Greenhalgh, Stephen (2024) *Exploring and visualising the purpose, concepts and development of hospices in England from the perspective of hospice chief executives.* PhD thesis.

Exploring and visualising the purpose, concepts and development of hospices in England from the perspective of hospice chief executives

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Submitted in fulfilment of the requirements for
the Degree of Doctor of Philosophy

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Submitted for examination on 25 September 2023

> "It is as if one were continually putting up two different poles and letting the sparks fly between. The truth is that we must preserve a readiness to ask new questions and seek new truth in all spheres. By establishing what look like opposites and not trying to achieve a false reconciliation, we may end by showing in fact that they can co-exist."

Cicely Saunders, 1980[1]

> "Hospice exists to provide a haven, to remind society of value.
> Life has its greatest value when it's going to end."

A respondent in the study

I know six wise and thoughtful friends
They show me what to do.
Their names are Why and Where and When
And How and What and Who.

Adapted from the Elephant's Child, Rudyard Kipling[2]

Abstract

This study sheds new light on the purpose, concepts and development of independent charitable hospices in England serving adults. Hospices in the UK are the largest charity group sharing a combined annual income of over £1.6 billion. The majority emerged in the late twentieth century to meet the needs of dying people that had been neglected by the NHS. Today, over 200 hospices function in very different health and socio-economic contexts across the UK. Hospice chief executives (CEOs) have oversight of all aspects of hospice operations and this is one of the first studies to identify their varied perspectives about why hospices are here, their conceptual basis, dynamic construction and developing contribution to end-of-life living, dying and death.

Adopting a qualitative methodology, 31 hospice CEOs were interviewed during 2019/20 with 17 taking place during the beginning of the Covid-19 pandemic in England. Their responses were analysed using thematic analysis and a social constructionist approach that drew on Gergen's concept of intelligibility nuclei and his application of Greimas's semiotics with context provided from hospice history, organisation, business and leadership studies. The study found a kaleidoscope of views amongst respondents which revealed awareness of tensions between science and humanity, medical and social needs, intimacy and scale. There was a consensus that society is still not dealing well with death and that many people are still missed by the system. Revealing the complexity of the hospice mission, the concept of hospice was understood in a variety of ways, for instance as: a vehicle to deliver care; a safe place to do things differently; a quality of care; a philosophy and belief; a community resource and a social movement. The study showed that hospices have many potential and actual strategic roles, such as those of provider, exemplar, collaborator, empowerer, explorer, agent, broker and disrupter. Significant obstructions to development, including physical threats to CEOs, were also identified.

The study is unique in having mapped this intricate and varied social construction of hospices through Gergen's application of semiotic squares. This visual device enables the variety of perspectives held within hospices and the landscape in which they are embedded to be presented in a way that has not been seen before. It therefore has relevance for the future development of hospices both locally and nationally, and for their impact on British society in the twenty-first century.

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Acknowledgements

The 31 respondents in the study (not named to protect anonymity)

Alexander Whitelaw, David Clark, Marian Krawczyk
Heather Richardson, Michael Hitchman

Susan Greenhalgh, Margaret Greenhalgh, Olivia Greenhalgh

Philip Jones, Fiona Duncan, Tony Bonser, Cliff Hughes
John Chesworth, Michael Lough, Hollie Dring, Emma Grzelczyk
Philip Forshaw, Jason McDermott, David Farr
Lynn Kelly, Sue Clemson

John Burn, Neil Boardman
Craig Duncan, Karl Benn, Toby Porter
Clare Roques, Joseph Wood, Julie Lang
David Burland, David Praill, Alan Baron
Alistair Baines, StJohn Crean
Peter Reiss

Christopher, Emma, Francesca, John, Marjorie and Philip
The administrators, IT, catering and housekeeping teams

Martin Ainscough and St Catherine’s Hospice, Lancashire,
for their financial support

Author’s declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Name: Stephen Greenhalgh

Signature:

Chapter One: Introduction

1.1 Purpose and approach

During the second half of the twentieth century the proliferation of hospices in the United Kingdom was dramatic. The majority of these new hospices were, and still are, local independent charities that help people to celebrate life and dignify death. At the beginning of the twenty-first century, that proliferation turned into expansion as each hospice grew individually, with today's network of over 200 hospices sharing a combined annual income of more than £1.6bn, which is far greater than any other charity in the UK.[3,4] The Nuffield Trust estimates that more than 300,000 people received care from hospices against a backdrop of c665,000 deaths in the UK in 2021,[5-7] and the need is growing because it is estimated that there will be 147,000 more deaths in the UK annually by 2040.[8-10] However, over half a century on from the landmark opening of St Christopher's Hospice, Sydenham, in 1967, questions continue to be asked about the ongoing contribution of hospices to the wider health and social care landscape, to society as a whole,[11,12] and about their future viability. This is especially so since the closure of St Clare's Hospice, Jarrow, in 2019, reductions in reserves for 50% of UK hospices in 2020[4,13] and 96% of them budgeting for a deficit in 2023/24.[14]

In 2010-13, there was great excitement around the work of Demos and their book *Dying for Change*,[15] the subsequent Commission into the Future of Hospice Care[16] and the rebranding of Help the Hospices (HtH) into Hospice UK (HUK) as a membership organisation,[17] all of which pointed to a tipping point and change in the sector. However, this was followed by a lull with just a short review of the work of the Commission being undertaken in 2016.[18] Whilst the Commission's work was well received, critics argued that it did not properly recognise hospice differences, saying, "one size does not fit all"[19] and little attention was given to the philosophical foundations of hospices. In this context, I shall suggest that the definition of 'hospice' and Saunders' concept of 'total pain' (that Barnard describes as palliative care's "conceptual linchpin"[20] but Klagsbrun questions)[21] has by its very nature always lacked definition.[22,23] Today, discussions about the meaning and significance of 'hospice' have become less prominent as palliative care and debates about its definition dominate the limelight.[24]

This study looks into this gap by exploring the purpose, concepts and development of hospices in England serving adults and those close to them through the perspectives of 31 hospice chief executive officers (CEOs). I adopt a qualitative approach using anonymised semi-structured interviews. Drawing on theories from social construction, including Kenneth Gergen's concept of intelligibility nuclei depicted through Julien Greimas's semiotic square,[25] I visualise the findings diagrammatically.

In 1980, with hospices opening throughout Britain, Saunders recognised emerging divergences and dichotomies. At the beginning of a conference that year, written up as *Hospice: the living idea,*[26] she said:

> "The truth is that we must preserve a readiness to ask new questions and seek new truth in all spheres. By establishing what look like opposites and not trying to achieve a false reconciliation, we may end by showing in fact that they can co-exist."[26]

This project shares a similar aim. By visualising the commonalities and contrasts amongst hospices today, a clearer picture emerges of what hospices are and where they are in the field which, in turn, enables them to consider where they might want to be. At a time when mainstream health and care services are overwhelmed,[27] the post-Covid-19 economy in the UK is struggling,[28] ten years have elapsed since the Commission into the Future of Hospice Care and hospices may be passing the peak in their industrial / organisational life-cycle,[4,11] I believe that it has never been more important for hospice leaders to explore their purpose, concepts and their application and to reimagine how their 'coexistence' in different modes, as Saunders described it, can be of greatest value in society. This study offers a contribution to that process.

1.2 Personal Motivation

I worked as the CEO of St Catherine's Hospice, Lancashire from 2005-2020 and during that period I also became the regional representative of northwest hospices and a board member of HUK. This gave me the opportunity to develop an understanding of the importance of hospices for society and the pressures on them going forward. In the lull that followed the work of the Commission (2013) there seemed to be a lack of shared understanding about what a twenty-first century hospice is and where hospices are heading. This concerned me, so I decided to undertake a project that would help to clarify these issues and felt that my experience offered a useful platform from which to garner the views of hospice leaders who are well placed to understand the strategic issues involved. I therefore contacted Professor Clark and commenced my PhD in October 2017. Following retirement, I became a trustee of Wigan and Leigh Hospice in 2021.

