3) Reported perceptions from those who were directly involved in caring for dying children.
- (4) The children referred to in the study were older than one year (neonatal or infantile deaths not a focus of this review), adolescents, teenagers, or young adults (younger than 19 years).

Articles were excluded if studies were as follows:

- (1) Not empirical research published in a peer-reviewed journal.
- (2) Reported in a language other than English.

No date limits were set. EndNote X7 software was used to manage citations, while NVivo 11 program supported analysis.

Appraisal of Selected Studies

The Australian Palliative Residential Aged Care (APRAC) Guidelines: Evidence Evaluation Tool was used to assess quality and relevance of selected studies.²³ Although not previously used in the pediatric setting, the tool had been customized based on the Cochrane and Campbell Collaboration guidelines.^{24,25} Quality was addressed using eight questions, each requiring a yes or no answer (scoring one or zero, respectively). The sum total ranges between zero to eight points, with score of eight implying best quality. Relevance was rated by assessing applicability of findings to the review question, with scores that can range from a low of one to a highest of four.

Data Synthesis

For dependability of findings, a protocol for the integrative review was set up in advance.²⁶ The steps in data synthesis¹⁷ involved the following:

- (1) Data reduction—extracting relevant sections from selected articles for an organized handling of data.
- (2) Data display—grouping excerpts from primary sources around meaningful variables in tables.
- (3) Data comparison—iteratively studying the displayed data, variables of interest are put into conceptual maps that show patterns, variations, or relationships.
- (4) Drawing conclusions—moving beyond describing patterns to higher levels of abstractions.

Selected articles were "coded" line by line, similar to how interview transcripts are handled in qualitative research. Emerging insights were recorded in memorandums. Relevant points are shared alongside findings in the Results section. In addition, in the process of coding, second-order findings that are interpretations of primary data by investigators were also coded and extracted. These were obtained from discussion sections of the articles. To achieve what Whittemore and Knaff¹⁷ referred to as an innovative synthesis of evidence, analytic approaches developed for qualitative and mixed-method designs were adopted. One such technique, the constant comparison method,^{27,28} was applied throughout. It entails categorizing, for example, an action, event, or participant into a general class, either conceptually or theoretically, through iterations during data analysis.

The first author (P.H.C.) performed most of the literature search, study appraisals, and data synthesis. The other authors provided oversight through participation for a sample of articles. A conceptual framework was drafted by P.H.C., before being developed further over virtual meetings between all authors.

Results

The review process is illustrated in Figure 1. Twenty-nine articles met the inclusion criteria initially (seven were added in May 2018).

Table 1 shows the quality and relevance scores for all 29 articles. Five studies^{43,47-49,53} (highlighted in italics) below threshold set for quality (above score of four) and relevance (above score of 1) were not included in the final synthesis.

Included studies ($n=24$) focused on children with cancer ($n=12$), nonmalignant disease ($n=3$), or a variety of diagnoses ($n=9$). Studies came from North America ($n=7$), Europe ($n=14$), Australasia ($n=2$), and a mix of five countries ($n=1$). Studies were conducted in diverse settings, including nationwide and regional centers, institutions and community agencies, single hospital across departments, wards, or individual services. Nineteen studies used qualitative methods, while five used mixed-method research.

Themes

Three broad themes were identified after the process of coding (data reduction) and categorization (data display): "level of needs," "the composite experience," and "control."

Level of needs

Needs were interpreted at two levels, that of day-to-day expectations and aspirational goals (Table 2). On the first level, "wish list or expectations" comprised practical needs that often varied in nature. These can be organized into three

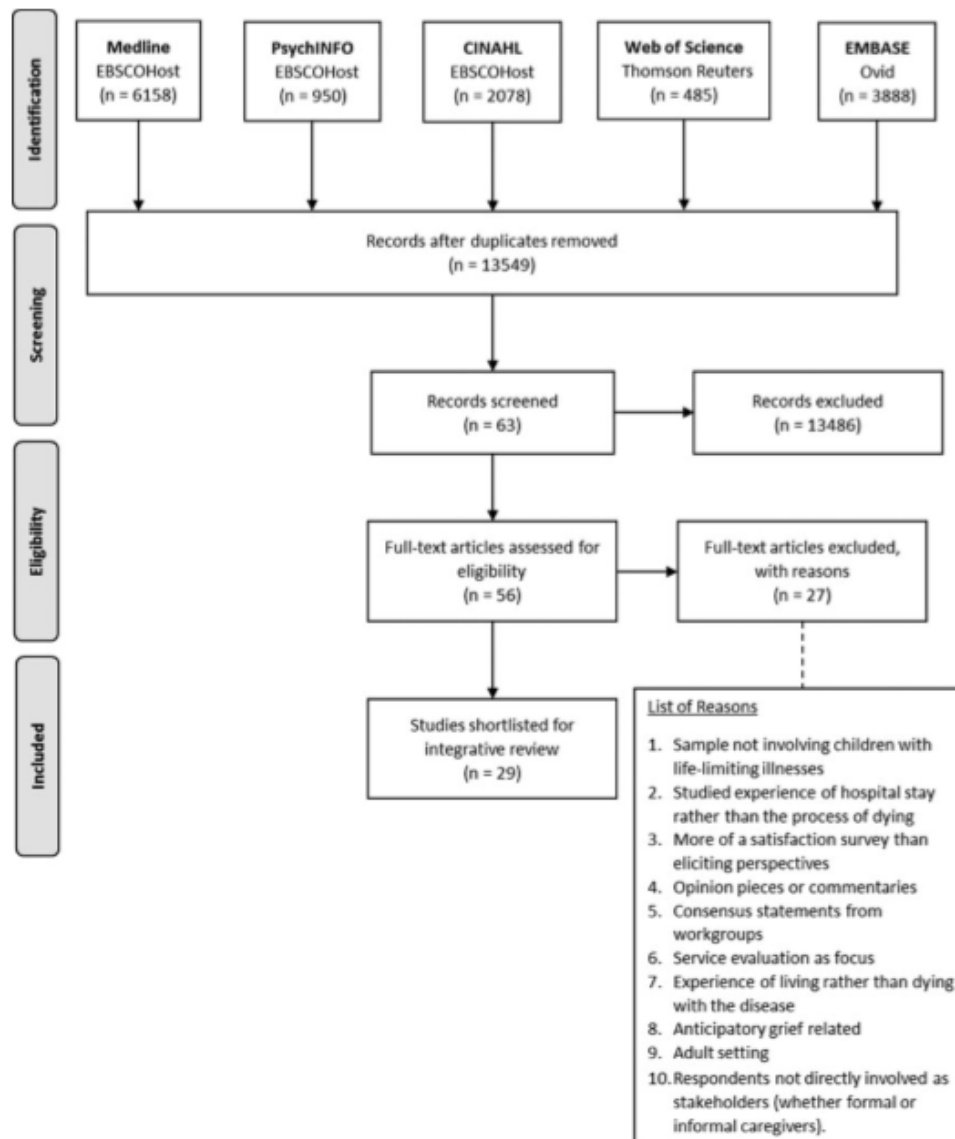


FIG. 1. PRISMA flow diagram showing literature search and selection.

aspects: structure related, for example, provision for respite or a quiet location in the ward to grieve; process related, for example, dedicated services for grief support or follow-up after the child's death; stakeholder related, for example, specifically attending to siblings or honoring parents' wishes to provide hands-on care. Conversely, on a higher level, aspirational needs such as "goals at the end of life" embody different types of longing frequently heard in practice, such as doing everything possible, maintaining hope, and minimizing suffering.

Closer examination of these needs revealed a common thread, that of duality and ambivalence. For instance, most

parents wanted to be personally involved in making critical decisions for their child. Yet, this might not extend to decisions involving withdrawal of treatment:

"Some parents clearly expressed the importance of being informed and participating ... but they did not want to ultimately decide about withdrawal of life support treatment."⁴¹

In addition, some wished that they could talk more openly with their own children when it became obvious that they were going to die, yet felt compelled to maintain hope for survival. Nevertheless, some did manage to keep both notions at the same time:

TABLE 1. RESEARCH FOCUS AND APPRAISAL OUTCOMES OF 29 SELECTED ARTICLES

Reference	Focus	Quality, (0–8 points)	Relevance, (1–4 points)
Balkin et al. ²⁹	Compare physician and parent perspectives regarding prognosis and end-of-life experience of children with advanced heart disease	8	2
Björk et al. ³⁰	Parents' experience of losing a child to cancer	7	3
Cataudella and Zelcer ³¹	Experience of children with brain tumor in their last month of life from parents' perspectives	8	3
Davies et al. ³²	Experience of mothers from different countries who each had a child die of cancer	8	3
Davies ³³	Experience (and needs) of mothers whose children died in different settings (hospital, home, and hospice)	7	4
Eskola et al. ³⁴	Parents' experience and needs during their children's end-of-life care at home	8	4
Flavelle ³⁵	Case study of an adolescent's experience of living and dying of cancer	5	2
Granek et al. ³⁶	Perspectives of pediatric oncologists on challenging patient deaths	8	3
Higgs et al. ³⁷	Perspectives of parents with children diagnosed with SMA type 1 from diagnosis to bereavement	8	3
James and Johnson ³⁸	Parental needs while their child was dying of cancer	8	3
Kars et al. ³⁹	Parental experience at the end of life (EOL) in children with cancer	8	4
Kars et al. ⁴⁰	Parental experience (and meaning making) when caring at home for their child with incurable cancer	8	4
Lamiani et al. ⁴¹	Parental experience of end-of-life care in a pediatric intensive care unit (PICU)	8	4
Lan and Yun ⁴²	Parental experience in the end-of-life care of children with life-limiting conditions	5	2
<i>Latha et al.⁴³</i>	<i>Perspectives of parents on their cancer child's end-of-life care</i>	4	2
Lovgren et al. ⁴⁴	Siblings' experience of brother's or sister's cancer death	8	2
Lovgren et al. ⁴⁵	Parental experience (and wishes) at end of life in children with SMA type 1 and 2	6	2
McConnell and Porter ⁴⁶	Experiences of care team staff providing end-of-life care in a children's hospice	8	2
<i>Midson and Carter⁴⁷</i>	<i>Developing an end-of-life care pathway through a survey of parental needs and experiences</i>	3	2
<i>Muskat et al.⁴⁸</i>	<i>Experiences of acute care pediatric social workers who work with dying children and their families</i>	8	1
<i>Nafratillova et al.⁴⁹</i>	<i>Experiences of parents with children suffering from cancer receiving palliative care</i>	4	1
Price et al. ⁵⁰	Parental experience of caring for children with terminal conditions throughout the entire trajectory and subsequent death	8	3
Price et al. ⁵¹	Compare priorities between health care providers (HCP) and parents in the care of children at the end of life	8	2
Eaton Russell et al. ⁵²	Perspectives of siblings with a brother or sister dying at home or in hospital	8	4
<i>Suryani et al.⁵³</i>	<i>Nurses' understanding of what comfort means to dying children</i>	4	1
Vickers and Carlisle ⁵⁴	Perspectives of parents caring for a dying child at home	8	3
von Lützu et al. ⁵⁵	Experience of children dying from cancer from the perspectives of parents	8	2
Zelcer et al. ⁵⁶	Experience of children with brain tumors and their families at the end of life	8	2
Zimmermann ⁵⁷	Perspectives of parents facing the death of their child (from four diagnostic groups)	8	2

References in italics have not met the threshold set for quality and relevance.

