

# Abstract

## Introduction:

This study of carer experiences of children with life-limiting illness in Bloemfontein, South Africa, sought to answer: to what extent does a good death occur in contexts where discussing death is taboo and agency is limited? Theories of good death inform adult palliative care provision in high-resource settings, focused on acceptance, control, and meaning-making. As children's palliative and hospice care (CPHC) develops in resource-limited settings, critical conceptualisations of a good death for children across diverse settings are unknown but important for effective CPHC design.

## Methods:

Semi-structured narrative interviews were conducted with 20 carers of children currently or previously receiving home-based care through Sunflower Children's Hospice (SCH). Three focus group discussions were held with 12 SCH home-based care providers. A mixed thematic and grounded theory analysis was completed to understand the extent to which a good death occurs as suggested in the literature reviewed.

## Findings:

Assessed alongside the high-resource setting literature's tenets of a good death from carer perspectives, the results find: agency is not part of carer experience; death is not discussed before it occurs; families experience high distress from many burdens; basic survival and material support are prioritised; physical pain is not an emphasised experience component; death occurs abruptly; carers are encouraged to publicly accept death quickly though privately grieving long-term.

## Conclusion:

If analysed from the literature's HRS perspectives of CPHC, a "good death" for children does not occur in a context impacted by constrained agency and lack of open discourse of child death. This does not mean alternate forms of discourse and good death do not occur. Critical, grounded conceptualisations of good death and its discourse in individual resource-limited settings should occur before CPHC assessment, design, and provision to effectively relieve expansive suffering in these contexts.

**Key Words:** South Africa; child health; good death; palliative care; hospice; resource-limited settings; discourse; carers

## Introduction

Children's palliative and hospice care (CPHC) is often overlooked in global child health.

Palliative care (PC), multidisciplinary relief of symptomatic and holistic suffering, occurs from diagnosis and alongside curative therapies. Hospice care employs PC when curative treatment ceases, immediately preceding death (Ens 2009, Scrimgeour et al. 2010). CPHC emerged in the 1990s, recognising children differ from adults by illnesses and symptoms; understandings of and relationships to dying and death; and family role (Amery et al. 2009b, Downing 2015a, Virdun et al. 2015). The World Health Organization defines CPHC as "active total care of the child's body, mind and spirit" that "involves giving support to the family" (WHO 2018).

An estimated 2.4 million children under 15 years need CPHC globally yet 65.63% of countries have no known provision (Connor & Sepulveda 2014, Harding et al. 2014, Downing et al. 2015a). 98% of global CPHC need is found in low- and middle-income countries and 49% in Africa, with little evidence regarding the effectiveness of limited existent provision (Connor & Sepulveda 2014, Downing et al. 2015b).

PHC established the 'good death' ideal in response to changing experiences of death influenced by industrialisation, urbanisation, secularisation, privatisation, and medicalization (Cottrell & Duggleby 2016). In 1997 the Institute of Medicine published 'Approaching Death: Improving Care at the End of Life', introducing the 'good death' into common parlance:

'...free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.' (Field and Cassel 1997 p4)

This is now utilised as a 'quality of death' reference and guide for effective care. For adult PHC in high-resource settings (HRS), good death has been commonly characterised as being timely, free from pain, at home with family, and occurring naturally in old age with acceptance and preparation (Van Brussel & Carpentier 2012, Cottrell & Duggleby 2016).

As CPHC develops, research and service provision remain dominated by HRS perspectives and understandings of good death for children in any context is limited.

### Study Context

Sunflower Children's Hospice (SCH) in Bloemfontein, South Africa (RSA) became the first independent children's hospice in sub-Saharan Africa (SSA) in 1998, caring for 400 children through inpatient and home-based care (Scrimgeour et al. 2010, Sunflower Children's Hospice 2018).

Considered an upper-middle income country by World Bank measurements, RSA is highly unequal with 15.9% of the population living on less than US\$1.90 per day and a 0.69 Gini coefficient of income (World Bank 2017). 70% of the population is black yet the majority of wealth lies with the 8% white population. This disparity is echoed in the fragmented health system where 44% of total health expenditure is private but serves just 16% of the population (Mills et al. 2012, Statistics South Africa 2018).

40% of RSA hospice patients are children (Amery et al. 2009b), but in their mixed-methods needs assessment, Connor et al. (2014) estimated 4.8% of 801,155 children needing CPHC nationally receive it. The main illnesses requiring CPHC in RSA are HIV/AIDS, cardiovascular diseases, and congenital anomalies (Connor et al. 2014), with many children facing comorbidities such as poverty, improper sanitation, and hunger (Ens 2009, World Bank 2017 & 2018).

## Research Rationale

CPHC research in SSA is limited. In their scoping review, Rhee et al. (2017) found 49 articles published between 2005 and 2016. Downing et al. (2015b) highlight need for evidence on CPHC provision in resource-limited settings (RLS) incorporating multiple perspectives and needs.