1.3 Structure of the study

Having set the scene by describing my purpose and approach, I now list my research question, aim and objectives, and summarise the structure of the study. There are additional explanatory notes in Appendix 3.

Research question

What do chief executives of hospices say about the purpose, concepts and development of independent charitable hospices serving adults in England?

Research aim and objectives

To explore what chief executives say about the purpose, concepts and development of hospices in England serving adults in order to inform the future development of hospices and their ongoing value to society.

1. To describe CEOs’ perspectives about why hospices proliferated in the twentieth century and why they are here today
2. To describe CEOs’ perspectives about the hospice concept, what hospices are and the form they take, including their roles, foci and outlooks
3. To describe CEOs’ perspectives about how hospices are developing and where hospices are heading
4. To explain and contextualise CEOs’ perspectives in relation to the literature and national landscape in an informative and inclusive way

In Chapter Two I provide a historical overview of hospices and their context. Due to the impact that hospices have had over the last half century, some of this ground is heavily trodden so I focus on aspects referred to in the transcripts and those that are most relevant to the research questions. I describe why hospices came into being originally, the human suffering that pioneers recognised and the human needs they identified. Of course, hospices were not founded simply because people were experiencing terrible suffering and deaths in that era; they were established because of the motivation and dedication of the pioneers to their cause. These include people like Cicely Saunders,[29] Richard Lamerton,[30] Robert Twycross,[31] Tom West,[32] Mary Baines[33] and Samuel Klagsbrun[21] who amongst others, developed the hospice idea and the form that it took in practice.[26] Therefore, I consider what hospices are in terms of their concepts, roles, foci and outlooks from historical and present-day perspectives.

Moving forward in history, as hospices develop, were called a 'Movement' in 1976[34] and extended their reach, questions began to be asked about 'whither'[35] their mission, approach and leadership was taking them in a rapidly changing landscape.[34,36] Describing tensions and ambivalences, I explain how that continued at the beginning of the new millennium through to the landmark book, *Dying for Change,*[15] in 2010, The Commission into the Future of Hospice Care 2011-13[16] and HUK's Future Vision Programme[37] in 2020.

Since hospices in this study are registered charities and companies / businesses as well as being sizeable organisations,[4] many of which employ hundreds of paid staff and volunteers, I describe aspects of organisation, leadership and business studies that inform themes in the research. This includes the importance of a shared understanding of why an organisation is here and what or who it is, as well as the operational knowledge needed to conduct its work.[38,39] In other words, organisations need to understand themselves, including their inherent tensions, as well as the market they occupy. Successful businesses are aware of their industrial / organisational life-cycle, the importance of reinvention,[40] innovation and maintaining their relevance.[41,42] I touch on points about leadership such as charisma and routinisation that were raised in relation to hospices as early as the 1990s.[34,43] I also consider issues of obstruction and how a dark side can emerge in hospices that challenges leaders and affects development. These act as landmarks to contextualise an understanding of hospice and hospices as they develop as charities, businesses and organisations in the twenty-first century.

In Chapter Three I explain the philosophical foundation, methodology and methods employed in the study. I describe the ontological and epistemological basis of the research in the social construction paradigm. Within this I use Gergen's concepts of intelligibility nuclei and implicit negation to underpin the study and Greimas's Semiotic Square to visualise the findings.[44] My primary aim is to bring new awareness to the sector that will, in turn, help inform future strategic development. I employ an inductive approach to address the research questions and since my interpretive process draws from both pre-existing interest and theoretical framing, as well as being open to new insights that come from the data, it is also abductive. I describe my rationale for using a qualitative methodology, the robustness of methods adopted and, as a former hospice CEO working as a researcher, I delineate my own contribution to the process. In practice, the Covid-19 pandemic and first lockdown took hold when I was in the middle of the information gathering phase so I explain how I adapted to ensure continuation within the framework agreed by the Ethics Committee. At the end of Chapter Three I set out my thematic approach to the analysis, the criteria I applied and the framework of themes and sub-themes that I selected.

In Chapter Four I present the results for Theme One: Why hospices are here. I begin with CEOs' perspectives on the suffering that hospice pioneers recognised in the twentieth century followed by the needs that they identified and their motivation for dedicating their lives to the hospice cause and making it happen. Moving from the past to the present, I go on to lay out respondents' views about the suffering that is still here, the needs that hospices seek to meet and CEOs' personal motivations for committing themselves to leading hospices today. I also explain participants' recognition of the importance of context in terms of how end-of-life needs have changed since the pioneering era and also how they are affected by geographic factors. Thus, in Chapter Four, I consider the perspectives of today's hospice leaders on the 'why, where and when' function of hospices.

In Chapter Five I move on to the form of hospices, presenting results from Theme Two: What and who hospices are. I begin by explaining CEOs' views about the hospice idea today through seven concepts that CEOs used. This is followed by their descriptions of the many roles that hospices undertake, their foci and outlooks.

In Chapter Six continuing with the form of hospices, I present results from Theme Three: How hospices are developing. Here, due to the emphasis in the interviews, I focus on economic development and issues of financial sustainability. All the CEOs in the study work in independent hospices that are both registered charities and companies. This being the case, I begin with the economic development of hospices as charities, followed by matters of sustainability as a business. Some participants also raise significant issues about obstructions to development which in specific cases takes on dangerous proportions. I then consider the relationship between development and purpose and look ahead through respondents' reflections on development and the long-term future.

In Chapter Seven I discuss the results against the theoretical background and landscape that I described in Chapter Two. I begin by summarising conceptual development in the study. I then provide visual examples of commonalities and contrasts revealed in the interviews through semiotic squares with explanatory commentary and comparison to the literature. Here tensions described by participants are shown, such as, for example: between suffering and need; between science and humanity; the paradox of intimacy at scale; between physical, practical, philosophical, clinical and social concepts of hospice; and in varied roles, approaches and obstructions to development. This visualisation opens up the social construction of today's hospices and shows that they are seen by most participants as being far more than charities delivering palliative care. Together, the three themes incorporate my adaptation of Kipling's poem (on page 2) about six wise friends,[2] namely the 'why-where-when and what-who-how' of hospices, that influence hospice development and may potentially have inference beyond the sector.[45]

In Chapter Eight I summarise the contribution and significance of the thesis. Originality in the study emanates from substantive interviews conducted with a rarely studied cadre of hospice leaders, consideration of the conceptual foundations of hospices that has drifted from current discourse, and visualising the dynamic of the sector through a device that is both sound and new in its application to hospices. I consider the research journey, strengths and weaknesses in the study, how the results can inform future development and avenues for further research. If hospices are to be reimagined, this study shows that in doing so leaders need to reflect on the energy of their inception, the intricacy of their surroundings, the heterogeneity of their development and their capability of fulfilling their mission.

Chapter Two: Background Literature

2.1 Introduction

A qualitative study exploring the purpose, concepts and development of English hospices could potentially move in many directions depending, for example, on the research questions and the emphases presented by respondents. The research domain is interdisciplinary covering a wide range of topics, so this called for a broad, flexible and pragmatic search strategy that needed to be expansive and inclusive rather than narrow and exclusive.

Searches were in two phases: before data collection and after data collection. In the first stage my primary focus was the hospice landscape and its historical roots because this shaped their inception, impacts on the conceptual nature of the study and influences what hospices are today. Having considered types of review methodologies,[46] I set out to scope the area as a process of reconnaissance[47] in order to present a descriptive overview. As Tricco et al. state: “Scoping reviews are used to map the concepts underpinning a research area”.[48] Although there is no definitive procedure for scoping reviews,[49] Arksey and O’Malley (enhanced by Levac et al.)[50] offer a useful framework which I followed.[51] My process involved clarifying the research questions, identifying and selecting relevant studies, pursuing subsequent avenues of investigation and collating them into a logical order. A broad set of search terms was used that included, for example: hospice; hospice purpose; hospice concepts; hospice history / development. I also searched using the names of prominent individuals in the field, for example pioneers such as Saunders, Lamerton and Twycross and authors such as Clark, James, Field, Kellehear, and Sallnow. My primary criterion was literature about hospices as organisations, charities and businesses rather than palliative and end-of-life care from a clinical or social care perspective. At the outset, I set up files for hospice history, hospice development, hospice care, hospice leadership, public health, social movements and the NHS. I subsequently added a file for Covid-19. This was in parallel with philosophical and methodological enquiry.