"Maintaining hope for a cure was a prominent theme across all focus groups, even at the end stages of life. Families described the ability to hold on to two dichotomous beliefs: the realism that their child's prognosis was poor and the search for a miracle."⁵⁶

This observation triggered a reflection; the goals to reduce suffering while doing everything possible do seem to conflict. The implication (and question) here is to what extent this factor burdens caregivers.

Respondents in several studies said that their needs were never met. One area cited was that of coordination and continuity of care.

"The lack of a key worker 24/7 left parents to navigate the healthcare system on their own, with no support and anticipatory guidance, especially during the night and weekends."⁴²

A mismatch between needs and response from care providers adds to the total burden of care, and this could contribute to perception of suffering.

TABLE 2. LEVEL OF NEEDS (MET OR UNMET)

<i>Excerpts from the literature</i>	
Wish list or expectations	
Actively caring for the dying child	<i>The only answer to the child's vulnerability and dependency was for parents to transform their boundless love into unconditionally caring for their child and being present.³⁹</i>
Follow-up after the child's death	<i>The need for connectedness remained ... would have welcomed some formal follow up after their child died.³⁸</i>
Involvement in EOL decisions	<i>Parents reported ambivalence about their involvement in end of life decisions. Some parents clearly expressed the importance of being informed and participating ... but they did not want to ultimately decide about withdrawal of life support treatment.⁴¹</i>
Respite care	<i>While the provision of respite care gives parents a much needed rest from caring for their ill child, of more importance was the fact that it enables them to focus on their other children/each other/other family members.⁵⁰</i>
Bereavement support service	<i>Awareness of families' manifest need for bereavement support and lack of relevant service.</i>
Talk openly with dying children	<i>Being able to talk openly with dying children is an important factor in facilitating a child's expression of choice and control over all aspects of care.⁵⁴</i>
Special treatment	<i>Because of the severity of their child's illness compared with other children, they should not have to wait long to see a physician.³⁸</i>
Goals at the end of life	
Reduce patient's suffering	<i>The majority of both physicians and parents reported that their primary goal for the medical care provided to the patient once they realized there was no realistic chance of child survival was 'to lessen the patient's suffering as much as possible'.²⁹</i>
Doing everything possible	<i>Parents expressed that they would never forgive themselves if they had not tried everything to save their child.³⁹</i>
Stay home	<i>During the final stage of illness, nearly two thirds of the mothers were given a choice of caring for their children ... most chose home whether or not established home care services were available.³²</i>
Be with patient at point of death	<i>"I wanted to be with him when he died and that made me very nervous at the end because you do have to sleep and I just couldn't stand the thought that he would die alone or with a stranger and it was my worst nightmare."³⁸</i>
Maintaining hope	<i>Maintaining hope for a cure was a prominent theme across all focus groups, even at the end stages of life.⁵⁶</i>
Unmet needs	
Spiritual care	<i>Twelve (63%) mothers indicated that they were in need of spiritual care during the last month of the child's illness. None reported receiving spiritual care from either the hospital chaplain or the hospital staff.³²</i>
Coordination and continuity of care	<i>Experiences with continuity and coordination of care were rated lowest of all quality domains by parents from all diagnostic groups, and perceived satisfaction with care within this domain was lowest as well.⁵⁷</i>
Access to respite	<i>The parents' need to be with and care for the dying child often presented conflicts when they had other responsibilities, such as parenting other children.³⁸</i>
No point of reference to guide own experience	<i>Parents felt a deep lack of a model: "You've never been in this situation before."³⁹</i>
Attending to the siblings	<i>During the last 24 hours before the loss, 43% of the siblings reported getting no information about the impending death of their brother/sister from a family member.⁴⁴</i>
Meeting health care providers after the death	<i>After their child died, some parents felt abandoned by professionals, because professional support stopped and there was no further regular contact.³⁴</i>

The composite experience

Beyond needs, stakeholders faced other challenges as they navigated the health care system (Table 3). These included negative experiences among health care providers themselves:

"Unexpected deaths were hardest on the families, and therefore, also hardest on the oncologists."³⁶

In this study, the oncologists shared a common humanitarian perspective with many; that the death of any child is against the order of nature. Another point made by the same group surrounded children with cancer dying from medical complications, where frustration related to lack of mastery or control is evident.

Not all experiences in this context were negative though. There were also moments when people felt gratitude in crisis,

TABLE 3. PERCEPTION OF SUFFERING IN RELATION TO THE COMPOSITE EXPERIENCE

	<i>Excerpts from the literature</i>
Negative experiences	
Receiving conflicting information	42% (13/31) of parents in this cohort felt they “sometimes” received conflicting information from members of the care team during their child’s EOL care period. ²⁹
Unprepared for the child’s death	55% (17) of parents reported feeling unprepared for the way the child died. ²⁹
Not given ‘time’ and space’ to be with dying child	Within hours, he was taken to the mortuary and she had to leave. She described her anguish: “I’ve got to say, in everything, the hardest thing I ever had to do is walk away from the hospital.” ³³
Suboptimal control of symptoms	Parents in this study also reported feelings of helplessness, frustration, and lack of control in relation to alleviating the child’s pain and suffering. ³⁸
Sense of abandonment by health care providers	“People do sort of disappear when the child’s going to die. It’s sort of like, they’re all gone because they can’t cope with it I guess...” ³⁸
Loss of parental role and family intimacy in the hospital setting	The parents who had the chance of experiencing their parenting role at home often felt that their knowledge of the child and their ability to provide care was disregarded by clinicians. ⁴¹
Inconsistent or change in health care providers near end of life	There was a change in shift on the ward at the time of death. ⁴⁵
Treatment withdrawal; complications related, sudden or unexpected deaths	Pediatric oncologists noted that even though withdrawing treatment or support was necessary and agreed on by the health-care team and the child’s family, it nonetheless posed an added difficulty when the child died. ³⁶
Altogether a most difficult journey	The on-going disruption is characterized by an unfolding succession of events over which parents feel they have little or no control, sometimes little or no understanding and which invariably demands complex decision-making. ⁵⁰
Positive experiences	
Relationship between HCP and child that facilitated death conversations	Many parents reported that the relationships developed between staff and their children helped to facilitate discussions about death and dying when as parents they could not. ³¹
Special qualities of HCP	Parents felt cared for when they thought the healthcare professionals were respectful, sensitive, compassionate, empathic and consistent. ³⁸
Given control over how or where child died	Forty three parents (90%) spent as much time as they wanted with their child after death and 44 of the 48 (92%) said goodbye in a way they wished. ⁴⁵
Be there with child at point of death	Although unable to ultimately protect their child (i.e., from death), ‘being there’ at the point of death comforts parents. ⁵⁰
Actively rendering care on their own	Parents were able to do something for their child, to become active participants and this was something that is perceived as “positive” and “good”. ⁵⁴
Access to HCP day and night	Reachability day and night (hospital and community care). ⁵⁷
Supported both individually and as a family	They supported by “just being there” or by connecting in some personal way such as through eye contact or with a smile. ³²
See death as “end to suffering”	The moment after death was described by parents as the only time in which they could have the child back, free of medical aids and restraints, in a human way that was not possible before. ⁴¹
Perceptions of suffering	
Loss of function and physical changes in dying child	“Up until then he had adjusted quite well to the diagnosis, and most of the time his spirits were pretty good, but not in the last month.” ³¹
Caregivers anticipating impending loss during the dying phase	Knowing this all will end, together with the awareness of the excruciating pain his/her absence will cause in their future life, brings about unbearable feelings of loss. ³⁹
Withdrawal from outside world commonly seen in dying child	Many parents experienced moments where their child withdrew from them by turning inward or not wanting to be touched ... Parents realized that, in the end, their child inevitably would have to go through the process of deterioration and dying alone. ³⁹
Whether “preserving” or “letting go,” sense of suffering prevails	“You are torn between these two things, that it would have been more comfortable and easier for her (to die) four weeks earlier, but at the same time you desperately wanted a little more time with her, that’s the way it is.” ³⁰
Lack of support at home (especially after hours) causing helplessness and distress	The lack of a key worker 24/7 left parents to navigate the healthcare system on their own, with no support and anticipatory guidance, especially during the night and weekends. ⁴²

validated for their selfless devotion, or simply well supported by their providers. Summation of these encounters both good and bad produced the composite experience that colored the perception of suffering for those involved. Most acknowledged that it was a difficult journey for everyone, although there appeared some ways to make the death “better.” For the professionals, their attitude and supportive acts in sharing information consistently or giving bereavement support were mentioned. From the parents’ perspective, directly rendering care themselves and being present at the time of death seemed critical. Finally, systemic factors included a family-centered approach to care, access out of hours, and adequate time and space in and around the death of a child.

Suffering (of different degrees) was a given, and both the family and health care professionals perceived it. Death in itself could be recognized as an end to suffering:

“The moment after death was described by parents as the only time in which they could have the child back, free of medical aids and restraints, in a human way that was not possible before.”⁴¹

Control (preservation and letting go)

A third theme identified mainly from second-order findings (described in Design section) was “control.” The imperative for control was pervasive and constant, and affected all stakeholders (patients, parents, and professionals).