Concepts of good death for children and carers in need of CPHC in RLS and service provision implications are unknown. This study seeks to fill this gap.

## Research Question

The research question evolved with greater contextual familiarization, as reflected upon in the discussion, and asks: To what extent does a good death for children occur in resource-limited settings where discussing death is taboo and agency is limited?

The objectives were to understand:

- carer perceptions of a good death for their children with LLTI;
- how these perceptions impact CPHC;
- how carer good death perceptions correspond with and could be incorporated into RLS CPHC.

## Literature Review

This non-exhaustive review assesses dominant literature found on good death theories, good death for children, and parent experiences of child death to create a partial framework for understanding carer experiences in Bloemfontein.

### Good Death

Meanings and quality characterisations of death and dying are not universally agreed upon. Many conceptualise death as a biomedical, physical event, as well as a sociocultural process that is contextually determined (Van Brussel & Carpentier 2012, Cottrell & Duggleby 2016).

While timing and occurrence of death's physical event are largely outside control, individual and collective discourse shapes a 'good death', providing frameworks for positioning, understanding, and making meaning from death experiences (Van Brussel & Carpentier 2012). Discourse is created by cultural, political, and social values and beliefs, shaped by subtly reinforced social interactions and narratives (Van Brussel & Carpentier 2012, Cottrell & Duggleby 2016). Seale (1998) argues individuals draw from multiple cultural scripts simultaneously, such as public discourse, religious teachings, and media, utilising these vocabularies to define good death, understand how it is achieved, and find its meaning. This makes what constitutes a 'good death' contextually specific and heavily externally influenced.

Writing in Anglophone HRS, Seale (2000) argues industrialisation and epidemiological transition, bringing increased non-communicable disease, medical and diagnostic advances, and improved symptom management, shifted understandings, timing, and experiences of death, where longer dying periods preceding biological death emerged (Long 2004, Cottrell

& Duggleby 2016). With modern medicine, death became private, managed, and hygienic, postponed by biomedical technology as long as possible (Green 2008, Van Brussel & Carpentier 2012, Cottrell & Duggleby 2016).

PHC emerged in resistance to medicalised death, seeking to make dying accepted, open, and individually determined, creating space for meaning and personal growth in the experience (Seale 1998, Long 2004, Green 2008, Van Brussel & Carpentier 2012, Cottrell & Duggleby 2016). Van Brussel and Carpentier (2012) argue PHC bridges biomedicine and autonomous dying, where biomedicine is utilised to control physical experience, allowing the surrounding psychosocial experience to be individualised and one's social death delayed, life continuing as 'normal' until the moment of biological death. This constructs the possibility of good, versus bad, death.

### Good Death for Children

Research on good death for children is limited. Dominant conceptualisations presume longevity of life, closure, and control, concepts not translatable to children. Existing literature is written from an HRS perspective where greater CPHC provision exists and therefore has limited applicability to CPHC in SSA.

This literature does not discuss children or their care independently, but within the context of family and carers. Studies find children want: truth about illness and death; continued relationships; respect for desires and age-appropriate decision-making opportunities; to play; to not be a burden; and assurance that survivors will recover (Hendrickson & McCorkle 2008, Van Brussel & Carpentier 2012, Yang 2013, Ito et al. 2015). Conceptualisations vary significantly between ill and healthy children and level of development. As a result generalised or universal definitions may not be possible or useful (Yang 2013).

## Carer Experiences of Child Good Death

Most literature on family experiences of child death discusses parents or siblings. In RLS with high mortality, including RSA, many children have lost one or both parents and are cared for by grandparents, extended family, and community members. This review assumes experiences of child death are similar for all primary carers, but does so critically.

### Burden

Caring for dying children significantly impacts carers. Price et al. (2011) discuss intense emotional responses to dying children from stressful symptom management, watching children in pain, frequent difficult conversations, and decision-making. Distress has many sources, particularly found when carers are not given adequate information, experience uncertainty about illness or impending death, or see children suffer, leading to long-term mental health problems, prolonged grief, and low quality of life (Hinds et al. 2005, Liben et al. 2008, Vollenbroich et al. 2012, Jones et al. 2014, Van der Geest et al. 2014). Families with dying children make significant life changes, struggling to care for other children and maintain responsibilities, social networks, and often strained marriages (Hinds et al. 2005, Aschenbrenner et al. 2012, Jones et al. 2014, Melin-Johansson et al. 2014).

### Meaning-Making

In a qualitative study of Dutch parents of children without curative cancer options, Kars et al. (2011) find parenting at end of life involves existential meaning-making. Carers want their role and expertise acknowledged and respected and to continue caring for children fully (Price et al. 2011, Vollenbroich et al. 2012, Jones et al. 2014, Melin-Johansson et al. 2014.) Parents need to know they are doing everything possible for their child, and to be empowered to separate their needs from their child's to create meaning when 'letting go'

(Kars et al. 2010). If able to make meaning out of the experience, carers are reportedly better able to grieve and cope long-term (Kars et al. 2011, Björk et al. 2016).