In the second stage, following the interviews, I focused pragmatically on significant issues presented by participants that I considered to be of strategic importance using the criteria laid out in my methodology (Section 3.4.2) to develop themes described in Chapter Three. Since hospices are organisations, this included organisation, business and leadership studies where I concentrated on work that broadly conceptualises and theorises the field[52] in order to support the foundation of the research. Then, I explored the developing themes and sub-themes in the thesis and in particular concepts raised by respondents. A summary of conceptual development in the literature is provided in Figure 1.

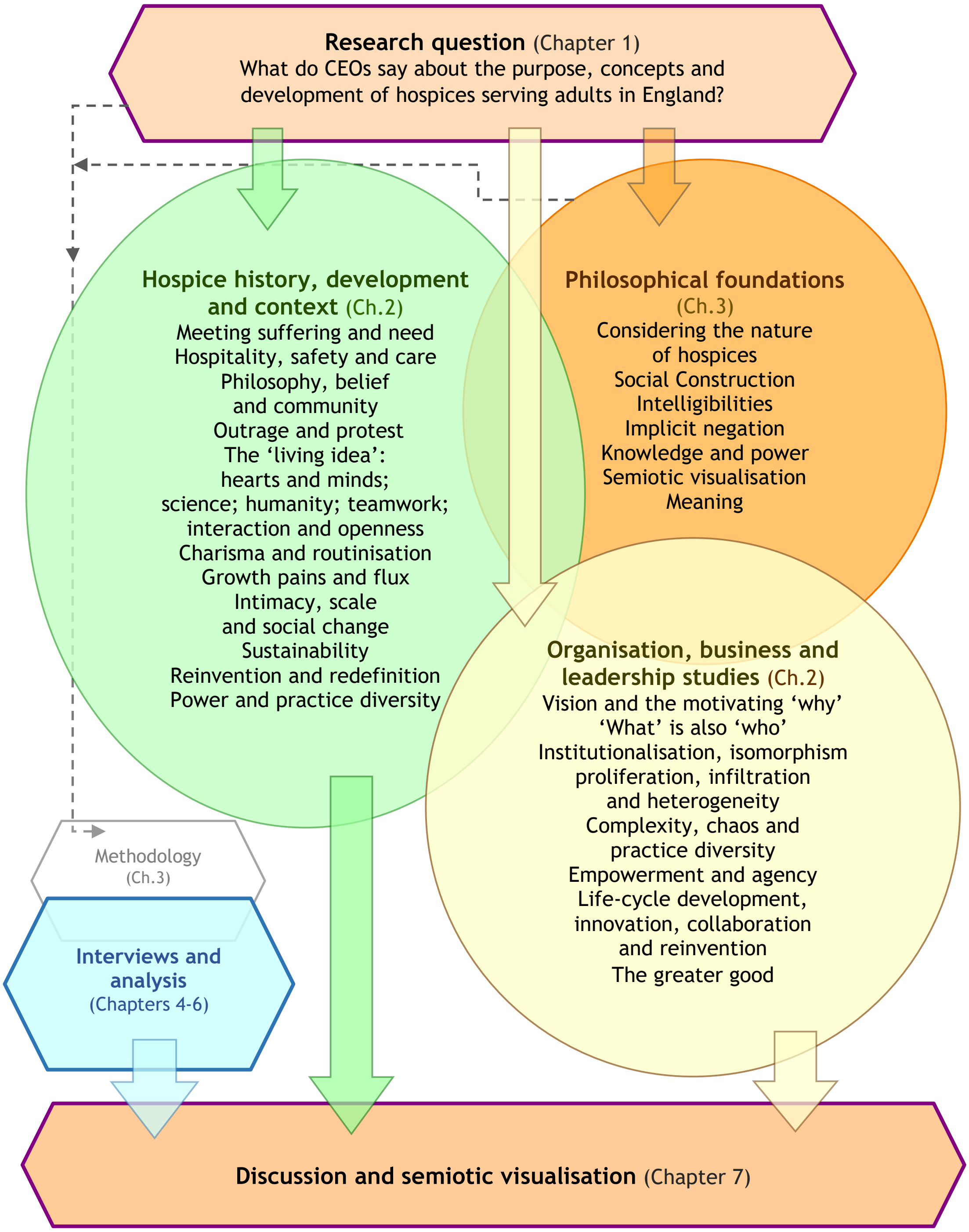

***Figure 1** – Conceptual development in the literature*

2.2 Why hospices began

2.2.1 Beginnings and 'hospitality'

Following a decree by the Emperor Constantine, inspired by the teaching of Jesus of Nazareth: "I was hungry and you gave me something to eat … I was sick and you looked after me,"[53,54] infirmaries were built in Roman towns in the fourth century.[55-57] Hospice care for travellers, the sick and impoverished is recorded in the Eastern Church and was brought to Italy by the wealthy widow Fabiola who became both host and a nurse in her institution.[55,58]

From its Sanskrit source,[59] *hospes* in Latin meant 'stranger' and then 'host'.[54] *Hospitalis* was a friendly welcome to a stranger and *hospitium* meant 'hospitality'.[54,60] Hotel, hostel, hospital and hospice share the same linguistic root.[55] Hospice was originally used to describe a charitable resting-place for travellers or the impoverished, maintained by a religious order.[61-63] In these places the 'relationship' was as important as the 'place'.[57] The Knights Hospitallers provided safety, hospitality and care in Jerusalem, Cyprus and Rhodes for pilgrims, the sick and the dying and, notably, put the safety and well-being of those they tended before their own.[63] More hospices followed in Europe, often in inhospitable locations, to aid weary pilgrims and were funded by local benefactors.[61] Cicely Saunders, the twentieth-century hospice pioneer, recognised these historic roots and the dedicated communities which operated them by choosing the word 'hospice' for her project.[34,64-67] Subsequently, nearly 60 hospices in the UK were named after Christian saints.[34,68]

The hospice tradition re-emerged through St Vincent de Paul who founded the Sisters of Charity in Paris in the seventeenth century.[63] Following the work of Jeanne Garnier in France,[56] Mary Aikenhead founded the Sisters of Charity in Dublin and it is her: "Spirit of love for the poor, of understanding their hardships, of dedication to their welfare … which conceived the idea of a Hospice for the *dying*".[69] For these pioneers, inspiration for the care of the dying came from the suffering that they saw before them and the deuterocanonical *Book of Tobit*.[56,70] When Our Lady's Hospice in Dublin opened in 1879, the first dreadful winter resulted in an outbreak of smallpox in the building[71] but the community of sisters was vocational and courageous. They worked amidst the known killers of cholera, typhus, tuberculosis and smallpox that were rife amongst Dublin's cramped population,[72] often at the cost of their own lives.[58] Like Fabiola and the Knights Hospitallers they were inspired by Jesus of Nazareth who gave his life for others.[58,73] In 1905, shortly after The Friedenheim (later called St Columba's Hospital)[74] and The Hostel of God (later called Trinity Hospice)[71] were founded, the sisters opened St Joseph's Hospice in London's East End, one of a number of homes for the terminally ill formed through the work of women such as Mary Aikenhead and Frances Davidson.[71,74] Another, St Luke's Home for the Dying Poor,[75] grew out of the Methodist West London Mission, and its special character, organisation and atmosphere, like St Joseph's and The Friedenheim, attracted Saunders' attention[74,76,77] with the latter becoming "a hothouse for Saunders' thinking"[78] in the mid-twentieth century.