Patient’s perspective:

“Ed was trying to navigate through adolescence while fighting a serious illness ... Like most teens, Ed fought for independence from his parents, but this became difficult as his mobility worsened and he was forced to rely heavily on his family.”³⁵

Parent’s perspective:

“Feelings of loss threaten parental strength and in reaction, parents seek control.”³⁹

Professional caregiver’s perspective:

“The unexpected, acute deaths from complications were described as especially difficult ... there was a sense of frustration and irritation over a death caused by a medical complication rather than the disease itself.”³⁶

Control seemed a precondition for fulfilling fundamental parental tasks.³⁴ Critically, it mediated the passage from “preservation” to “letting go” as the sick child entered the dying phase. This process was not unidirectional but rather an oscillating one, not unlike the dual-process model of grief.⁵⁸ A swing in locus of control between parents and health care professionals was anticipated in the process of transition. Parental perception of suffering was reported to be influenced considerably by the entire experience.³⁹

Demonstrating interdependence of various stakeholders (and other “conditions” within the system), provision of informational, emotional, and instrumental support by health and social care providers, enhanced the sense of order and personal control for some, and sense of authority over the child’s care and life with wider family for others. Overall, this aspect of control was inferred to have kept fear and uncertainty (contributing to a perception of suffering) that marked day-to-day living within limits of tolerability, particularly for parents involved.⁵⁰

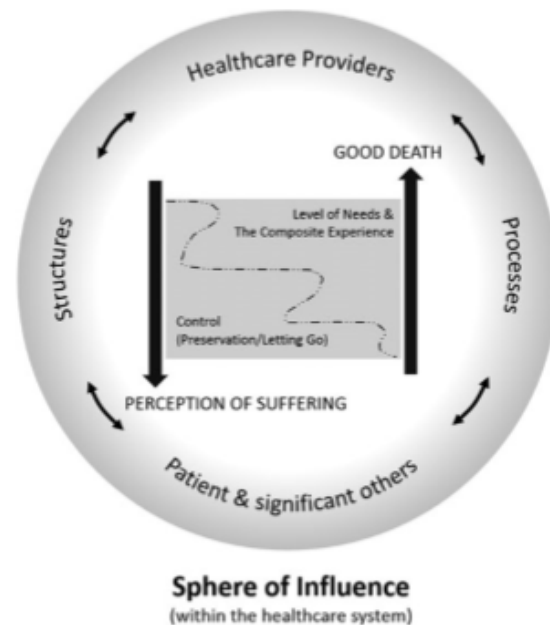


FIG. 2. Concept map for a good death in children with life-shortening conditions.

Synthesis of preliminary findings

Sphere of influence (overall construct of a good death)

Analysis and interpretation of all the findings, expressed as functions of distinct yet interconnected categories brought synthesis to a different level of abstraction. It involved searching for patterns, variations, and relationships among those three themes, within and across different variables (data comparison and drawing conclusions—steps 3 and 4 of data synthesis in an integrative review described earlier). A concept map was created to display and explain the conclusions that were drawn (Fig. 2).

The sphere of influence (a tentative model that requires further testing) refers to the entire health care context (whether in hospital or home) within which stakeholders interact. In line with critical realism, not only does the sphere cover relational experiences and meanings among stakeholders (e.g., unmet needs and perceptions of suffering) it also includes structures and processes (such as 24/7 support or loss of parental roles in the hospital setting) within the health care system that contain and drive these interactions. Whether it is the patient, family, or health care provider, each one could have his or her own intricate balance of needs, experiences, and sense of control. Since needs may be dualistic with ambivalence, and control oscillating between preservation and letting go, the blend between all factors (needs, experiences, and control) determines the extent of suffering at any point in time. It is postulated here that the measure of good death is inversely related to the perception of suffering. Given how its putative attributes are interdependent and fluid, it is posited that the quality of death itself is never constant, at least in and around the dying phase where this review is focused.

Discussion

This review adds to knowledge through synthesizing the scarce evidence related to good death in children with life-shortening illnesses. Previous reviews either drew heavily on adult literature⁵⁹ or focused on a specific group such as cancer.⁶⁰ Findings revealed a dynamic and multilayered ecosystem that incorporates different elements (control, needs, and experiences) and players (patients, family caregivers, and professionals), within a space bounded by the health care setting. It is dynamic in that the predominance of different elements could change over time, between and within themselves. Yet, they are also intimately layered, influencing how each element is expressed or experienced. In creating this concept map, the work of Corbin and Strauss on the trajectory framework was referenced.⁶¹ The diversity, multiplicity, and complexity of problems in chronic illness described in their trajectory framework appear to be an almost similar journey that evolves over time, involving interactions between various “actors” and different “schemes” (management goals and treatment plans) with associated trade-offs and impact, ultimately ending in death.

These concepts are similar to that of Hendrickson and McCorkle⁶⁰ who stated that a good death in a child dying of cancer is “the final social process that involves many perspectives and is the sum of the interactions of multiple dimensions and their influences.” The work of Hendrickson and McCorkle postulated that each stakeholder brings his or her own definition of a good death. In this review, a single unifying construct is displayed, supported by data that showed how different stakeholders and external factors (both situational and ecological) interact and influence each other. This draws from the philosophical perspective of critical hermeneutics,⁶² where an integrative approach that emphasized both subjective meanings for individual actors and social structures within a dynamic system is adopted. Not unlike what has been reported in adult literature,^{63,64} dying children (and their caregivers) similarly face social pressures to fit the norm of a good death, such as open communication or acceptance of dying. That notwithstanding, departure from convention is common. For instance, the duality and ambivalence described earlier frequently define the unique experience. The implication for practice is a need for the professional caregiver to be free of assumptions, and to explore in-depth what may appear to be opposing or shifting positions.

Its methodological design is one strength of this review. The protocol by Whittemore and Knaff¹⁷ facilitated identification of universal concepts from heterogeneous data. Following a stepwise approach that is outlined *a priori*, rigor is preserved and bias minimized.^{18,65} The quality of all 24 studies was appraised to be above average, and all were found to be relevant. A good spread of literature across countries, settings, and diagnoses was reviewed. Of the 12 studies (half of total) that sampled patients with noncancer conditions, eight covered diagnoses across all categories (one to four) in Together for Short Lives’ typologies of life-limiting conditions.⁶⁶ Different stakeholders, including siblings, were also represented.

Nevertheless, there are several limitations. Only one study reflected the child’s perspective (single-person case study). Six studies^{30,31,37,44,45,56} recruited respondents whose chil-

dren had died more than six years before, with risks of recall bias and perspectives that could have changed over time. The sampling frame had restricted articles to only those published in peer-reviewed journals. Sociocultural attitudes or values did not surface as contingent factors. Finally, the impact from location of care and death, or support from palliative care, was also not evaluated. These present research priorities in future research.

Conclusion

An integrative conceptual framework to the holistic and contextualized understanding of a good death in children with life-shortening illnesses is presented. The “sphere of influence” model should be verified and strengthened in future research. A study design that accommodates the experiences of multiple stakeholders and myriad influences within a dying child’s ecosystem would need to be conceived. Nevertheless, preliminary ideas shared here can immediately inform practice and even policy. For example, to appreciate why caregivers suddenly change decisions to start aggressive life-sustaining treatment as their sick child is dying despite a prior do-not-resuscitate order; and at the systems level, shifting the locus of control back to parental caregivers within a family-centered model of care could mitigate the perception of suffering among stakeholders as a seriously ill child dies.

Author Disclosure Statement

The authors do not have potential conflicts of interest, including relevant financial interests, activities, relationships, and affiliations related to this article.

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Appendix 2. Search strategy on Medline database

#	Query	Limiters/Expanders
S1	newborn* OR infan* OR baby* OR babies OR neonat* OR child* OR minors* OR adoles* OR teen* OR youth* OR "young person*" OR "young people"	Search modes - Find all my search terms
S2	pediatric* OR paediatric*	Search modes - Find all my search terms
S3	S1 OR S2	Search modes - Find all my search terms
S4	death OR mortality OR "palliative care" OR "terminal care" OR "hospice care" OR ("hospice and palliative care nursing") OR "palliative medicine" OR "terminally ill" OR "critical illness" OR palliat*	Search modes - Find all my search terms
S5	terminal* OR advanced OR "end-stage" OR "last year of life" OR "life's end" OR "end of life" OR "quality of death" OR "quality of life" OR "good death" OR dying OR "life limiting" OR "life threatening"	Search modes - Find all my search terms
S6	"life shortening"	Search modes - Find all my search terms
S7	S4 OR S5 OR S6	Search modes - Find all my search terms
S8	perception* OR thinking OR attitude* OR "attitude of health personnel" OR "attitude to health" OR "attitude to death" OR "affective aspect*" OR "cognitive aspect*" OR "emotional aspect*" OR "psychological aspect*" OR "psychosomatic aspect*" OR "health attitude"	Search modes - Find all my search terms
S9	"illness behavio*" OR "patient attitude*" OR "physician attitude*" OR "staff attitude*" OR "nursing role" OR understand* OR experienc* OR view* OR observation* OR "lived experience" OR psychology OR concern	Search modes - Find all my search terms
S10	distress OR voice* OR perspective* OR belief* OR feel*	Search modes - Find all my search terms
S11	S8 OR S9 OR S10	Search modes - Find all my search terms
S12	S3 AND S7 AND S11	Search modes - Find all my search terms
S13	parent* OR famil* OR caregiver* OR "significant other*" OR "next of kin" OR sibling* OR grandparent* OR guardian* OR relative* OR "family member*" OR spouse*	Search modes - Find all my search terms
S14	hospice OR "palliative care" OR "general practitioner*" OR community OR "primary care" OR "multi-disciplinary" OR "health personnel" OR "allied	Search modes - Find all my search terms

#	Query	Limiters/Expanders
	health personnel" OR "medical staff" OR nurses OR "nursing staff" OR "personnel, hospital"	
S15	physicians OR "social workers" OR doctor* OR "primary physician*" OR "healthcare provider*" OR "healthcare worker*" OR "healthcare professional*" OR "allied health provider*" OR "allied health worker*" OR "allied health professional*" OR "social care provider*" OR "social care worker*"	Search modes - Find all my search terms
S16	"social care professional*" OR psychologist* OR chaplain*	Search modes - Find all my search terms
S17	S14 OR S15 OR S16	Search modes - Find all my search terms
S18	S12 AND S13	Search modes - Find all my search terms
S19	S12 AND S17	Search modes - Find all my search terms
S20	S18 OR S19	Limiters - Peer Reviewed; Publication Type: Peer Reviewed Journal; English; Language: English; Exclude Dissertations Search modes - Find all my search terms
S21	AB newborn* OR AB infan* OR AB baby* OR AB babies OR AB neonat* OR AB child* OR AB minors* OR AB adoles* OR AB teen* OR AB youth* OR AB "young person*" OR AB "young people*"	Search modes - Find all my search terms
S22	AB pediatric* OR AB paediatric*	Search modes - Find all my search terms
S23	S21 OR S22	Search modes - Find all my search terms
S24	AB death OR AB mortality OR AB "palliative care" OR AB "terminal care" OR AB "hospice care" OR AB ("hospice and palliative care nursing") OR AB "palliative medicine" OR AB "terminally ill" OR AB "critical illness" OR AB palliat*	Search modes - Find all my search terms
S25	AB terminal* OR AB advanced OR AB "end-stage" OR AB "last year of life" OR AB "life's end" OR AB "end of life" OR AB "quality of death" OR AB "quality of life" OR AB "good death" OR AB dying OR AB "life limiting" OR AB "life threatening"	Search modes - Find all my search terms
S26	AB "life shortening"	Search modes - Find all my search terms
S27	S24 OR S25 OR S26	Search modes - Find all my search terms