## Needs

Carers articulate particular needs for coping and positive recovery. The literature finds in inpatient and home-based care these include: control, choice, communication, information, and social support.

Parents want honest, open communication about their child's condition and inclusion in decision-making (Aschenbrenner et al. 2012, Vollenbroich et al. 2012, Jones et al. 2014, Melin-Johansson et al. 2014, Van der Geest et al. 2014). Hinds et al. (2005) find poor doctor-carer communication can cause short- and long-term harm, arguing that how parents learn their child will die is crucial to coping ability.

The literature points to symbiotic relationships between carers and children where both are focused on the other's wellbeing. Parents face burdens informing and supporting children through illness and death, emphasising need for guidance and support (Hinds et al. 2005, Melin-Johansson et al. 2014). Popoviciu et al. (2014) found parents afraid to talk to children, wanting to protect against distress though aware this was potentially not best for their child.

Parents want positive relationships with doctors during illness and after death, emphasising empathy, availability, continuity, and individualised, holistic, and respectful care for their children and families (Vollenbroich et al. 2012, Jones et al. 2014, Melin-Johansson et al. 2014, Van der Geest et al. 2014). Studies find lost relationship with doctors after death leaves families feeling abandoned, increasing grief (Hinds et al. 2005, Jones et al. 2014).



## Critiques

While data from HRS supports PHC's 'good death' ideal, theoretical critiques question its universal applicability. Some criticise PHC's hegemonic discourse and good death ideal for constructing a singular way of dying well, scripting and denaturalising death to fit one trope while positing other death as failed (Cottrell & Duggleby 2016, Van Brussel & Carpentier 2012). Cottrell & Duggleby (2016) believe PHC's discourse, or "regimes of truth" according to Foucault (1977), prescribes a social script for a good death that determine attitudes and behaviours, encouraging social pressure around ways of dying by shaming and blaming patients and carers who deny or resist. Emphasis on ability to control one's death is particularly problematic; not only is agency limited for some, but the trajectory and physical components of death cannot ever be fully predicted or planned, potentially positioning people to never achieve a good death (Green 2008, Cottrell & Duggleby 2016). Long (2004) argues how one experiences, understands, and acts around death is not determined by cultural scripts of dying, but the extent to which individuals are able to access and utilise those scripts within experienced constraints.

## Methodology

This study took place in Bloemfontein, RSA through Sunflower Children's Hospice (SCH).

### Data Collection

Fifteen interviews with twenty carers and three focus group discussions (FGDs) with twelve SCH CPHC workers (CPHCW) providing home-based care to children with LLTI were completed in April-May 2018.

A qualitative, narrative interviewing methodology was used, which emphasises discourse, story, and subjectivity to describe social phenomena from individual and collective perspectives (Jovchelovitch & Bauer 2000, Muylaert et al. 2014). Interviews began unstructured, asking for carers' story having a child with LLTI, allowing participant-guided conversation on sensitive topics that was unbiased by external language and conceptualisations (Van Brussel & Carpentier 2012). Where full translation interrupted unstructured narratives, interviews became semi-structured, prompting further response using open-ended topic guides adapted to the information and language offered by individual participants. Semi-structured FGDs were completed to triangulate interview data and gain additional perspectives on culture around death.

Notes recorded throughout data collection assisted determination of important themes but were not included in results.

### Recruitment

Participants were identified and recruited through convenience sampling while on home visits with SCH CPHCW and when working in SCH's inpatient unit.

Participants received information sheets and consent forms assuring anonymity, confidentiality, and right to withdraw. Where English was limited, CPHCW translated and verbal consent was given before obtaining written signatures.

## Participants

Interview participants were individuals primarily responsible for a child currently or previously receiving home-based CPHC. As the population served by SCH, all participants identified as members of RSA's 'black' racial category and lived in Mangaung and Botshabelo townships, historically, politically, and culturally understood as locations belonging to the 'black' racial category (Whitehead 2010). The sample was stratified to include carers of currently living and deceased children, and across different relationships to children found in the community served, including parents, grandparents, extended relatives, and foster carers.

FGD participants were all twelve SCH CPHCW, who were all 'black' women providing home-based care, and living, in Mangaung and Botshabelo townships.

## Translation

With consent, CPHCWs were present for translation from Sesotho to English during interviews. As they also provided the child's care, CPHCW participated in conversation. While introducing a potential bias, their presence made carers comfortable and prompted more open testimony, especially with regard to sensitive topics. Given this advantage the approach was embraced.

## Analysis

Interviews and FGDs were digitally recorded, transcribed verbatim from the English audio recording, coded manually to maintain sensitivity to nuance using Microsoft Excel software, and analysed using a mixed inductive and deductive approach. Inductive codes were formed from the literature reviewed, and deductive codes from extensive data familiarisation. The data was then synthesised and understood through mixed framework and grounded theory methods (Glaser & Strauss 1967, Gale et al. 2013), utilising *a priori* ideas of good death and allowing stories to expand and challenge conceptualisations.