In 1920, before the advent of antibiotics, average life expectancy in England was 56 for males and 59 for females[79] but by 1960 it had risen to 66 and 72 respectively with the more common causes of death changing from infectious to degenerative diseases.[34,80] Post-war euphoria, improving standards of living, advances in medical science (such as antibiotics, immunisation, genetics and surgical techniques) and the advent of the NHS, raised public hope and the focus of the medical profession in England moved from caring for people to curing illnesses.[34,61,63,81]

The former Regius Professor of Medicine at Oxford, William Osler, whom Saunders quoted,[82] sensed this coming at the beginning of the twentieth century by repeatedly expounding the importance of the *art* as well as the *science* of medicine and putting patients before diseases.[83,84] This depersonalisation or soulless medicalisation[85-88] as it became known (that is still a concern today, including within hospices)[89] resulted in a determination to keep patients alive at all costs,[63] and where this was no longer possible a whispered silence descended and physicians visited less frequently.[90] Seemingly, dying patients were either neglected or over-treated through radical surgery as an object of medical inquiry.[36,91] Even death was being re-defined,[92] which in turn created fear, ethical concern and a public mood of anxiety.[34,93,94] In this sense, the NHS maxim "from the cradle to the grave" was only half right.[95]

Interestingly, Pearce's *General Textbook of Nursing*, 1946, shows great sensitivity towards nursing those who are dying,

> "The nurse, who spends many hours with her patient, will feel his dying … she has learnt to know him intimately … her presence will help to console and comfort him now, and it will comfort his relatives also. A dying person is very lonely … (and) is glad to feel the presence of someone he knows."[96]

However, Pearce also stated that when a patient thinks they might be dying, the doctor must decide "whether the patient can bear the answer".[96] In 1975, this medical paternalism was still present in another standard nursing textbook:

> "The final decision to tell or not to tell the patient that he has uncontrollable cancer and is going to die rests with the physician. The majority of physicians still do not tell their patients."[97]

However, as with Pearce, sensitive nursing advice was proffered, including commending Kubler-Ross's best-selling book on death and dying.[98,99]

As was the case with many other hospice pioneers, the primary reason why Saunders committed her life to the dying was her first-hand experience with hundreds of patients, including her brief intimate relationship with David Tasma in 1947-8. Du Boulay observed that Cicely was drawn to people in pain and "learnt from the dying in order to help the dying", remembering people by name and in great detail.[100] Listening, watching[101,102] and being-with are central tenets for Saunders which Clark describes as caring-*about* rather than caring-*for*,[103] and more recently, Dodd affirms.[104] Hence, Saunders' oft-repeated sentence: "You matter because you are you and you matter to the last moment of your life"[105] that continues to be referred to as a significant landmark.[106] Added to this motivation was her defining Christian inspiration that, as with the first hospice founders, drove her forward along with other pioneers[29,107] to meet the practical needs of the dying.[108] In this regard, Saunders cites Victor Frankl, who wrote from his experience in Auschwitz where every circumstance conspired to make a prisoner lose their hold but a last freedom remained: to choose one's own attitude and even in that darkest of places, to rise above it.[109] Therein Frankl quotes the German philosopher Nietzsche: "He who has a *why* to live can bear with almost any *how*".[110,111] Hence Saunders wrote many papers and letters about the transcendent dimension of 'hospice' and the search for meaning and truth in dying and death.[112]

Registered as a charity in 1961, St Christopher's Hospice opened in 1967.[113] This is often seen as the start line for the Saunders' era of hospices from which proliferation followed in the late twentieth century. In summarising why hospices began, James and Field[34,36] include the reasons I have described above along with the publication of a Marie Curie report, 1952,[114] concerning patients with cancer nursed at home that included heart-wrenching experiences of patients dying in dreadful conditions. (There was also a Gulbenkian Foundation Survey of terminal care entitled, 'Peace at the Last', 1960,[62,115] that offered similar findings and with which Saunders had contact.)[116,117] James and Field also refer to discussions in the NHS about the form that care of the dying should take, including using multi-disciplinary teams. However, it was the hospice pioneers who took this up as part of their robust response calling for improved care rather than voluntary euthanasia.[62,91,118] These, they argue, are the reasons why the public became open to new ways of caring for the dying outside the mainstream NHS.

Significantly, in 1992 James and Field also saw the importance of charismatic leadership as a key driver that turned aspiration into operation in order that the needs of the dying might actually be met. Citing Max Weber, the German sociologist, and his thinking on charismatic power coming from within,[43] they point to the inspiration of hospice pioneers,[119] their vision and clear focus, their opposition to mainstream provision for the dying, a preparedness to disrupt the status quo[120] and Saunders' high profile,[121] as key factors that brought hospices into existence and that the public found so appealing.[34] This included courage and determination. For example, when they were part-way through the construction of St Christopher's Hospice, funds ran out. In response, Saunders simply said: "There is nothing like a crisis to mobilise things … it is the idea, not one individual, that will get us the means to go on … I believe it will come".[122,123] Interestingly, this revolution in the care of the dying took place in the age of post-war social rebellion,[88] reform and the 'religious crisis' of the 1960s[124] where Saunders could be seen as a follower of the established church,[107] a pioneering physician in the care of the dying and a charismatic renegade fighting the bastions of medicine.[121]

There are also other contextual factors that may have affected the founding of hospices at that time, including memories of a culture of publicly supporting voluntary hospitals of which there were 1,255[71,125] shortly before the NHS was formed, through subscriptions, donations, flag days[81] and wealthy benefactors.[126,127] However, A.J. Cronin's *The Citadel*[128] that draws attention to corruption in small private medical practices, the British statesman Clement Attlee's snipe about ineffective sympathy[129] and, perhaps more significantly, the country's economic crisis in the era of Prime Minister Harold Wilson,[130] may have been hindrances. Nonetheless, from a fund-raising perspective, Saunders' charisma, extraordinary range of social and professional contacts, the magnetism of individual hospice founders and the support of local churches were huge assets.[29,107] Finally, Saunders' influence came not only from her social background and Christian associations but also because she followed the advice of Dr Barrett (who had an interest in homes for the dying)[131] to "go and read medicine … [or] they won't listen to you".[132] Saunders qualified as a doctor in 1957.[107] Clark describes this as a momentous decision[133] which gave her the platform and authority that she needed.[29]

Richard Lamerton, a GP who worked at St Joseph's and St Christopher's hospices in that era, summarised why hospices came into being:

> "The aim of the care of the dying is to make the patient's body a comfortable enough place to live in … to prepare for death mentally and spiritually. It was this work that brought forth the present-day hospice movement, but *the idea is much bigger* … [and includes] the knowledge that hospitality is a duty owed to the weary traveller and to the sick."[134]

Thus, hospices were established because of the suffering that was recognised, the practical needs of dying people that pioneers identified, the resonance of hospice aspirations with public outrage and their disassociation with current practices. However, it was also the motivation, inspiration, vocation, self-sacrifice, courage and dogged determination of hospice founders like Saunders who were prepared to stand up against the establishment and do something, their deeply held philosophy and 'big idea', along with contextual factors of the era that enabled the hospice movement to come into being and begin to change society's view of dying and death.[64]

2.2.2 Organisation

As hospices like St Christopher's were established the majority were registered as businesses at Companies House and as charities with the Charity Commission.[135] They were also organisations with a mix of voluntary and paid staff that required leadership. As such, I consider aspects of organisation, business and leadership studies that relate to the research questions and to issues and theories that have been raised by respondents in the study from these bodies of literature. To maintain coherence with the historic literature, I discuss some of this material here and some at pertinent points later in the chapter.

Organisation studies have roots in the nineteenth century in the likes of the French political theorist Henri de Saint-Simon who sought to understand and assess industrial capitalism.[38] At that time there was a belief that scientific collective thinking and organisation can overcome major industrial challenges in order, for example, to extract coal from the ground, keep people warm and society happy.[38] However, by the post-war 1950s it was obvious that rational-technological authority over a workforce and society were, on their own, devoid of moral value and, disturbingly, could carry similar preconditions to those that led to the holocaust.[136] According to Reed, effective industrial and social organisations need a sense of community and willingness based on shared values.[38,137] In other words, people want to understand 'why' they are working together rather than simply functioning as automatons on production lines. In the twenty-first century, citing companies like Apple and Harley-Davidson, Sinek emphasises the importance of businesses and their employees starting with 'why they are here', not the fundamental purpose of making money but more the causal belief at the heart of what they are doing.[138] His premise is that people invest in why organisations do something, and that great organisations excite the human spirit, inspire people to become involved in the 'cause' and behave like a social movement.[138] Similarly, Bass and Riggio argue that effective transformational leaders build emotional commitment to an organisation's mission through values and beliefs in why they are here.[139] As Dougherty argues: "People working on successful innovation know what their jobs are, who they work with and how, to whom they report, what the priorities are and how their activities fit with those of the enterprise as a whole".[39] Thus, how a company performs depends on its understood purpose, its idea about how to solve a problem and who is involved in doing so, as well as about how they approach it practically.