#	Query	Limiters/Expanders
S28	AB perception* OR AB thinking OR AB attitude* OR AB "attitude of health personnel" OR AB "attitude to health" OR AB "attitude to death" OR AB "affective aspect*" OR AB "cognitive aspect*" OR AB "emotional aspect*" OR AB "psychological aspect*" OR AB "psychosomatic aspect*" OR AB "health attitude*"	Search modes - Find all my search terms
S29	AB "illness behavio*" OR AB "patient attitude*" OR AB "physician attitude*" OR AB "staff attitude*" OR AB "nursing role" OR AB understand* OR AB experienc* OR AB view* OR AB observation* OR AB "lived experience" OR AB psychology OR AB concern	Search modes - Find all my search terms
S30	AB distress OR AB voice* OR AB perspective* OR AB belief* OR AB feel*	Search modes - Find all my search terms
S31	S28 OR S29 OR S30	Search modes - Find all my search terms
S32	S23 AND S27 AND S31	Limiters - Date of Publication: 19960101-20161231; Abstract Available; English Language; Human; Clinical Queries: Qualitative - Best Balance; Publication Type: Journal Article; Language: English Search modes - Boolean/Phrase
S33	AB parent* OR AB famil* OR AB caregiver* OR AB "significant other*" OR AB "next of kin" OR AB sibling* OR AB grandparent* OR AB guardian* OR AB relative* OR AB "family member*" OR AB spouse*	Limiters - Date of Publication: 19960101-20161231; Abstract Available; English Language; Human; Clinical Queries: Qualitative - Best Balance; Publication Type: Journal Article; Language: English Search modes - Boolean/Phrase
S34	AB hospice OR AB "palliative care" OR AB "general practitioner*" OR AB community OR AB "primary care" OR AB "multi-disciplinary" OR AB "health personnel" OR AB "allied health personnel" OR AB "medical staff" OR AB nurses OR AB "nursing staff" OR AB "personnel, hospital"	Search modes - Find all my search terms
S35	AB physicians OR AB "social workers" OR AB doctor* OR AB "primary physician*" OR AB "healthcare provider*" OR AB "healthcare worker*" OR AB "healthcare professional*" OR AB "allied health provider*" OR AB "allied health worker*" OR AB	Search modes - Find all my search terms

#	Query	Limiters/Expanders
	"allied health professional*" OR AB "social care provider*" OR AB "social care worker"	
S36	AB "social care professional*" OR AB psychologist* OR AB chaplain*	Search modes - Find all my search terms
S37	S34 OR S35 OR S36	Limiters - Date of Publication: 19960101-20161231; Abstract Available; English Language; Human; Clinical Queries: Qualitative - Best Balance; Publication Type: Journal Article; Language: English Search modes - Boolean/Phrase
S38	S32 AND S33	Search modes - Find all my search terms
S39	S32 AND S37	Search modes - Find all my search terms
S40	S38 OR S39	Limiters - Date of Publication: 19960101-20161231; Abstract Available; English Language; Human; Clinical Queries: Qualitative - Best Balance; Publication Type: Journal Article; Language: English Search modes - Boolean/Phrase

Appendix 3. Standard cover letter (professional caregiver)

[Date]



INVITATION TO PARTICIPATE IN A RESEARCH STUDY "Understanding Death and Dying in Children with Life Shortening Illness: An Exploratory Case Study"

Dear [professional caregiver],

I hope this letter finds you in good spirits.

A new research study to understand what makes a good death in a child with a life limiting condition has been designed, with the hope of improving the care we provide to families in this unfortunate situation. Perspectives of both family caregivers as well as the healthcare team that had attended to the child will be sought. Research findings will go toward completion of a thesis as part of my PhD studies with Lancaster University, UK.

You are approached as a participant as you had previously supported a now deceased child in his/her last month of life. It will involve a face to face interview with me, conducted at a time and place of your convenience. Expecting to last slightly over an hour, perceptions and insights around the death of the child will be sought from you. While your views are most invaluable, participation in this study is strictly voluntary. Information gathered will be anonymised, aggregated, and eventually analysed with others to build a unifying construct that can inform and impact future practice.

If you have further questions or would like to participate in this study, please contact me via email @ chongpohheng@gmail.com OR call/text me at my mobile 9889 8084 to proceed. The secretariat for NHG Domain Specific Review Board (DSRB) that has approved conduct of this study can be reached at 64713266 for any other related query. Your support is very much appreciated. I look forward to hearing from you.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Chong Poh Heng", written in a cursive style.

Dr Chong Poh Heng
Principal Investigator
Visiting consultant, Department of Paediatrics, NUH
Medical Director, HCA Hospice Care
Programme Director, Star PALS
PhD candidate, Department of Health Research, Lancaster University



Appendix 4. Participant information sheet and consent form (professional caregiver)



Participant Information Sheet and Informed Consent Form (professional)

Study Title: UNDERSTANDING DEATH AND DYING IN CHILDREN WITH LIFE SHORTENING ILLNESS: AN EXPLORATORY CASE STUDY

Principal investigator and contact details: Dr Chong Poh Heng; Medical Director; HCA Hospice Care, 12 Jalan Tan Tock Seng, Singapore 308437; Tel 62512561 or HP 98898084. PhD candidate, Department of Health Research, Lancaster University, United Kingdom.

What is the study about?

The purpose of this study is to build a better understanding of the experience of death and dying in a child suffering from a life shortening illness.

Why have I been approached?

You have been approached because we would like to talk to professional caregivers who have previously cared for a child with a life shortening illness near the end of life. If you were not the primary physician, you will most likely have been recommended by him/her as suitable participants in this study. This study will only involve caregivers of patients who had previously received treatment in National University Hospital. A maximum of sixty four individuals (caregivers and medical professionals included) who had been involved in the care of up to eight children would be approached to share their experiences over a period of 2 years.

Do I have to take part?

No. It is completely up to you to decide whether or not you would like to take part. However, if you do decide to participate, research findings may help us appreciate what makes a 'good death' in a child with terminal illness. We can potentially learn to better support other children and families who face similar circumstances in future.

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

If you decide you would like to take part, you will be asked to first sign a consent form and then share your thoughts and perceptions in a single interview (lasting about one to one half hours). We are interested to hear from you, on looking back, what had been positive or negative experiences along the way. Examples of questions that may be asked: "*Can you share some recurring thoughts or feelings?*"; "*What have you come to realize or learn?*" The interview session will be audio-recorded and transcribed for the purpose of research analysis.

Will my data be identifiable?

The information you provide is de-identified in that personal details will be removed from all reports generated. Number codes linking these two sets of documents will be stored in an encrypted file with the principal investigator only. All information collected for this study will be stored securely and only the researchers conducting this study and his research supervisors at Lancaster University will have access to the anonymised or de-identified data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Hard copies of paper transcripts of your responses will be kept in a locked cabinet.

- The files on the computer will be encrypted (that is no-one other than the researcher and his supervisors will be able to access them) and the computer itself password protected. These files will similarly be deleted once the project has been submitted for publication/examined, unless the university requests for them to be archived safely in the university server after study completion.
- At the end of the study, hard copies of any collected data will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The interview transcript will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses (described above).

Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, NHG Domain Specific Review Board and Ministry of Health will be granted direct access to original medical records to check study procedures and data (in the rare event that it is required), without making any of your information public. By signing the Informed Consent Form attached, you are authorizing (i) collection, access to, use and storage of your "Personal Data", and (ii) disclosure to authorised service providers and relevant third parties. "Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected are the property of National University Hospital and Lancaster University. In the event of any publication regarding this study, your identity will remain confidential.

By participating in this research study, you are confirming that you have read, understood and consent to the Personal Data Protection Notification available at <http://www.nuhs.edu.sg/personal-data-protection/nuhsnuh-data-protection-policy.html>

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

What will happen to the results?

The results will be analysed, interpreted and reported in a thesis by the principal investigator, and will be submitted for publication in an academic journal or shared with other professionals at conferences in oral presentations. It is also hoped that an advocacy document will be produced and used to engage policy makers, with a goal to ultimately improve the care of children who are dying.

Are there any risks?

You may find talking about your experiences upsetting. If you experience distress, either you or I can stop the interview. If significant distress persists or follows afterwards you are encouraged to inform the researcher and contact the counsellor provided at the end of this sheet.

Are there any benefits to taking part?

There is no known benefit from participation in this study. However, your participation in this study may add to the medical knowledge, potentially improving medical practice and patient care.

Costs and Payments if participating in the study

There will be no costs nor any reimbursement involved for participating in the study.

Compensation

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

What happens if I decide to leave the study?

Participation is voluntary. You can withdraw from the study at anytime, including during the interview. Information shared will then not be pooled with others for analysis. In the event that you decide to withdraw from the study *after* the interview, information shared will be removed as much as possible, subject to extent that they have been ~~anonymised~~, aggregated with others and incorporated into themes.

Who has reviewed the project?

This study has been reviewed both by the NHG Domain Specific Review Board (the central ethics committee), and the University Research Ethics Committee at Lancaster University for ethics approval. If you want an independent opinion to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, you may contact the NHG Domain Specific Review Board Secretariat at 64713266. You can also find more information about participating in clinical research and the NHG Domain Specific Review Board at www.research.nhg.com.sg. If you have any complaints or feedback about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher (principal investigator): *Dr Chong Poh Heng. Tel: 6251 2561 or 9889 8084; Email: chongpohheng@gmail.com or his research supervisor: Dr Catherine ~~Walshe~~. Tel: 01524 510124; Email: c.walsh@lancaster.ac.uk*

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact: NHG Domain Specific Review Board Secretariat at 64713266.

Resource in the event of distress

Should you feel distressed immediately as a result of taking part, or even sometime in the future, the following professional may be of assistance. ~~Mrs~~ Geraldine Ho, Counsellor from the Star PALS ~~paediatric~~ palliative care service. She may be reached during the workday (office hours) for confidential discussion or support (on the phone or face to face) at mobile 9228 0354. Email: geraldineT@hcahospicecare.org.sg

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

Consent Form

We are asking if you will like to take part in a research project that seeks to better understand the experience of death and dying in a child who had a life shortening condition.