The structure of the presented results is framed around reviewed literature and carer experiences, organised into themes based on the data collected. This thematic analysis is then critically analysed in the discussion. This structure illuminates the interplay between *a priori* ideas from HRS conceptualisations and experience grounded in the very different realities of the study context.

## Reflexivity

My positionality as a white, Anglophone woman could not be divorced from post-Apartheid RSA when interacting with carers, CPHCW, and children. While this could have created potential bias or impacted full understanding, working in SCH inpatient unit at the time of the study provided opportunity to build rapport with FGD and interview participants, encouraging more nuanced and fully expressed thoughts and feelings. Flexible narrative interview methods assumed and engaged my presence within data collection and analysis, seeing this as important for understanding interactions between hegemonic and local death discourse, as elaborated upon in the discussion (Muylaert et al. 2014).

## Ethics

The University College London Research Ethics Committee approved this study (12557/001) in February 2018. Sunflower Children's Hospice gave ethical consent with written documentation.

The research complies with the UK Data Protection Act 1998.

## Results

The results are presented as an interaction between the literature reviewed and the data, an approach taken by other qualitative studies (Broom & Cavenagh 2010, Zuccherro 2011). This approach illustrates accord and discord between HRS perspectives of good death and the study context in three themes: meaning-making; impact of instability; and tenets of good death for carers.

### 1.0 Meaning-Making

The literature suggests carers find existential meaning in a good death by fulfilling roles, decision-making, and contributing to peaceful dying (Kars et al. 2011, Price et al. 2011, Björk et al. 2016). The hegemonic discourse on good death assumes open discussion of death, control, and agency (Green 2008, Cottrell & Duggleby 2016).

#### 1.1 Discourse

In the literature meaning-making through agency over dying is assumed to occur with open acknowledgment and preparation for death (Kars et al. 2011, Van Brussel & Carpentier 2012). Yet in the study context death discourse was characterised by lack of speaking, with articulation of death and dying actively avoided even when biological dying is evident.

Only bereaved carers discussed death; of four, two discussed advance awareness of their child's death. None discussed open communication or preparation for death. No carers of living children discussed possible death.

*"...he was heartbroken knowing that the child would one day die. He says that his wish was that she could recover and maybe become okay and live for some time. And sometimes when she was healthy, he was also happy that at least she has recovered." (bereaved grandfather, INT6)*

CPHCW felt discussing death was not their role and would hurt carers, stating that they are only “harsh”, telling carers their children will die, when carers are noncompliant or refuse hospitalisation (FGD1).

## 1.2 Role Fulfilment

The literature discusses positive existential understandings of parent role and suffering over inability to fulfil this (Price et al. 2011, Jones et al. 2014, Melin-Johansson et al. 2014).

This is complicated in the study context where children often do not stay with biological parents and carers have varied relationships with children, potentially understanding roles differently. Of fifteen families, nine cared for children not their own.

No carers discussed agency as part of their experience or as something desired. However, carers desired control and resisted this being taken away.

*"...we're telling her this thing is a serious thing, being like this, and see she must take this child to treatment. She was fighting me. 'This child is not sick!' 'But are you seeing the child? But she's sick.' 'I can tell you she is not sick.' 'Give me the car let me take him to the clinic.' 'Ahh this child is not your responsibility.' She was just fighting me." (aunt, INT10)*

Carers struggled fulfilling roles at basic levels of survival and showed their distress and fear of being judged, but also their pride in the care quality they could provide under duress.

*"...she sometimes feels hurt because she wanted to see them having a bright future and then when the daughter doesn't have anything that maybe she's asking for, and...she can't afford, she become so hurt. Very hurt. To say that 'I can't afford to give my child one, two, three, four, five.' That is one of her fears. Not having to achieve what she wants to achieve for her children, or what she want to give for her children." (mother, INT15)*

High disease burden appeared to exacerbate distress. Carers often experienced constrained agency over death, seemingly tied to lost parental role as well as lost legacy.

*"He's the only survivor from her. That he's the only reminder that she was here on earth, that she did give birth on earth. So it's her only grandson. The only one left... [child] is the only beneficiary to her." (grandmother, INT9)*

One carer not experiencing poverty who had worked in CPHC described a lack of depression when her first child died, happy she gave him quality of life. CPHCWs found closure in their own contributions.

*"A good death is when me as a carer, I carry... that person nicely until his last year...So that he can sleep nicely. And me who are at the end are set free because I've done my work." (CPHCW, FGD2)*

These suggest possible different experiences based on financial stability and familiarity with CPHC. Some gender differences among carers appeared in interviews and FGDs, potentially influencing role fulfilment and meaning-making. These require further research.