An aspect of this can be seen in Agency Theory[140] (that is referred to by a participant in the study). Agency Theory focused originally on the relationship between managers and stockholders[141] but is applied more widely to internal and external stakeholders in companies, including their customers.[142] Since the hospices referred to in the study are registered companies there are lessons to be learned regarding stakeholders in the sector. Agency Theory deals with the issue of the differing interests of a manager and an agent, the possibility of opportunistic self-serving behaviour and how that can be controlled.[140] For hospices, Agency Theory raises questions about why a hospice is here and the moral question of whom a hospice is the agent of. Hospices, like other companies, also run the risk of being adversely affected by self-serving behaviour. Thus, if a hospice sees itself as an agent of the people but is part-funded by the government, does it have a conflict of interest and will it remain entirely focused on the needs of those whom it serves? Alternatively, if a hospice is understood to be an agent of mainstream services, can it stay unaffected when suffering at the end of life is ignored by the system? Hence, it is important for hospices to have an agreed understanding of why they are here and whom they serve. Chambers et al. make reference to Agency Theory and the issues of conflict that it raises for boards of UK hospices, arguing that they need to adopt a triadic position of high challenge, high support and strong grip in order to mitigate these risks.[143] In addition, they also affirm the importance of boards having a clear understanding of why they are here, their mission, contextual factors and that there is heterogeneity in the sector.[143]

Moore, a former hospice director and nurse, emphasises ‘why’ in her book *No Mission, No Margin* in 2014.[144] She cites a Delta airlines’ CEO, Richard Anderson, who says that common values are more important than policies because when you are flying 150 million people a year there are too many variables to write rules for.[145] Moore argues that, likewise, hospices must understand their values and purpose. For example, are they: “focused narrowly on hospice care [or] contributing to the greater good” or both, and do they know?[146] Moore states, “hospice is a reflection of those ancient hospices, way-stations for weary travellers … on their final journey … that is so much more than simply health care".[147] Her overarching argument is that hospices must understand their mission in relation to why they are here and manage their financial margin if they are going to be effective and thrive.

Similarly, in 1998 Johnson's examination of corporate vision and leadership in hospices[148,149] argues that the leader is subordinate to the vision. Founding hospice leaders respond to an external demand; some are single individuals and others consensual teams but for all, Johnson says: "The vision remains uppermost. The necessity of hospice founding teams appears to be having some*thing* they believe in rather than some*one*".[150] As Saunders said when funding was running out part-way through the building of St Christopher's Hospice: "It is the *idea*, not one individual that will get us the means to go on".[122] Cross-referencing this to leadership studies, Baliga and Hunt stress the importance of commitment to a vision in effective transformational leaders and that regeneration requires a reimagining of the vision during organisational life-cycles.[151,152]

The issue of life-cycles is relevant to this study because hospices are now half a century on from the opening of St Christopher's Hospice and the great proliferation that followed. Charles Handy, a specialist in organisational behaviour and management (whom respondents referred to) writes about businesses needing to reinvent and begin a second upward curve whilst things are going well rather than before progress falters, saying: "The past we are used to may not be our best future".[153] Similarly, Larry Greiner's growth model describes stages of organisational life-cycles and that without the essential fuel of regeneration needed to pass through them organisations will end up in repeated crises and burnout.[154] Greiner also argues that leadership styles and strategies for one stage are usually maladaptive for others.[152] So whilst it is accepted that leadership approaches are critical and may need to vary for healthy organisational development to continue, the point here is that understanding 'why' within its changing 'where-when' context remains paramount.

However, organisation and leadership studies also point to the importance of who and what organisations are if they are to be effective. This includes "getting the right people on the bus" and doing so early enough.[155] According to Collins, an American business management researcher, this is "not a genius with a thousand helpers"[156] since, he argues, geniuses rarely build great management teams because they do not need them, and when they leave, the institutionalised helpers become rudderless.[156] This recalls James and Field's concerns about charisma and routinisation in hospices and Greiner's argument for the necessity of leadership changes in different stages of organisational life-cycles.[34,154] To be successful, Collins says, it is important to bring the right highly motivated people on board early because 'who' determines 'what' a company is.[157] Putting this succinctly, Collins says: "The factors that determine whether or not a company becomes truly great, even in a chaotic and uncertain world, lie largely within the hands of its people".[158] As such, he says, purpose, philosophy and values are foundation-stones that determine how a company functions.

Thus, 'why' an organisation is here in its 'where-when' context, and 'who' and 'what' an organisation is, precede 'how' it develops.[157] These are, of course, Rudyard Kipling's (the 1907 Nobel prize winner in literature)[159] six wise friends:

I know six wise and thoughtful friends
They show me what to do.
Their names are Why and Where and When
And How and What and Who.

Adapted from The Elephant's Child, Rudyard Kipling[2]

In terms of the global landscape, Kate Raworth, the economist and researcher (who some respondents referred to) argues that it is important that any organisation or business perspective sits within an economic world-view. That view can be based on economic theory or humanity's long-term goals which frequently do not coincide. For the latter, success is not measured in terms of being bigger and better but in being part of the global picture of reducing human deprivation and suffering.[160] In her argument, a business should not be focused only on its own individual success but also on facilitating a better world, and she says that to achieve this will probably involve rethinking growth and handing power to others.[161] In terms of hospices as businesses, this view chimes with Moore's vision of hospices serving the greater good.[144]

2.3 What and who hospices are

Having considered why hospices came into existence through the historical literature and some relevant aspects of organisation studies, I now move on to discuss what hospices are and how they are developing. I will also consider why hospices are here today. In this section I describe the hospice concept and relevant aspects of its early application in hospices. In this regard, James writes about the hospice vision being an approach, a concept and a philosophy;[162] others, like Baron et al., talk about the hospice culture and identity,[61] and Saunders describes *Hospice: the living idea*.[26] Here, I lean towards the latter and rather than dissecting the various components and terminology, I describe the many ingredients in the literature that contribute to the recipe that makes hospice and hospices.

I begin with Saunders' plans for a hospice community, its nature, philosophy and priorities. This leads to a description of the 'living idea' with its inherent tensions and application in hospices that quickly gain momentum and recognition for their wider social value. Hospice is described as being all about people; it incorporates the idea of 'total pain' but with an early warning that this is but one facet of a bigger idea. Hence, this section describes the hospice concept and then its early application in the strategic roles and foci of hospices.

2.3.1 Philosophy and community

When St Christopher's Hospice opened in Sydenham on 24 July 1967 it followed a period of gestation. It was ten years after Saunders submitted her first paper on the care of the dying[29] and 19 years after her encounter with David Tasma.[107] In an unpublished strategic document called *The Scheme,* probably written in 1959,[163] Saunders set out: "in broad but precise terms what her hospice would be for and how it would function".[164] St Christopher's and its 'living idea'[26] was not thought up overnight and, as Clark puts it, there was no "simplistic blueprint for the hospice and the 'window' it contained".[165]

Saunders' *The Scheme* opens with a description of a home that imbues a feeling of belonging, permanence and security, run by staff who regard the work as a full vocation. Saunders wants people who choose, love and believe deeply in what they are doing.[163] Her idea is born from knowledge of the earliest hospice beginnings, experience at St Joseph's Hospice and St Luke's and communications with other institutions such as The Freidenheim.[56] As Broome points out, these proto-hospices[166,167] have different forms and Saunders, who visited many,[168] learned from them all.[74,169] Here in *The Scheme*, her hospice idea stands on philosophical foundations and lives in a community or 'extended family'[107] of people with the necessary nursing skills, experience of pain-relieving drugs and belief in their purpose and values.[170] At The Friedenheim, Frances Davidson wanted her guests to be in warm, homely surroundings filled with kindness,[74] and similarly Saunders wanted all in the community to feel welcome, comfortable and secure.[163] In Handy's descriptions of modern-day successful entrepreneurs, that include Richard Branson, Tim Waterstone and Geoff Mulgan, creator of Demos[15] (that I will refer to later), one of the common threads is how, at the outset, they made their workplace feel like a family.[171] Whilst these are not care settings, Handy's point is that successful entrepreneurs recognise the importance of a mutually supportive work environment.