Before you consent to participating in the study we ask that you read the participant information sheet (attached). Please initial each box below if you agree with the statement. If you have any questions before signing the consent form, please speak to the principal investigator, Dr Chong Poh Heng.

Please initial each statement

- | | |
|---|--------------------------|
| 1. I confirm that I have read the participant information sheet and fully understand what is expected of me within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. | <input type="checkbox"/> |
| 4. I understand that audio recordings will be kept until the research project has been examined. | <input type="checkbox"/> |
| 5. I understand that my participation is voluntary and that I can withdraw from the study at anytime I chose. | <input type="checkbox"/> |
| 6. I understand that once the information I have given has been anonymised and incorporated into themes (around two weeks after completion of interview) it may not be possible for things I shared to be removed completely, though every attempt will be made to extract them, up to the point of publication. | <input type="checkbox"/> |
| 7. I understand that the information from my interview will be pooled with other participants' responses and may be published, reused or shared in other future studies. | <input type="checkbox"/> |
| 8. I consent to information and quotations from my interview being used in reports, conferences and training events. | <input type="checkbox"/> |
| 9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with his research supervisor (or any other appropriate person/s), and take immediate steps to optimise safety of relevant parties if indicated. | <input type="checkbox"/> |
| 10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished, including their being used for another study (as secondary data) on a related topic if appropriate. | <input type="checkbox"/> |
| 11. I consent to take part in the above study. | <input type="checkbox"/> |



Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Appendix 5. Standard cover letter (informal caregiver)



[Date]

INVITATION TO PARTICIPATE IN A RESEARCH STUDY "Understanding Death and Dying in Children with Life Shortening Illness: An Exploratory Case Study"

Dear [informal caregiver],

I hope this letter finds you well.

My colleague Dr Chong Poh Heng, a Visiting Consultant in the Department of Paediatrics is doing a research study to evaluate the past experience of caring for a child with an incurable illness. The perspectives of BOTH family caregivers as well as the healthcare team that had attended to the child will be sought.

This letter seeks your support as participant in the study. It will involve a face to face interview (expected to last slightly over an hour) conducted personally by Dr Chong at a time and place of your convenience. Your views will be combined with others to construct a better understanding of the experience of supporting a dying child through a particularly difficult time. It is his hope that findings from this study can improve the care that is provided to other families with children who are terminally ill.

All personal information collected during the interview will be kept confidentially by Dr Chong, the principal investigator. Results from this study that eventually gets disseminated will not identify you or your loved ones. Lastly, while a favourable response is very much anticipated, your participation is strictly voluntary.

If you have other questions about the project or would like to participate in this study, please contact Dr Chong via email @ chongpohheng@gmail.com OR call at the following phone number 98898084 to speak with him directly. The secretariat for the ethics board that had given prior approval to conduct this research may also be contacted at 64713266 to address any other query.

Thank you for taking time to consider this. Do take good care.

Yours sincerely,

Dr [Name]
[Appointment]

Appendix 6. Participant information sheet and consent form (informal caregiver)



Participant Information Sheet & Informed Consent Form (informal caregiver)

*Study Title: UNDERSTANDING DEATH AND DYING IN CHILDREN WITH LIFE SHORTENING ILLNESS:
AN EXPLORATORY CASE STUDY*

Principal investigator and contact details: Dr Chong Poh Heng; Medical Director; HCA Hospice Care, 12 Jalan Tan Tock Seng, Singapore 308437; Tel 62512561 or HP 98898084. PhD candidate, Department of Health Research, Lancaster University, United Kingdom.

What is the study about?

The purpose of this study is to build a better understanding of the experience of death and dying in a child suffering from a life shortening illness.

Why have I been approached?

You have been approached because we would like to speak with family caregivers who had previously cared for a child who died from a life shortening illness. We asked your child's primary physician to invite you to participate in this study. This study will only involve caregivers of patients who had previously received treatment in National University Hospital. A maximum of sixty-four individuals (caregivers and medical professionals included) who had been involved in the care of up to eight children would be approached to share their experiences over a period of 2 years.

Do I have to take part?

No. It is completely up to you to decide whether or not you would like to take part. However, if you do decide to participate, research findings may help to provide better support to other children and families facing a similar situation. For those who are in a position to provide care, they may learn how to better support other children and families who face similar situations in future.

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

If you decide you would like to take part, you will be asked to first sign a consent form and then share your thoughts and perceptions in a single interview (lasting about one to one half hours). We are interested to hear from you, on looking back, what had been positive or negative experiences along the way. Examples of questions that may be asked: "Can you share some recurring thoughts or feelings?"; "What have you come to realize or learn?" The interview session will be audio-recorded and transcribed for the purpose of research analysis.

Will my data be identifiable?

The information you provide is de-identified in that personal details will be removed from all reports generated. Number codes linking these two sets of documents will be stored in an encrypted file with the principal investigator only. All information collected for this study will be stored securely and only the researchers conducting this study and his research supervisors at Lancaster University will have access to the anonymised or de-identified data:

- o Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- o Hard copies of paper transcripts of your responses will be kept in a locked cabinet.
- o The anonymised files on the computer will be encrypted (that is no-one other than the researcher and his supervisors will be able to access them) and the computer itself password protected. These files will similarly be deleted once the project has been submitted for publication/examined, unless the university requests for them to be archived safely in the private university server after study completion.

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

Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, NHG Domain Specific Review Board and Ministry of Health will be granted direct access to original medical records to check study procedures and data (in the rare event that it is required), without making any of your information public. By signing the Informed Consent Form attached, you are authorizing (i) collection, access to, use and storage of your "Personal Data", and (ii) disclosure to authorised service providers and relevant third parties. "Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected are the property of National University Hospital and Lancaster University. In the event of any publication regarding this study, your identity will remain confidential.

By participating in this research study, you are confirming that you have read, understood and consent to the Personal Data Protection Notification available at <http://www.nuhs.edu.sg/personal-data-protection/nuhsnuh-data-protection-policy.html>

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

What will happen to the results?

The results will be summarised and reported in a thesis by the principal investigator, and will be submitted for publication in an academic journal or shared with other professionals at conferences in oral presentations. It is also hoped that an advocacy document will be produced and used to engage policy makers, with a goal to ultimately improve the care of children who are dying.

Are there any risks?

You may find talking about your experiences upsetting. If you experience distress, either you or I can stop the interview. If significant distress persists or follows afterwards you are encouraged to inform the researcher and contact the counsellor provided at the end of this sheet.

Are there any benefits to taking part?

There is no known benefit from participation in this study. However, your participation in this study may add to the medical knowledge, potentially improving medical practice and patient care.

Costs and Payments if participating in the study

There will be no costs nor any reimbursement involved for participating in the study.

Compensation

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

What happens if I decide to leave the study?

Participation is voluntary. You can withdraw from the study at anytime, including during the interview. Information shared will then not be pooled with others for analysis. In the event that you decide to withdraw from the study *after* the interview, information shared will be removed as much as possible, subject to extent that they have been ~~anonymised~~, aggregated with others and incorporated into themes.

Who has reviewed the project?

This study has been reviewed both by the NHG Domain Specific Review Board (the central ethics committee), and the University Research Ethics Committee at Lancaster University for ethics approval. If you want an independent opinion to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, you may contact the NHG Domain Specific Review Board Secretariat at 64713266. You can also find more information about participating in clinical research and the NHG Domain Specific Review Board at www.research.nhg.com.sg If you have any complaints or feedback about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher (principal investigator): *Dr Chong Poh Heng. Tel: 6251 2561 or 9889 8084; Email: chongpohheng@gmail.com or his research supervisor: Dr Catherine ~~Walsh~~. Tel: 01524 510124; Email: c.walsh@lancaster.ac.uk*

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact: NHG Domain Specific Review Board Secretariat at 64713266.

Resource in the event of distress

Should you feel distressed immediately as a result of taking part, or even sometime in the future, the following professional may be of assistance. ~~Mrs~~ Geraldine Ho, Counsellor from the Star PALS ~~paediatric~~ palliative care service. She may be reached during the workday (office hours) for confidential discussion or support (on the phone or face to face) at mobile 9228 0354. Email: geraldineT@hcahospicecare.org.sg

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

Consent Form

We are asking if you will like to take part in a research project that seeks to better understand the experience of death and dying in a child who had a life shortening condition. Before you consent to participating in the study we ask that you read the participant information sheet (attached). Please initial each box below if you agree with the statement. If you have any questions before signing the consent form, please speak to the principal investigator, Dr Chong Poh Heng.

Please initial each statement

1. I confirm that I have read the participant information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I can withdraw from the study at anytime I chose.
6. I understand that once the information I have given has been anonymised and incorporated into themes (around two weeks after completion of interview) it may not be possible for things I shared to be removed completely, though every attempt will be made to extract them, up to the point of publication.
7. I understand that the information from my interview will be pooled with other participants' responses and may be published, reused or shared in other future studies.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with his research supervisor (or any other appropriate person/s), and take immediate steps to optimise safety of relevant parties if indicated.
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished, including their being used for another study (as secondary data) on a related topic if appropriate.
11. I consent to take part in the above study.



Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Appendix 7. Interview guide

OPENING

Put interviewee at ease with general questions eg, family structures or vocational appointments
Gradually establish rapport

OBJECTIVE 1

- A. Explore events leading to the child's death
- B. Talk about the process of dying and its aftermath
 - Can you recall a few significant events or moments, shortly or around the time he/she died?
 - What about the time immediately after?
 - Why were they special / important in your opinion?

OBJECTIVE 2

- A. Discuss the thoughts and feelings during that period
- B. Reflect on any insights gained through the process of caring
 - Can you share with me some recurring thoughts throughout that period?
 - How about feelings that kept coming up at the time?
 - What have you come to realise or learnt from these experiences if any?

OBJECTIVE 3

- A. Invite to share the good and bad experiences
- B. Suggest what a 'good death' might look like in their opinion after this
 - Looking back now, while caring for XXX near the end, what might have been some of the positive experiences? How about the negative ones?
 - When death becomes inevitable, what might you say makes a good death in a child with a life shortening illness?
 - How did you come to this conclusion?

ENDING

- A. Finishing thoughts (if any)
- B. Acknowledgement and appreciation
 - Is there anything else that I did not ask, or you think I should know before we finish?
 - Thank you so much for giving me your time. Please take good care.

Note: The interview may proceed in any order other than that outlined above, and this preliminary guide will likely develop iteratively as interviews are successively completed.