## 2.0 Impact of Instability

In accordance with the literature, families were highly distressed during child illness and death (Price et al. 2011). This was complex and not solely caused by the ill child but many burdens facing families simultaneously.

### 2.1 Poverty

Financial instability impacted daily life and child illness. Of fifteen families, two were meeting basic needs. Eleven fully depended on limited government support.

*"So I decide to leave the job and say there is no finance that I can make because he's always at the hospital. He must go in, he must come home, tomorrow he is ill again, he must come home and go.... So I must stay. That's all." (bereaved foster mother, INT1)*

CPHCW suggested that helping families access public assistance and meet basic needs was critical, with basic survival as first priority. CPHCW recognised this, building care not solely



focused on illness but helping families cope with many stresses while facing the additional burden of child illness.

## 2.2 Many Burdens

Of fifteen families, seven had more than one child with LLTI and seven had ill carers as well. Nine discussed additional deaths, five of children. For example, one grandmother being treated for cervical cancer cared for twelve grandchildren after losing eleven of fourteen children (INT7).

Carers feared loss of many forms. Some feared biological parents reclaiming children, others unable to cope feared children being taken away.

*"...she feared that they are going to take her child. The only person that she has in life. Because all her children has died. All her grandchildren has died."(grandmother, INT9)*

Some carers adopt negative coping mechanisms, with alcoholism, negligence, and abandonment frequently described, resulting in denied or delayed treatment or failure to provide basic care, like bathing and feeding, for the dying child.

While carer motives and degree of active choice to neglect and abandon are unknown, they did describe feeling overwhelmed seeing their child dying. This both relates to and reinforces instability.

*"...[the mother] was really heartbroken. You could see that the mother really loved her children...it's difficult having to have so many children that are sick in your house...it was really heavy for her to cope. To attend to this actual problem. It was difficult also for her to, maybe, be able to accept at the moment that even when she's still struggling to adapt to the situation then people comes and takes her children away... She had so many problems that really it was too much...that was really too much for her." (CPHCW, INT10)*

### 3.0 Tenets of Good Death for Carers

The literature highlights key factors helping carers reduce distress, contribute positively in roles, and let go to find meaning in a good death, including: acceptance, communication, normalcy, emotional attachment, and absence of suffering.

#### 3.1 Acceptance

The literature suggests carers may feel guilt over child illness, good death occurring with full acceptance that removes fear (Long 2004, Liben et al. 2008, Van Brussel & Carpentier 2012).

Open acceptance of dying was not evident in the study context.

Some carers displayed obvious denial. Some accepted illness but struggled telling children, with eight of fifteen yet to tell. Many feared causing pain or distress and being judged, bullied, or discriminated against by the community.

Fourteen of fifteen families had children born with HIV resulting from mother-to-child transmission. Carers expressed feeling blame and regret over this, and CPHCW believed this contributes to disclosure resistance.

*"...others they are ashamed...they are the ones that makes the child to be ill." (CPHCW, FGD1)*

Ensuring happiness and removing fear by not discussing death was a rare instance

CPHCW characterised good death in terms of dying period.

*"...tell the child that everything is going to be okay. You must always encourage the child that she's not going to die or he's not going to die. He must not be afraid of anything. He will be fine." (CPHCW, FGD1)*

### 3.2 Communication

The literature suggests good death occurs with open, honest communication and information from doctors, finding carers struggle communicating directly with children about illness and associated psychosocial difficulty and that carers are distressed when not fully aware or experiencing uncertainty (Hinds et al. 2005, Vollenbroich et al. 2012, Jones et al. 2014, Melin-Johansson et al. 2014, Van der Geest et al. 2014).

Carers in the study context also expressed difficulty talking with children directly, appreciating ability to seek CPHCW assistance.

*"I always go to [CPHCW]...I say 'there's a problem, one, two, three...' Then [CPHCW] knows that she has to sort it out with [child]. And then when [child] comes back she's happy, normal." (bereaved aunt, INT13)*

No participants expressed desire for disease or death information. Open communication with doctors did not appear to occur and was not expressed as a need.

### 3.3 Normalcy

The literature emphasises continued normalcy (Hendrickson & McCorkle 2008, Kars et al. 2010 & 2011, Ito et al. 2015).

Discussing facilitating normalcy, CPHCW focused on meeting basic needs and child protection. Carers focused on continued education for more stable financial futures.

Carers desired seeing children grow without illness, describing normalcy as tied to cure. Focus on cure is reinforced by doctors and CPHCW, who see children dying but do not disclose this.

*"The family don't talk about the child who is dying. The only thing, when you visit them, you must comfort them. But not telling them that the child is going to die. You*

*only comfort them, make them feel like the child is going to recover. Yet you see that this child is not going to recover." (CPHCW, FGD3)*

### 3.4 Emotional Attachment

The literature emphasises maintaining relationships, social networks, and continuity for carers to maintain control and navigate uncertainties (Hinds et al. 2005, Vollenbroich et al. 2012, Yang 2013, Melin-Johansson et al. 2014, Van der Geest et al. 2014). The data suggests agreement, carers in the study context appreciating family and CPHC presence.