Similarly, Woodward-Carlton says, "beliefs and attitudes" were essential ingredients in the emerging hospice movement and in which its founder held an inclusive view.[172] Thus, whilst Saunders was deeply committed to her Christian faith, allegiance to it was not a requirement for working in the new hospice.[34,163,173] Denominational allegiance,[174] vows or shared possessions were not required; patients were not to be preached at or seen as conversion fodder,[56,175,176] and board members were from a mix of religious affiliations and agnostics.[112,177] Saunders quotes Albert Camus's atheist doctor and priest saying: "We're working side by side for something that unites us – beyond blasphemy and prayers[178,179] … as a community of the unlike".[180]

Saunders worked with Peter Smith on 'an architecture of healing' based on patients' perspectives that kept them in view rather than out of sight as they were in hospitals, and she rejected a site at Denmark Hill because of its proximity to King's College Hospital.[181] Saunders spent much time wrestling with what kind of community St Christopher's should be. In practice it became an informal community with rooms for retired members, a playgroup and a chapel,[29] and there is no doubting the value that Saunders placed on a positive environment and welcoming community in enactment of her 'living idea'.[181-183]

For Saunders, hospice meant a team or a community,[184] involving mutual support that she experienced herself both formally and informally,[185] and included learning from the courage and patience of their guests, adults and children alike.[56,186,187] Saunders recognised the importance of being as well as doing,[188] of "living as well as dying",[189] of shared suffering, security, love and openness[56] as a setting in which her brand of medicine could flourish and end-of-life experiences could become richer and more peaceful.[36,190] Hence, whilst hospice is centred in patients' lives, those lives should not be seen in isolation because they are part of the organism of community and the philosophy of society.[88] As Saunders put it, "The dying need the community … the community needs the dying"[102] and, as such, "a society which shuns the dying must have an incomplete philosophy,"[102] a fact which the writers of the Lancet Commission Report on the Value of Death still see as relevant today.[191]

A key hallmark of Saunders' community was her practice, teaching and research triangle.[192,193] Her vision was of a hospice not only providing a new form of care but also sharing lessons through education and breaking new ground in, for example, pain control. Saunders said: "[We are] not the first hospice, but the first to set out to bring the pursuit of excellence to the care of dying people"[194] and she described St Christopher's as: "the first modern research and teaching hospice".[195] Herein, Broome argues, are the reasons why Saunders' ideas proliferated so dramatically.[74,196]

2.3.2 The living idea

The foundations of the hospice movement were established in the years preceding and immediately following the opening of St Christopher's in 1967.[29] The next three decades are described as the expansive years.[29] James and Field wrote of under 15 hospices operating in Britain in 1965, 62 hospice services by 1980 and 430 in 1991.[36] Clark describes these services, including the development of care at home,[35] triggered by the likes of Mary Baines at St Christopher's.[197,198]

In 1980, an international conference was held that reflected hospice philosophy, practice and achievement with presentations from 28 contributors.[26] At that conference, Saunders described the hospice foundation as "a symbol of all kinds of openness"[1] that helps people to cope with dying more positively.[199] Here she saw a mix of: "truth of the mind in skill and understanding, with truth of the heart in vulnerable friendship”[1] that are able to work together in a setting where people experience the security of belonging. As David Tasma said: “I only want what is in your mind and in your heart”.[132,200] In practical terms, Saunders said, “[Hospice combines] the sophisticated science of our treatments … with the art of our caring bringing competence alongside compassion”.[1] For Saunders, *Hospice: the living idea*[26] includes other tensions too, such as caring for an individual and responsibility to the whole community.[26] Hence, her hospice idea is dynamic, multifaceted and often in tension with itself because it involves: “a readiness to ask new questions and seek new truth in all spheres”.[1] However, this is not seen as problematic because: “By establishing what look like opposites and not trying to achieve a false reconciliation, we may end by showing in fact that they can coexist”.[1]

Robert Twycross, Saunders’ clinical research fellow,[201] conveyed some of these tensions in his description of hospice as a concept of care that is a ‘protest’ and an attempt to redress the balance in medicine of cure, relief and comfort.[30,120,202] As Lamerton put it: “Medicine, after all, is no longer in charge of the situation: death is taking over”.[203] Expressing this more broadly, he also said: “[Hospices] condemned the neglect of the dying in society” and that they are a “corrective [for the practice of medicine]”.[204] The controlling medical oversight of the NHS, reflected in nursing textbooks referred to earlier (Section 2.2.1) offers an indication of why Saunders chose to work out ‘an alternative way of dying’[34] in an independent institution. This offers a response to Ahmedzai’s unfounded criticism of Saunders for taking her ideas into a ‘religious enclave’ that he infers resulted in the legal right to palliative care needing to be enacted today.[205,206] I say ‘unfounded’ because Ahmedzai offers no evidence that Saunders’ choice to step away from the medical enclave is a wrong turn, which Sugden points out.[207] As Hartley and Hinton[208] explain, dying was never part of the original NHS vision.[209-211] Indeed, Saunders embraces the religious-medical tension, finding it energising and beneficial.[34,179] Whilst Saunders’ strategy does not mean isolation,[1,212,213] the hospice pioneers did want freedom and flexibility[214] to choose their own direction of travel[107,212] and to disassociate themselves from current mainstream practices[214] in order that eventually: “attitudes and knowledge could move back in”.[1] In seeking to show a balanced perspective, it is important to remember the enormity of the NHS at that time that inevitably held a variety of views on dying and death amongst its employees. As such, whilst it was certainly not the prevailing culture, there were still some voices inside the medical establishment who remembered the art as well as the science of medicine that Osler had expounded.[215]

The ‘living idea’ was unpacked by different contributors at the 1980 conference. Sir George Young, Parliamentary Under-Secretary of State at the Department of Health and Social Security, spoke of hospices opening up the unspoken subject of death, identifying unmet needs and finding new ways to meet them, laying great emphasis on the role of hospices in sharing those ideas through education and research which, of course, was not always going to be popular with the establishment.[216,217] Young recognised the hospice philosophy of caring for the person before the disease and the importance of humanisation rather than depersonalisation in all aspects of medicine.[216] As with Young, Klagsbrun emphasised unmet need especially for “less popular elements of the population” which included the frail elderly.[21] He talked about broad aspects of hospice care, noting that pain management had been picked up, partly because of its value but partly because it could be recorded more easily, rather than other important ingredients that make up hospice such as the atmosphere, qualities of interaction, functions, feelings and openness.[21] Consequently, he said, for hospice to be known only because of pain control misses the point. For Klagsbrun, hospice is the people involved in hospice care, including patients:[21] “the care of the dying is the care of all of us … in a way it is the dying who are giving us a much better awareness of the gift of life”,[218] a view with which Torrens and Saunders concur.[199,219] Likewise, Lamerton wrote of patients caring for one another and for staff, and of staff caring for each other in a way that Enid Henke, a patient, described as “true neighbourliness”,[220] and another patient as a “bringing together illness”.[195]

Saunders’ ‘living idea’ is based on the ancient belief of offering hospitality to the weary traveller. It germinates in the hearts and minds of carers and patients as they come together and combines science, humanity and collaborative working with a philosophy that every person matters until the end of their days. For the likes of Saunders and Lamerton, hospice is organic, scientific, situational, social and spiritual with patients, families and friends, front and centre. Sitting inside the ‘living idea’ is Saunders’ concept of ‘total pain’ that she introduced three years[221] before the opening of St Christopher’s Hospice.[23,222-224] This moved beyond the traditional “nothing more can be done”[225,226] and “all of me is wrong”[195,222] to a new start point and the unpacking of “Pain? It was *all* pain”[227] and how it can be alleviated.[222,228] Clark describes her concept as: “An approach that saw pain as the key to unlocking other problems and as something requiring multiple interventions for its resolution. Her way into it was through close attention to what patients were saying”.[229] This is not naivety because Saunders recognised that taking away pain is not the: “whole hard thing that is happening”[23,230] but, in her terms, it does help travellers on their life’s journey.[30,231] Hence, Saunders’ hospice is named after their patron, St Christopher, and she disliked the term ‘terminal patients’ because, for her, death is not a terminus.[232] Saunders writes that “the dignity and worth of each individual patient is central to the hospice philosophy”[233] because her philosophy, whilst including total pain and patient dignity, is broader than both of them.