Appendix 8. Data abstraction form for documents

DATA ABSTRACTION FORM

CASE number:

No 1

Type of document eg case notes, care plans, DNR forms: _____

Setting eg ward, ICU or home: _____

Period eg before death, during dying: _____

Documented by eg doctor, nurse, social worker: _____

Significant findings eg medical crisis, unusual circumstances: _____

Investigator comments or questions: _____

No 2

Type of document eg case notes, care plans, DNR forms: _____

Setting eg ward, ICU or home: _____

Period eg before death, during dying: _____

Documented by eg doctor, nurse, social worker: _____

Significant findings eg medical crisis, unusual circumstances: _____

Investigator comments or questions: _____

Date completed: _____

Appendix 9. Coloured matrix and network displays (Case 1 as illustration)



Codes with 5 entries (yellow) – 9 items

Codes	Notes
Being home	
Being prepared	
Burden on family	
Conflicted over decisions	
Control	
Good death	
Needs	
Preservation and letting go	
Suffering	

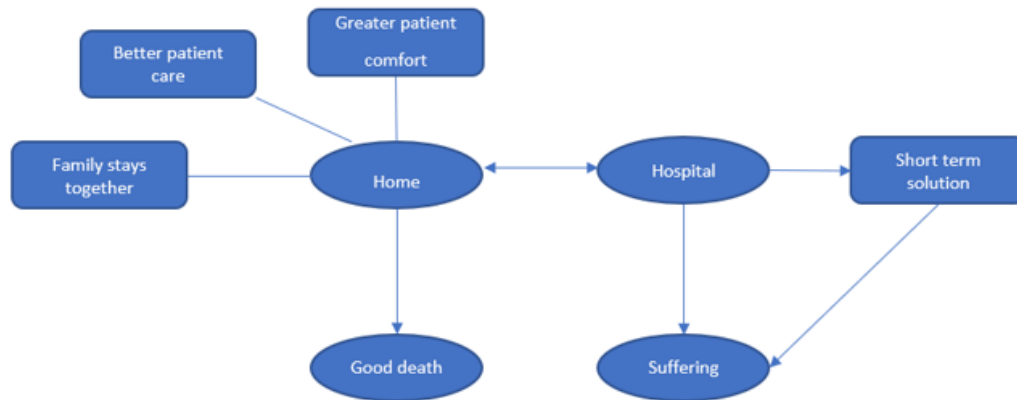
Codes with 4 entries (blue)

Codes	Notes
Culture, beliefs and religion	Religion supported coping and meaning making
Experiences along journey	Uncertainty (prognosis and decisions); bearing witness to suffering; support from palliative care at home; hypervigilance
Palliative care	24/7 support at home; reduce hospitalization; 'assist, assure and affirm'
Referencing peers	Individual circumstances differ, hence mostly unhelpful but offers a perspective for reflection
Surrogate for the child	Reclaiming the right due to them as learned caregivers and parents

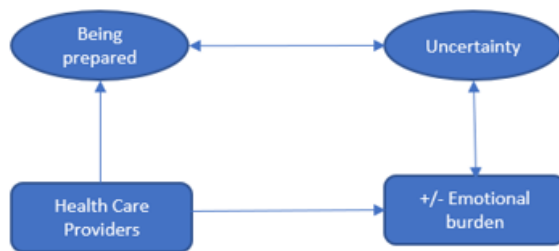
Codes skewed to one participant group ie healthcare professionals vs informal caregivers (red)

Codes	Notes (in this case all mentioned only by HCP)
Acknowledging the child (2/3)	Sharing information and giving them a voice
Holding difficult positions (2/3)	Being their 'anchor' and making judgement calls
In-depth understanding (3/3)	Acquired through time and events, but concerned being judged adversely if articulated
Individuality (2/3)	Not being expressed can lead to suffering but may not apply uniformly
Level playing field (2/3)	When facilitated, caregivers will express their decisions (that they will face and live with)
Living with illness (3/3)	Deterioration obvious to everyone; impact on burden to family and perceived quality of life
Patient's perspectives (2/3)	Suffering or QOL ought to be defined by the patient (or proxy)
Priorities differ between stakeholders (3/3)	Hierarchy shift near EOL between individual stakeholders (children, parents, HCP)
Realisation (3/3)	In terms of disease progression, and also afterwards in terms of meaning making
Serious conversations (3/3)	Preservation or letting go; existential questions that arise during this time
Switch (2/3)	Crossing a particular threshold that triggers rethink of goals