While carers wanted loving relationships and CPHCW found this part of a good death, this was not commonly discussed in relation to the child's illness or death. When discussed retrospectively, this did not appear to be an intention or goal, but instead an aspect that provided comfort after death. CPHCWs discussed the impossibility of family presence in hospital or inpatient hospice due to abandonment and finances.

While acknowledging stress, when discussing challenges and CPHC's assistance, most carers focused on basic needs, emphasising material over emotional support.

*"Right now, how am I feeling? I'm painful, always painful. Because I struggle a lot about these little children. Because my sister, she doesn't work. I got a disability grant, it's too little. I pay policies, I pay for school fees for the children. And I buy the food. Now I struggle to buy my children's clothes for the winter. They have nothing." (bereaved mother, INT12)*

Carers did not discuss continuity in terms of transitioning from curative to hospice care or maintaining relationships after death, but in terms of depending on CPHC assistance for problems beyond illness, including insufficient resources, community violence, and housing.

### 3.4a Religion

Christian religion played a large role in carer experience. Most participants discussed belief and prayer as sources of comfort and strength. Some discussed prayer as means to a cure, employment, or basic needs.

Carers saw God in control, understanding illness, survival, challenges, and role fulfilment through God's will, mercy, and plan.

*"...there was a doctor...who always say 'oh! We are doing the great job.' I say to the doctor, 'it's not me, it's not us, it's God, who give us that power to look after [child].'" (bereaved aunt, INT1)*

Time and manner of death is out of individual control and determined by God.

*"...at first he didn't accept. He was still in denial. But after a long run he accepted that if it's God's will, let his will be done. If anything is happening to my child, that will happen when God wants anything to happen to him." (father, INT8)*

This suggests religion may impact carer ability to navigate, cope, and find meaning in child death, requiring further research.

### 3.5 Absence of Suffering

The literature suggests good death occurs at home and without pain, a child's peace increasing carer ability to let go of children while dying and find acceptance after death (Hinds et al. 2005, Van Brussel & Carpentier 2012, Van der Geest et al. 2014, Björk et al. 2016, Cottrell & Duggleby 2016).

### **3.5a Location**

No carers discussed death location as a choice. This may be resistance to discussing any aspect of dying or death in advance, though bereaved carers also did not emphasise location in any way when telling stories.

When carers are unable to acknowledge or cope, CPHC encouraged hospitalisation to avoid neglect. CPHCW saw good death occurring in inpatient hospice where they receive total care and are not alone.

### **3.5b Unexpected Death**

Hastened and unexpected deaths often occurred with limited healthcare access, delayed treatment, and insufficient finances. Doctors discharged children immediately before death, telling families the child will recover at home.

*"It is not easy at the hospital to tell the family that they discharge this person to go and die at home. It's we who understand that this person is nearly to die. That is why they take him home." (CPHCW, FGD3)*

Doctors' attitudes and actions are outside the bounds of this study, but warrant further research.

Carers believed doctors gave up despite hope for recovery and had no time to accept, prepare, or make decisions around dying.

*"And then she just passed away. She didn't...she was not sick...But at that time, really, I was shocked. When they say she had passed away." (bereaved aunt, INT13)*

CPHCW believed carers are often aware their child will die, but denial and distress prohibit publicly acknowledging or acting upon this.

### 3.5c Pain

No carers described distress associated with extent of pain or as a significant experience element. One CPHCW discussed peace in terms of death creating freedom from suffering while living, not lack of pain while dying.

*"...sometimes you feel like 'at least you are pain free.'...So you become a little bit relieved because now this poor child was in pain." (CPHCW, INT1)*

### 3.5d Burial

Some bereaved carers and CPHCW discussed burial providing closure, signifying good death, and providing meaning. This may suggest where families have little agency over illness or death, burial facilitates control and meaningful participation, warranting further research.

## 3.6 Letting Go

The literature suggests carer grief and ability to conceptualise good death impacts long-term wellbeing (Aschenbrenner et al. 2012, Jones et al. 2014). Bereaved carers expressed distress at time of death, focusing on children no longer living as others, watching them die, and losing close relationship.

*"I was loving my boy very much... I was loving him, until now. I still love him. He was my friend. I didn't have a friend...It was painful. I don't forget that pain even now. Because I was alone. I didn't have anyone else." (bereaved mother, INT12)*

Carers and CPHCW discussed needing to publicly accept death and move on quickly as *"the only thing they can do"*, despite long-term grief.