For Clark, ‘total pain’ is one of the most enduring concepts of palliative care[214] (now an international priority);[234] for Barnard it is its conceptual linchpin[20,23] and for Kubiak, the key idea.[88] However, Wood argues,[23] citing James and Field,[34] Jeffrey[235] and Krawczyk,[236] that Saunders’ concept of ‘total pain’ is ill-defined and, consequently, risks being applied reductively or simply as a marker through ongoing routinisation and expansion of the field.[23] As I have already explained, in 1980, Klagsbrun also expressed concern about reduction.[21] ‘Total pain’ is *part of* Saunders’ broader ‘living idea’ that, as I have shown, has philosophical and sociological dimensions[102] and therefore also carries a natural lack of definition and consequent potential for reduction.

The various descriptions of ‘hospice’ that I have explained in this section show a multi-faceted maturing concept that one might expect from a ‘living idea’ which is perhaps why Saunders named it as such. There are many tensions within the growing concept and the pioneers used that energy positively whilst also issuing an early warning about a tendency to neatly package and oversimplify.

2.4 How hospices are developing

In this section, I move forward in time describing the rising profile of hospices, growth pains, flux, tensions and heterogeneity. Following the millennium these led to the landmark Commission into the Future of Hospice Care, calls for the reinvention of hospices and issues of power, sustainability and definition. During this period attention shifts from the ‘living idea’ of hospice to hospice care and then palliative care.

2.4.1 Profile and proliferation

By the end of the 1980s, the core of the hospice philosophy is described by Lewis as completeness of caring and helping people to live until they die.[237] Thus, holism is affirmed and death, rather than being hidden away, is seen as part of life. Hospices have been described as a ‘movement’ by the *Nursing Times* in 1976[34,121] and as a result of their growing significance[34] national political leaders share the limelight. Margaret Thatcher writes of this frank and open approach to death and dying,[238] Neil Kinnock of social value and hospices representing the highest ideals of our communities,[239] Paddy Ashdown of hospices as exemplars and a community resource,[240] and David Owen says that whilst hospices “pioneer and innovate, and provide a lead, they cannot be expected to take on the whole task of caring for dying patients. That would be to turn the whole ethos of the NHS on its head”.[241]

Thus, alongside the contribution of hospices to the environment of death and dying in society, their disruptive innovation,[242] example, leadership and social value, Owen points to the obvious fact that hospices are not the NHS and as such have complementary and different roles through their charity sector contribution with its strengths and limitations.[243] In this regard, hospices, like their forbears, are not immune to philanthropic insufficiency and amateurism[74,243] and the inevitable tension with professionalisation.[217] Hence, professionalisation is challenged for the barriers it creates[120,244] whilst charitable endeavour is criticised for providing care for the favoured few,[119] disorganisation, unnecessary fund-raising paraphernalia and affording governments an excuse not to develop an effective mainstream service.[12,172,217]

Lewis also identified the risks of hospices appearing élitist and being overly critical of the NHS as an unintended problem that hindered joint working.[237,245] As Douglas showed, in his 1992 ‘obituary’ to the hospice movement published in the BMJ (and in which he commented “well done, thanks and goodbye”)[118,217] and Ahmedzai more recently, no one likes to be told that they are not getting things right, not least the establishment,[205,217] but not necessarily without some justification.[246] So, as Lewis intimates, disruption has to be managed positively by all the protagonists, including hospices themselves, if effective joint working is to follow.[237] This means that as hospices develop they need to understand their role and functions as Owen pointed out.[241] In this regard, their ad hoc proliferation had already been challenged by the Wilkes Report (1980)[247] that considered the organisation of terminal care services for cancer,[62] and by others[248,249] supported by Saunders, in relation to buildings: “We want to spread care and too many buildings might stand in the way of doing that. We will have to give care in a variety of ways if it is to be integrated into the general hospitals and the general community services”.[250] Consequently, she says, communities must search for what is right in their own situation. In that regard, the Wilkes Report recommended an integrated and coordinated system of care,[247,251] with similar language being used in the Health and Care Act 2022.[206]

The emerging national profile of hospices prompted the formation of Help the Hospices (HtH) by the Duchess of Norfolk in 1984, to support and lobby for hospices. It rebranded as Hospice UK (HUK) in 2014 as a membership body.[62,119,237] HtH soon became involved in hospice funding and although a commitment was made by government to match voluntary income it rarely transpired locally.[62] From the outset, there was a degree of uncertainty in relations between hospices and HtH,[252] partly because of its perceived relationship with the British Medical Association[119] and partly as a result of hospices’ hard-fought independence. However, Saunders thought it beneficial that HtH formed from outside the medical world.[253]

The establishment of the national body took place shortly before palliative medicine became recognised as a sub-speciality in 1987.[71,254] The word ‘palliative’ derives from the Latin *pallium,*[255] meaning ‘to cloak’ or ‘wrap around’ and in 1890, Dr Herbert Snow published *The Palliative Treatment of Incurable Cancer*.[256] ‘Palliative care’ was couched by Balfour Mount, a Canadian physician, in 1974;[228] this was for linguistic reasons in French Canada with the intent to transfer ideas from hospices into other settings.[257] In a recent blog about the terms ‘hospice’ and ‘palliative care’, Clark wrote about hospices successfully capturing the imagination of the public and challenging the system to change[258] but that a prerequisite for progress was a change of name that could break out of the association of ‘hospice’ with charity, religion and ‘homes for the dying’ to something broader.[258] In England, a year before Mount introduced the phrase ‘palliative care’, Lamerton had already written about the hospice concept operating in different contexts saying: “[that teams] will no doubt find ways of implementing ‘hospice care’ appropriate to their time and place”.[59] Nonetheless, Saunders came to accept Mount’s phrase, his rationale for choosing it and its defining value for applying hospice principles in many contexts around the world.[259] Mount held Saunders in the highest regard, ascribing her the title “hurricane Cicely” and at the end of her life he said he was honoured to write an obituary.[260,261]

2.4.2 Growth pains, heterogeneity and flux

Whilst international recognition, the scale of development and mainstream awakening to the needs of those near the end of life brought opportunities, they also led to tensions such as those between local and national perspectives, transpositions of terminology[34] to palliative care and palliative medicine[228] and concerns about bureaucratisation, medicalisation and absorption into the mainstream.[34] For Weber, these are natural growth pains from the infancy of a charismatic idea to the maturity of major development,[43] and as Ahmedzai points out, there are benefits to routinisation that should not necessarily be seen as a constrictor of innovation or wider benefit.[262] However, hospices had to face the implications of potentially being drawn into the NHS like a moon into the gravity of a planet through what has been called ‘institutional or coercive isomorphism’, i.e. organisations putting pressure on and drawing others into their cultural norm that, in turn, changes priorities.[255,263,264] Also, as James and Field intimated, they had to discover that redevelopment and reinvention are less likely where charismatic or creative leadership is inhibited.[265]