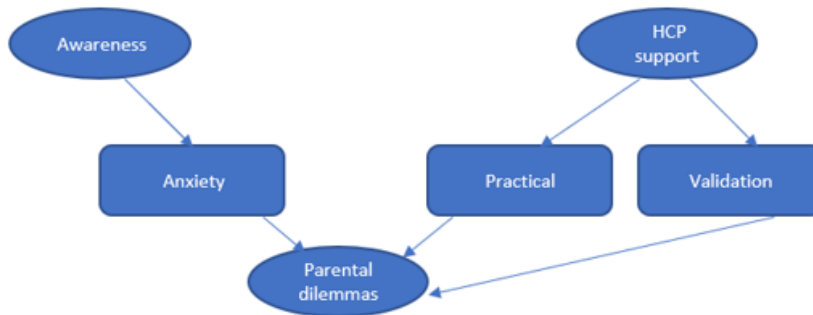
Being home



Being prepared



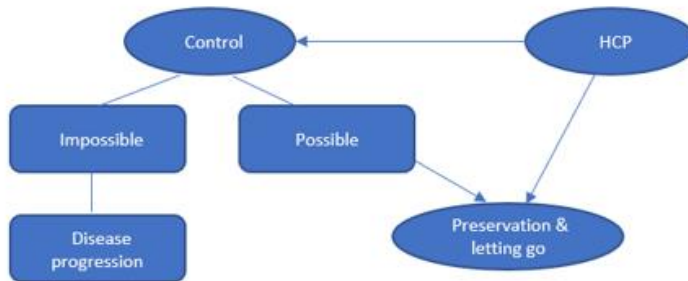
Burden on family



Conflicted over decisions



Control



Good death



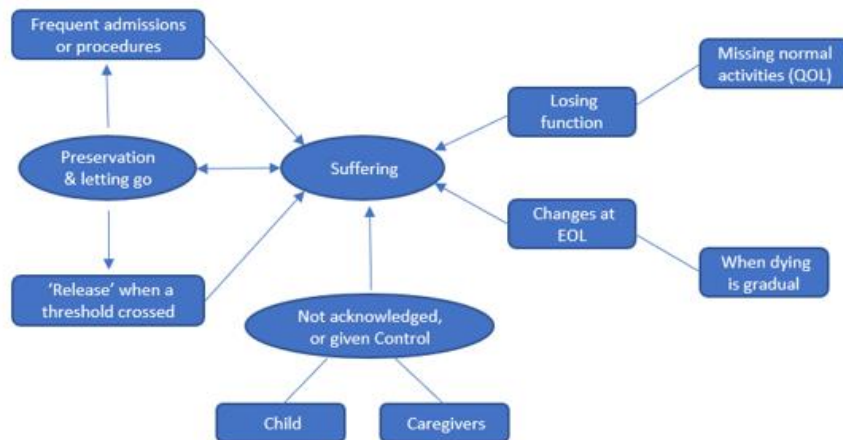
Needs



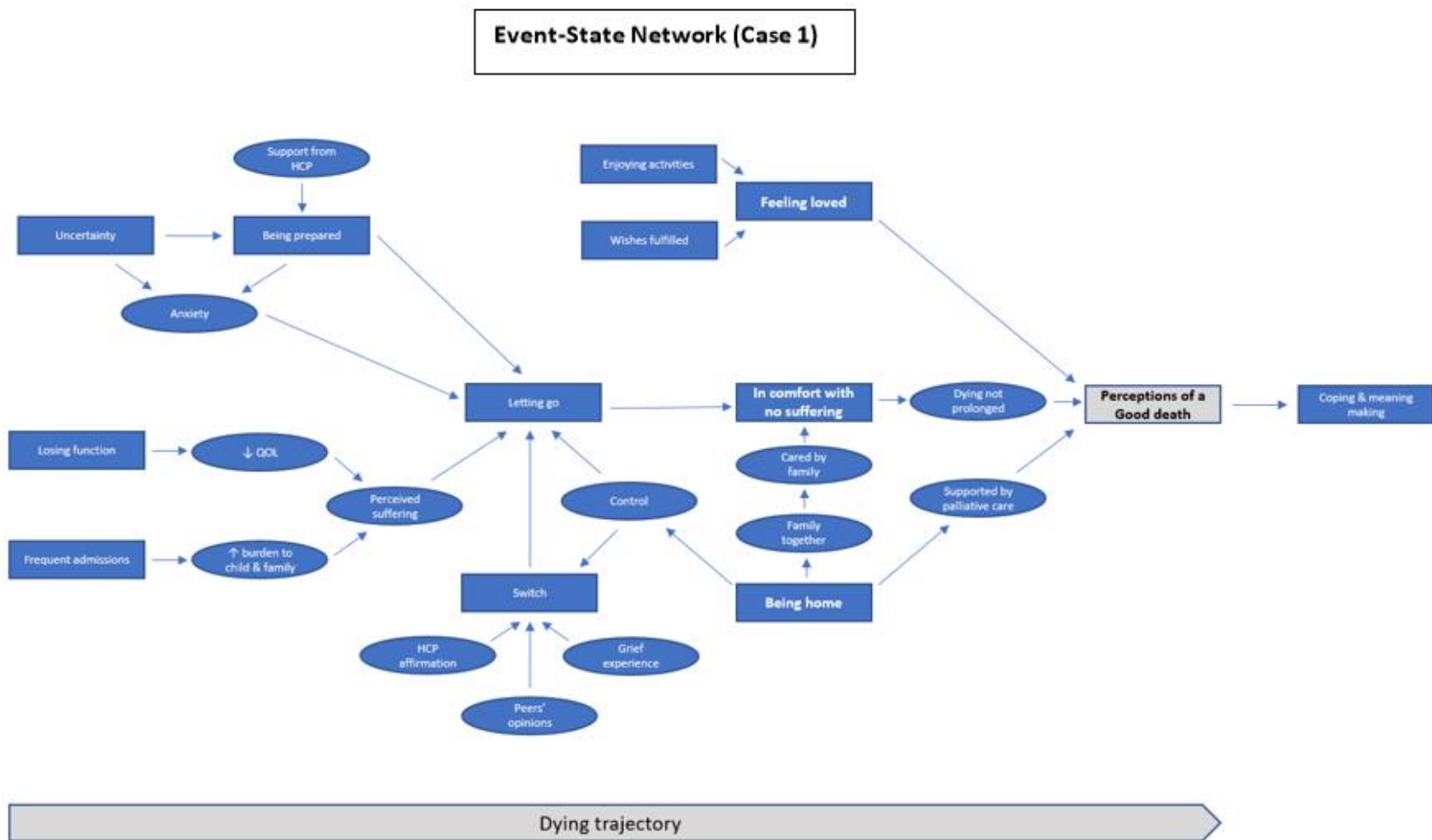
Preservation and letting go



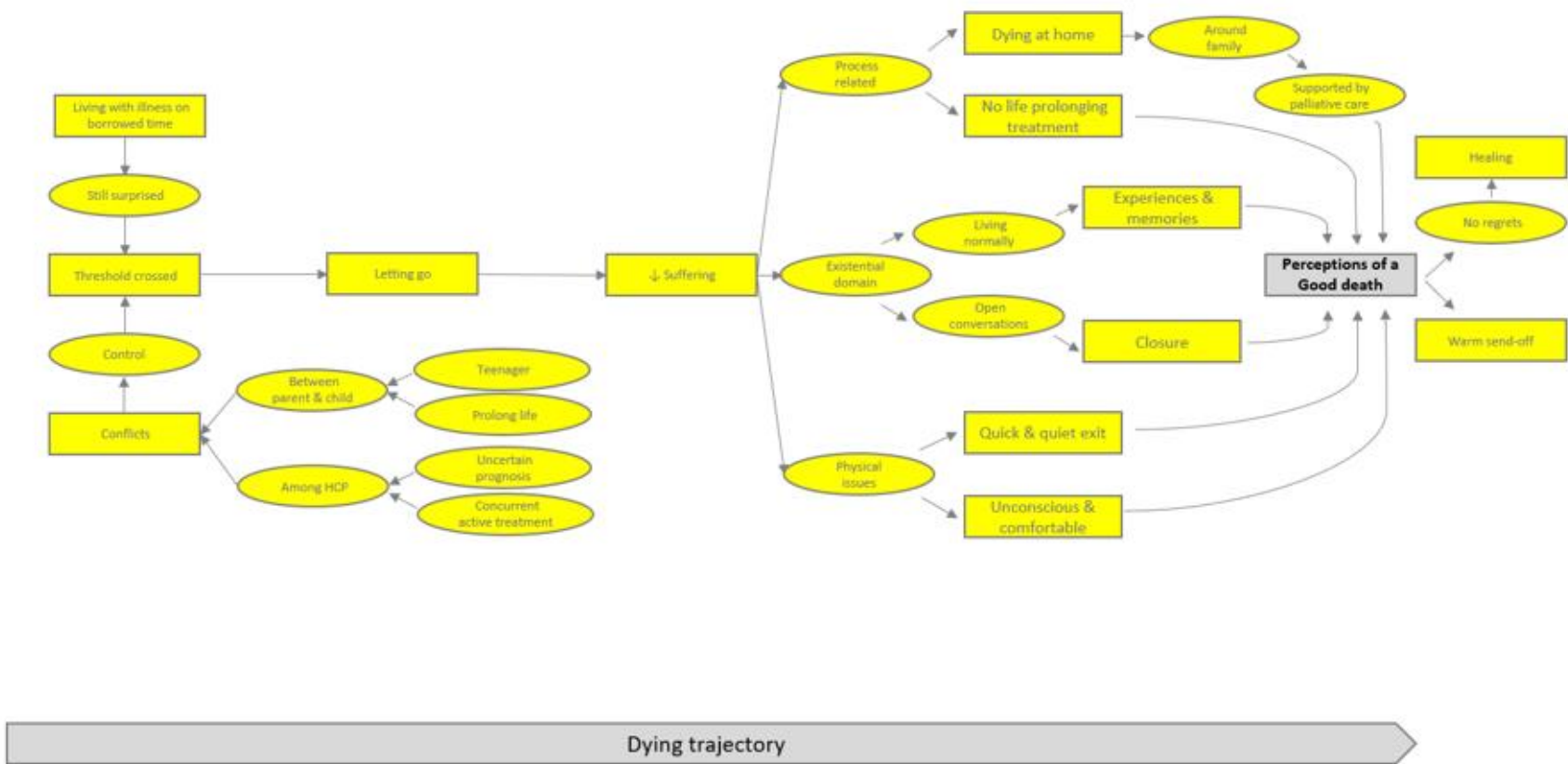
Suffering



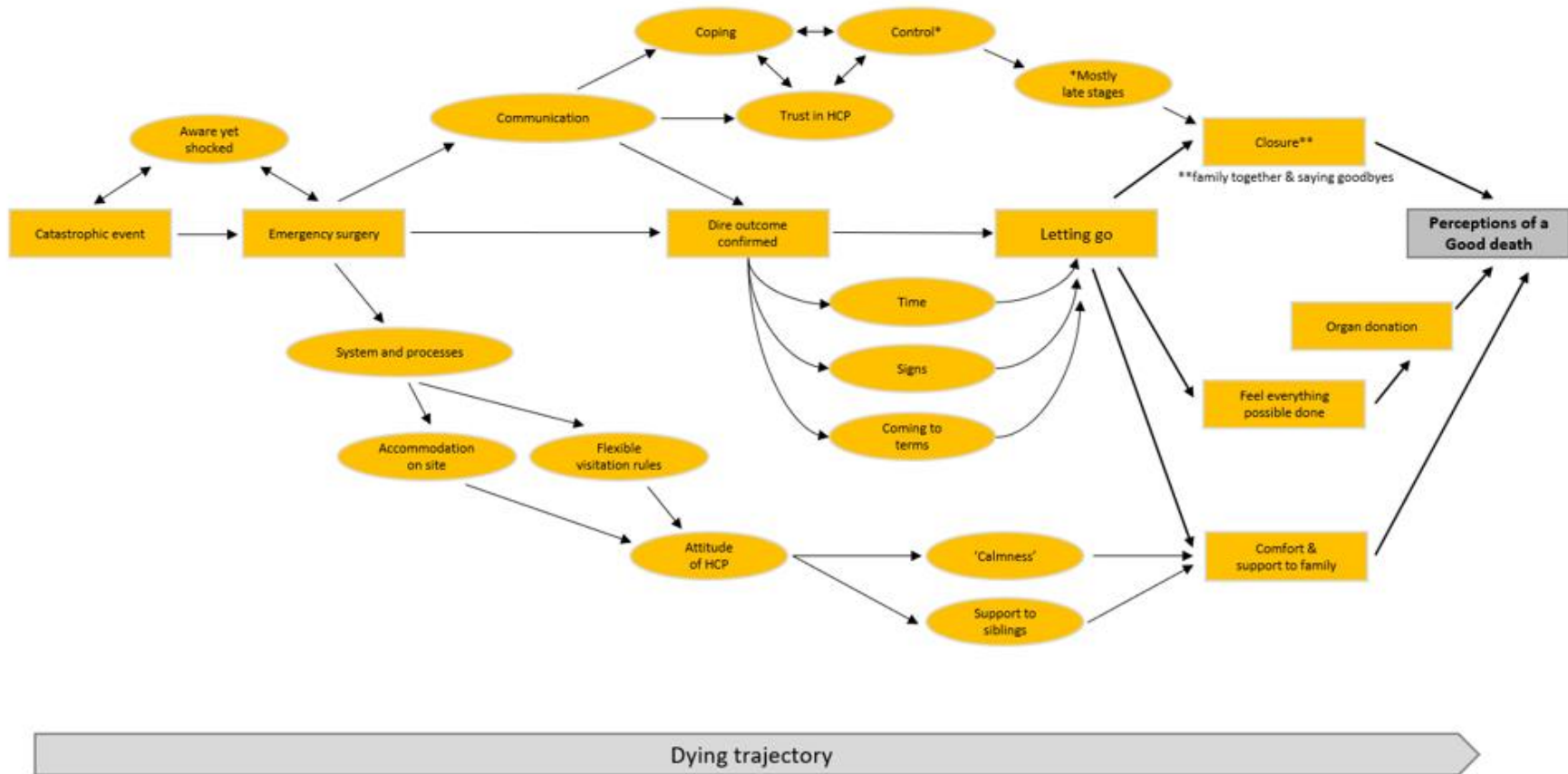
Appendix 10. Within-case analysis: Event-State Networks (all cases)



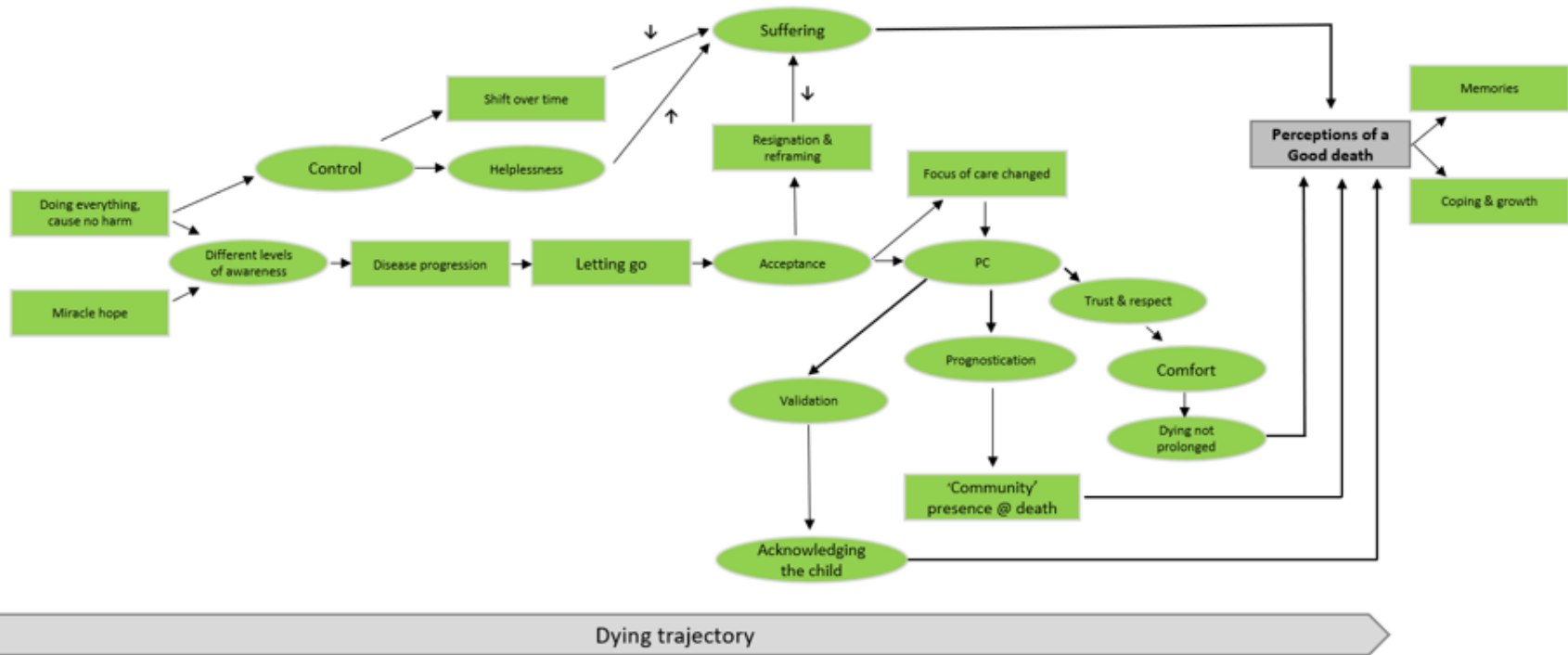
Event-State Network (Case 2)