*"...some of them, they're still crying now. Their child died...they are not accepting very easy. It's only by mouth saying they accept, but deep down in the heart they don't accept. It's not easy." (CPHCW, FGD3)*

## Discussion

This study sought to understand the extent to which a good death for children occurs in RLS where discussing death is taboo and agency limited. If analysed within hegemonic good death discourse focused on control, relief of pain and suffering, and carer meaning-making through agency, the results find accord with and add to theoretical critiques, complicating the universal occurrence and meaning-making process of *the* good death as defined in HRS, but suggest *a* good death may be possible in other, unknown ways (Field & Cassel 1997, Green 2008, Van Brussel & Carpentier 2012, Cottrell & Duggleby 2016).

The literature suggests HRS CPHC models would effectively achieve good death in RLS with modernisation and disease burdens matching industrialised contexts, cultural and religious beliefs remaining the most significant barriers (Seale 2000, Walter 2003, Amery 2009a, Downing et al. 2015a, Hannon et al. 2016). Nuances in the results complicate this: differences and disparities cannot be explained in dichotomies such as secularisation, individualism, or blanket labels of 'culture'. With globalisation, countries experience multiple overlapping and contradicting processes and transitions simultaneously, dying shaped not solely by individual choice and acceptance but interacting historical, economic, political, and sociocultural factors (Amery 2009a). The results reveal a complex context differing from PHC's good death origin in both macro processes, like poverty, as well as micro systems, like cultural death taboos. Critical analysis of complex interactions of power, agency, and culture that recognises development differs from contexts whose values and structures defined the 'good death', could be helpful for understanding what and how differences in experience, need, and effectiveness occur, and their impact on theory and practice.



## No Dying

The results reveal accepted and controlled dying periods preceding death do not occur as hegemonic good death ideals are premised upon, due to interwoven limited agency, lack of open communication about death, and discharge practices (Seale 2000, Green 2008). From HRS CPHC perspectives, the results would suggest carers experience no letting go period, biological death is not prepared for, and social death occurs abruptly, hindering avenues for carer agency, role fulfilment, and contribution to peaceful death. While delayed social death meets CPHC goals, here this occurs without open acceptance or physical pain alleviation, key elements of a good death (Field & Cassel 1997, Van Brussel & Carpentier 2012).

## Expansive Suffering

The results suggest extensive suffering for whole families may enhance or supersede individual physical symptoms, revealing pain may be understood and prioritised differently where families in impoverished, uncontrollable circumstances struggle to meet basic needs, care for multiple ill members, and grieve many deaths. Carers not discussing physical pain could suggest it is expressed, witnessed, and interpreted differently or that a form of 'learned helplessness' occurs, where suffering is assumed uncontrollable and discussion futile (Rabow et al. 1983).

Suffering may not only be tied to epidemiological disease or cultural pain understandings, but social suffering and structural violence. Kleinman and Lock (1997) conceptualise social suffering as institutional, economic, and political power's effects on individuals and their available responses. Suffering is thus not universal but simultaneously individual and communal, subjective and expansive, affected by specific events and global processes. Farmer (2003, 2004) understands structural violence as social, political, and economic

structures constraining individual and collective agency. Here this is seen through processes such as colonialism, apartheid, and corruption that create instable contexts in the black socio-political grouping, including dependence on insufficient government support, inadequate infrastructure, and limited healthcare access (Whitehead 2010).

These theories should be applied critically. The results do not necessarily show carers resigned, hopeless, or passive. Both social suffering and structural violence emphasise bilateral relationships, with individuals constrained and constraining. Carers' available responses to ill or dying children are affected by uncontrollable instability; within that context, individuals create and recreate silent discourse around death, further constraining agency over the experience (Long 2004).

### Assessing Discourse

Vollenbroich et al.'s (2012, 2016) clinical studies in HRS argue carer perceptions of symptoms and distress be assessed and incorporated into effective CPHC. Carers' focus on daily survival suggests such assessments could be helpful here, if inclusive of expansive suffering. Farmer's Partners in Health in Haiti and Rwanda illustrates this potential, adapting to locally defined contexts to improve health by meeting immediate clinical need alongside structural barriers like unemployment and hunger (Drobac et al. 2013).

Some adult PC studies utilise qualitative assessments for program design, such as Downing et al.'s (2014) street surveys on Kenyan care preferences and Graham et al.'s (2013) assessment of Xhosa traditional healers' determinants of good death, indicating these could also be successful facilitating good death for children. These utilise HRS discourse and tenets to form questions, finding individuals presented with dominant good death terminology will respond and give preferences. It is unknown if such assessments yield full understanding of

wishes, assets, and needs, or produce biased understanding; as theoretical critiques suggest, negative implications for promoting universalised good death criteria are unknown, but possible (Green 2008, Cottrell & Duggleby 2016).

The results suggest another component necessary for RLS CPHC applicability: if good death is constructed through individual and collective discourse and achieved in line with family wishes and cultural standards, such discourses around illness, dying, and death should be listened to and incorporated as resources, not barriers, for relieving child and carers' immediate and long-term suffering (Field & Cassel 1997).