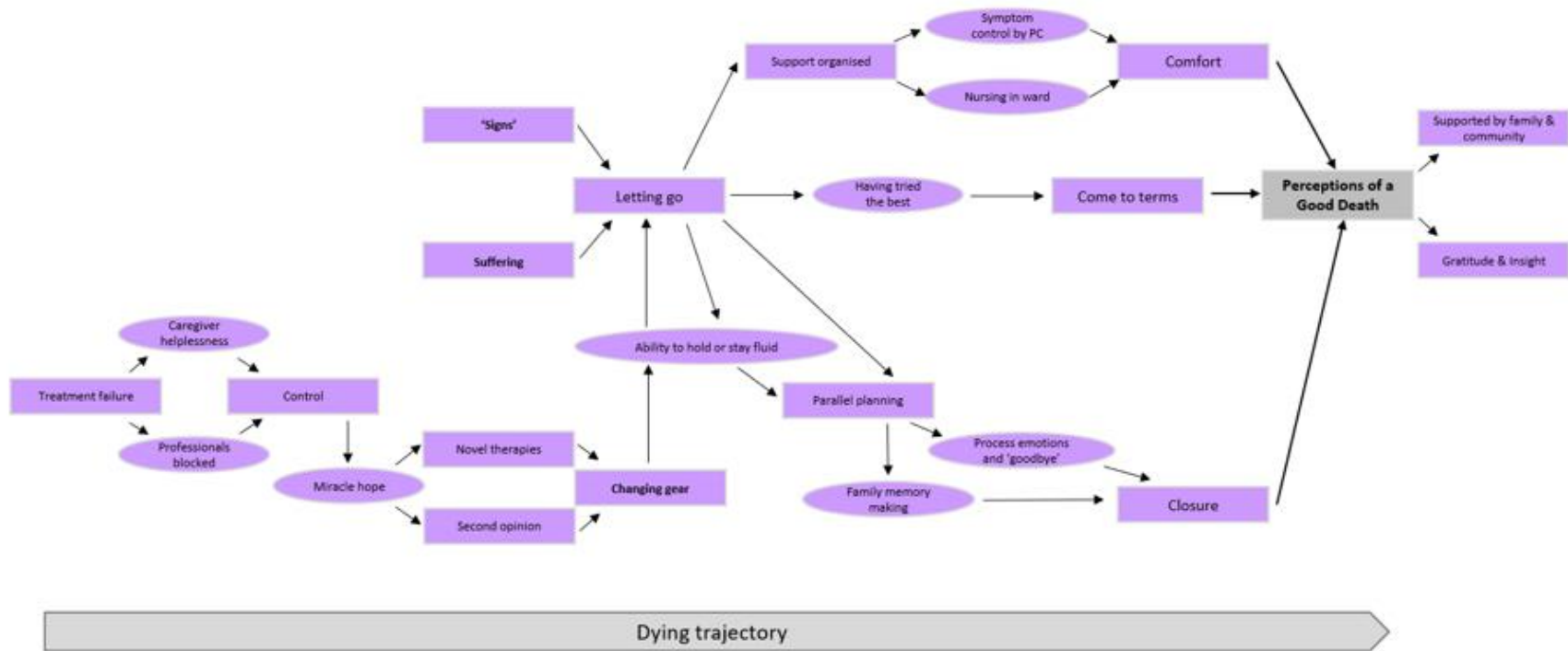
Event-State Network (Case 3)



Event-State Network (Case 4)



Event-State Network (Case 5)



Appendix 11. Excerpt of reflection in the research diary

This interview went much easier than expected. In fact, it was the longest. We met at a McDonald's outlet. Mum was forthcoming and seemed happy to meet me. It was unexpected, as she spoke little previously. Dad always did most of the talking and made all the decisions. She also seemed to be coping poorly with grief, at least at the time. However, she appeared to have made huge leaps in terms of meaning making. I wanted very much to congratulate her but held back immediately. Thank goodness! I had the presence of mind then.

I reminded myself what I told her before we started the session. She was to imagine speaking with someone she did not know, who was then doing an interview with her as part of a study to find out her experience. In the process, she should not make any assumptions, thinking that I already knew facts about the family or that my colleagues had already told me. I may even ask questions that sound a little out of place given the same fact, like inviting her to tell me about her job.

Later in the interview, when asked about the artefact she brought along, she suddenly broke down and sobbed in the middle of the restaurant. She related how the patient had presented her a tracing of her little palm she did for Mother's Day in school. She somehow uttered innocently yet wisely that if they were ever separated, mum could just touch the painting of her daughter's hand and they would be reunited once more... I almost reached out to give her a hug but held myself back. I let her cry for almost five minutes, handing over some tissues that luckily I brought. She eventually composed herself and continued with the rest of the interview smoothly.

Appendix 12. Approval documents for ethics application



3 Fusionopolis Link
#03-08 Nexus@one-north
Singapore 138543
Tel: 6496 6600 Fax: 6486 6870
www.nhg.com.sg
RCB No. 200002150H

NHG DSRB Ref: **2016/00720**

01 September 2016

Dr Chong Poh Heng
Department of Paediatrics
National University Hospital

Dear Dr Chong

NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL

STUDY TITLE: UNDERSTANDING DEATH AND DYING IN CHILDREN WITH LIFE SHORTENING ILLNESS: AN EXPLORATORY CASE STUDY

We are pleased to inform you that the NHG Domain Specific Review Board has approved the application as titled above to be conducted in **National University Hospital**.

The approval period is from **01 September 2016** to **31 August 2017**. The NHG DSRB reference number for this study is **2016/00720**. Please use this reference number for all future correspondence.

The documents reviewed are:

- a) NHG DSRB Application Form: **Version No. 1**
- b) Study Protocol: **Version 2 dated 06 August 2016**
- c) Interview Guide: **Version 2 dated 06 August 2016**
- d) Invitation Letter (Caregivers): **Version 2 dated 06 August 2016**
- e) Invitation Letter (Caregiver - Reminder): **Version 2 dated 06 August 2016**
- f) Invitation Letter (Professional): **Version 2 dated 06 August 2016**
- g) PIS & ICF (Professional): **Version 3 dated 23 August 2016**
- h) PIS & ICF (Caregiver): **Version 3 dated 23 August 2016**

Continued approval is conditional upon your compliance with the following requirements:

1. Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.
2. No deviation from or changes to the study should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.
3. Any deviation from or changes to the study to eliminate an immediate hazard should be promptly

reported to the NHG DSRB within seven calendar days.

4. Please note that for studies requiring Clinical Trial Certificate, apart from the approval from NHG DSRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

5. Please submit the following to the NHG DSRB:

a. All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NHG DSRB. For more than minimal risk studies, all problems involving local deaths must be reported immediately within 24 hours after first knowledge by the Investigator, regardless of the causality and expectedness of the death. For no more than minimal risk studies, only problems involving local deaths that are related or possibly related to the study must be reported immediately within 24 hours after first knowledge by the Investigator. All other problems that fulfil the UPIRTSOs reporting criteria must be reported as soon as possible but not later than seven calendar days after first knowledge by the Investigator.

b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.

c. NHG DSRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond **31 August 2017** until approval is renewed by the NHG DSRB.

d. Study completion – this is to be submitted using the NHG DSRB Study Status Report Form within 4 to 6 weeks of study completion.

Established since May 2006, the NHG Research Quality Management (RQM) Program seeks to promote the responsible conduct of research in a research culture with high ethical standards, identify potential systemic weaknesses and make recommendations for continual improvement. Hence, this research study may be randomly selected for a review by the Research Quality Management (RQM) team. For more information, please visit www.research.nhg.com.sg.

The NHG DSRB operates in accordance to the ICH GCP, Singapore Guideline for Good Clinical Practice and all applicable laws and regulations.

Yours Sincerely

Dr Patricia Yap
Chairperson
NHG Domain Specific Review Board F2

Cc: Institutional Representative, NUH
c/o Research Office, NUH
Departmental Representative of Paediatrics, NUH

(This is an electronic-generated letter. No signature is required.)



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RCB No. 200002150H

NHG DSRB Ref: **2016/00720**

21 November 2016

Dr Chong Poh Heng
Department of Paediatrics
National University Hospital

Dear Dr Chong

NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL OF AMENDMENT

STUDY TITLE: UNDERSTANDING DEATH AND DYING IN CHILDREN WITH LIFE SHORTENING ILLNESS: AN EXPLORATORY CASE STUDY

We are pleased to inform you that the NHG Domain Specific Review Board has reviewed and approved the amendments submitted for the application as titled above.

The documents reviewed are:

- a) NHG DSRB Study Amendment ID: **2016/00720-AMD0001**
- b) NHG DSRB Application Form: **Version No. 2**
- c) Study Protocol: Version 3 dated 03 November 2016
- d) PIS & ICF (Caregiver): Version 4 dated 14 October 2016
- e) PIS & ICF (Professional): Version 4 dated 14 October 2016

The NHG DSRB operates in accordance to the ICH GCP and all applicable laws and regulations.

Yours Sincerely

Dr Patricia Yap
Chairperson
NHG Domain Specific Review Board F2

Cc: Institutional Representative, NUH
c/o Research Office, NUH
Departmental Representative of Paediatrics, NUH

(This is an electronic-generated letter. No signature is required.)

Applicant: Poh Heng Chong
Supervisor: Catherine Walshe
Department: Health Research
FHMREC Reference: FHMREC16012

07 November 2016

Dear Poh Heng

Re: Understanding death and dying in children with life shortening illness: An exploratory case study

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

As principal investigator your responsibilities include:

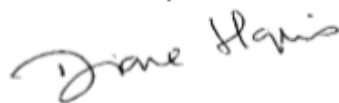
- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research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

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,



Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.