While the results suggest open death discussion does not occur, this is not necessarily denial or lack of good death. Discourse, even silent, may take place, recognising 'silence' or 'denial' are constructed in contrast to hegemonic discourse of openly discussed prognoses, articulated preparation, and expressed wishes (Liben et al. 2008, Van Brussel & Carpentier 2012).

### Meaning-Making

The results suggest carer meaning-making of good death through agency does not occur as the literature defines. However, carers could find meaning outside controlling the dying experience, such as meeting basic needs, as emphasised. Religious belief may also facilitate meaning-making for carers (Selman et al. 2013). If analysed through CPHC's emphasis on open acceptance, carer prayers for cure may be concluded as extreme denial, prohibiting good death. This may be sound, but carer reliance on and comfort found in prayer could also assist processing and letting go and discussing God's mercy could form good death discourse (Liben et al. 2008).

## Grounded Theories

This study initially intended to assess factors determining a child's good death in the study context, before it was clear discussing death would cause carers avoidable distress.

Challenged to understand carer perceptions, experience, and needs around child death while communicating outside hegemonic discourse scripts illuminated different pictures of construction, possibility, and hindrances of a good death.

This challenges future research and practice: where death is taboo and agency constrained, perhaps assessments of need and good death goals first require determining grounded theories of dying. Methodologically, grounded theory allows contextually specific, substantive language and actions to establish, modify, and enhance formal theories, such as good death (Glaser & Strauss 1967, Charmaz 2006). Thomson et al. (2016) propose grounded sociologies of dying to articulate processes and interactions of death and dying within micro- and macro-social contexts, prohibiting individuals' isolation from structure, or cultural relativism superseding universal human rights to freedom from suffering, against which Farmer (2004), Downing et al. (2015a), and CPHC advocates warn.

For instance, if listening further to discourse around death points to burial's significance, as the results intimate, this could provide opportunity to promote carer meaning-making in contexts where structures limit controlled or pain-free dying, without interrupting culturally-constructed silent discourse. Without critical, nuanced understanding of local death discourse, it is unclear how carers released from structural constraints would relate to, cope with, and understand child illness and death. Repeated articulations of stress with limited government assistance might suggest need for income-generation support, potentially granting carers emotional space to discuss death openly. Such possibilities'

effectiveness are unknown, but warrant exploration, requiring future research to ask: What is the suffering experienced? How is it understood, coped with, and relieved? Is dying an acknowledged biological and/or social period? What is the discourse around illness, dying, and death, and how is it constructing good death? What meaning-making is desired, how is meaning made, and what is required to achieve it?

### Further Research

As indicated, further study of religious, gendered, racial, and socioeconomic influences, child and doctor perspectives, and burial is needed. This study finds grounded theories of good death should inform RLS CPHC needs assessments, programme design, and evaluations to promote good death occurrence. These should critically assess CPHC adaptation to stages of epidemiological transition, existential concepts of life, death, and meaning, socio-political understandings of health and pain relief, and diversity of illness experience impacted by socio-geographic positioning, global processes, sub-cultures, and economic structures.

### Limitations

As the first known study of good death for children in RLS, future research can learn from its limitations. Language and translation were more difficult than anticipated, potentially creating miscommunication or un-captured nuance. While studying within existing CPHC provided participant access and rich triangulation, this also left room for bias. The sample was stratified across key characteristics of carers served by SCH that could differentiate their experience, but more sample diversity by socioeconomics or race could have led to deeper critical analyses, had resources allowed sampling from other hospices serving different populations. Depth of sensitivity and complexity of discussing death became more apparent

upon data collection, which resulted in a necessary adaptation of the initial study methodology and language used in order to maintain cultural appropriateness and decrease avoidable distress to carers. This adaptation made the study feasible. Resultantly it is recommended that future research in under-represented, RLS should be critically mindful of and adaptable to cultural taboos, language, translation, and potential for silent discourse when discussing highly sensitive topics.

## Conclusion

This study engaged existing 'good death' literature from HRS and explored grounded conceptualisations from qualitative data to suggest a good death for children does not occur in this context as in the literature, but may in different, unknown ways, supporting and adding to existing theoretical critiques of a universal 'good death'.

Good death is shaped by contextually determined discourse, but research and practice is informed by HRS. From these perspectives, it could be concluded that discourse, and thus a good death, do not occur in this context; this study suggests some discourse does occur, even if silent, and requires further study.

Addressing self-defined, holistic, and structurally-determined needs to support meaning-making pathways working within and challenging agency constraints requires subjective, expansive, and critical understandings of suffering. Sociologies of dying, grounded determinations of good death discourse and critical analysis of factors constructing, providing, and detracting from good death in individual contexts are needed. A good death for children where death is taboo and agency constrained can occur to the extent that such grounded knowledge forms bases for CPHC to meet universal standards of physical pain alleviation and critically-understood suffering. If utilising cultural discourses of good death as resources rather than barriers, such CPHC can empower carers to find meaning and positively recover long-term, on their own terms.

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