In 1988, Woodward-Carlton’s perspective describes tension amongst hospice colleagues between the integration that Wilkes commends[247] and their hard-fought independence.[172] Woodward-Carlton sees the desire for integration linked to funding, legitimacy, scale and status enhancement whilst independence is guarded out of concern to protect the qualitative aspects of the hospice concept that could so easily be squeezed out in a cost-saving bureaucracy.[172] Reflecting on social movements more broadly, Woodward-Carlton recognises growth pains and their subsequent tensions, citing McAdam who claimed that “the establishment of external support linkages threatens to tame a movement by encouraging insurgents to pursue only goals acceptable to external sponsors”.[266]

McAdam also states that hospices in North America that became increasingly integrated lost some of their idealism and their critical force was blunted.[172,267]

Since that period there has been much debate about agency, politics and contestation in institutional analysis. Schneiberg and Lounsbury[268] argue for recognising the more human dimensions of institutions,[264,269] and with Di Maggio's consideration of isomorphism[61,263] scholars now view this field as more dynamic and complex, commending an approach to social movements and institutions that "celebrates the heterogeneity of actors, multiple logics and practice variation".[268] This view focuses less on singularity and more on fields as "multiple, fragmented and contested".[268] It includes considering how "historical legacies of prior social action become embedded in existing fields"[268] and subsequent overlaps such as "the dependence of … organizations in one field on organizations in another".[268,270] Thus, a more preferable start point than singularity for understanding organisations involved in social change lies in recognising the kaleidoscope that develops over time and the blurring of boundaries between what started out as a contestation against institutionalised orders but evolves through proliferation and infiltration.[264] Consequently, returning to my earlier planetary metaphor to depict the context of the hospice movement and mainstream institutions 50 years on from its twentieth-century inception, a more helpful image would be of multiple moons and planetary systems with their myriad of orbits, contrasting masses and gravitational influences.

A number of studies point to heterogeneity, cultural and practice variation in hospices. For example, aspects of internal and external influences on hospice development are assessed by Baron[61,255] and Hodges[264,271] with both recognising the challenge of amorphousness, multiplicity and perspective. Baron's ethnographic study examined the culture, or as he describes it the 'soul',[272] of a hospice in northern England and concluded that its integrative culture embraced beliefs around patient-centred, empathic and holistic care with perspectives amongst some staff tracing back to Saunders. In this regard, he says that the pioneers' views can sometimes be so deeply held that colleagues become inordinately resistant and unchallengeable.[255] Baron offers a metaphor of culture in the hospice as a river flowing through an organisation over time that he describes as a "multiplicity of amorphous and overlapping meanings which, though they have a central flow, are constantly in flux".[273] Similarly, McVey's study recognises this complexity, saying that there are multiple cultures and sub-cultures in hospices and that it is their relationships with collaboration, strategy and leadership that ultimately determines effectiveness.[274] Hence, with Watson, McVey commends 'leading from the middle'[275,276] in order to optimise the benefits of hospices' cultural and organisational complexity.[274,277] As Watson and Shannon state in their abstract: "Middle managers have the ability to operate as organisational strategists … In their unique position, they are closer to the values and culture of their organisations".[276]

In this regard, complexity and chaos theories are vast fields[278] so there is a risk of over-simplification here; hence I make only a fundamental point in relation to this study. Complexity leadership theory recognises the "interconnected actions of individuals acting out of personal values or vision"[279] from which a degree of order emerges. This leads to the emergence of more organic, distributed leadership approaches to counter historical, individual leadership models to cope with more complex situational contexts.[280,281] This applies to organisations interacting directly with others and "non-linear interplay between heterogeneous agents".[279] In this regard, there is an "edge of chaos that exists between order and disorder, stability and instability continuously changing"[279] that, like weather systems, it is wise to accept and work with.[282] However, traditional leadership approaches sometimes wish to subdue chaos or deny it because they fear mayhem.[279] According to Houchin and MacLean, leadership that simply seeks to reduce conflict and maintain control does not adapt and often only survives for a short time.[283] Thus, if meta-organisations, such as NHS England or HUK, adopt a one-size-fits-all approach for independent hospices across England, this carries the potential to constrict because a bureaucracy of that nature is not usually designed to be adaptive,[279] as Di Maggio argues.[263] As a recent worldwide survey states: "The world's private and public sector leaders believe that a rapid escalation of complexity is the biggest challenge confronting them".[284] In this context, a preparedness to accept heterogeneity and the history from which it has emerged, with all its inherent edge-of-chaos turbulence,[285] is more likely to enable "adaptation, learning and evolution"[286] through a decentralised approach than those that seek to create order through singularity, uniformity and isomorphism.[287]

In 2019, Hodges examined how institutional context impacted hospice development. Addressing a rise in the number of dementia sufferers, and hospice responses, she concluded that institutional factors were so strong and resistant that ‘de-coupling’ and a new social movement may need to emerge to meet the dementia need collectively.[271] In other words, the institutionalisation of hospices may be so rigid that it sometimes prevents innovation. In her study, Hodges defined hospice in two ways: functionally as “care provided by hospice organisations” and symbolically by saying “the definition will depend on the perspective and interpretation of the individual or group being asked and how that makes sense to themselves”.[288] Like Saunders’ ‘living idea’ and Baron’s ‘flowing river’,[273] Hodges’ symbolic understanding of hospice is easier to experience than define, mirroring the dynamic of flux and heterogeneity that Schneiberg and Lounsbury speak of.[268] Following this line of thought, some organisations ‘de-couple’ to survive, as “a result of heterogeneous organizational fields that exert multiple and often contradictory pressures on an organization”.[289] Thus, for hospices working in a diverse sector heterogeneity may lead to similar developments.

As I have shown, both Baron and Hodges identified significant strength of feeling and belief within and between hospices that can sometimes be highly resistant to change. In 2006, Harmer described an aspect of this in hospices in New Zealand that, like most English hospices, are modelled on St Christopher’s.[290] He wrote of differences of outlook amongst staff, reflecting the multiple cultures that McVey encountered.[274] Identified tensions are between motivations of altruism and professional achievement and between conserving the hospice and developing it. Thus, one group is seen as tearing the heart out of the hospice and another as romantics whose time has passed.[290] These situations grew because of what is described as a ‘tyranny of niceness’ and ‘helpless tolerance’ where managers did not confront differences amongst staff and were simply nice to them.[290] Consequently, according to Harmer, whilst adversarial tension can be beneficial in commercial organisations, in a hospice it carries the potential to divert attention from patients and upset teamwork.[290,291] Harmer’s suggested solution is to explore common ground and to enable protagonists to see “that neither party has the awful intention to bring the downfall of the other, unless of course it is true”.[292] That common ground may be more likely to be found where there is leadership at every level in an organisation, as the work of Houchin, McLean and Watson infers.

Offering a psychological explanation of cultural tension in 1994, the hospital chaplain Peter Speck wrote about ‘chronic-niceness’ that can develop amongst colleagues who unconsciously “collude to split-off and deny the negative aspects of caring daily for the dying”.[293] He argued that a collective fantasy of niceness develops that protects colleagues because “the relationship between the carers and the dying can often arouse very primitive and powerful feelings which are disturbingly not-nice”.[293] So, in order for mutual niceness to maintain its protective shield, the not-so-nice feelings are pushed outside the close-knit caring group. This, Speck says, may take the form of challenging managers or others whom they perceive do not understand or value their day-to-day pressures. Whilst a lack of understanding might be present, this may also indicate that the carer group is adopting a paranoid-schizoid position to guard their collective screen.[294,295] As this attitude grows, the group believe that only they know best, a position which can be reinforced by the receipt of thank you messages from bereaved families describing them as ‘angels’.[296,297] Speck describes ‘chronic-niceness’ as an aspect of the desire to be the perfect carer but being a good-enough carer dispels this impossibility,[298] allowing the real conflicts around dying to exist because “inevitable imperfection is no longer felt as bitter persecuting failure”.[296,299] According to Sallnow and Taylor, chronic-niceness may also be fuelled externally by idealised hospice images and, from a philosophical perspective, palliative care seeking to ‘own’ death.[300-302] I should add that some hospices have been subject to other forms of self-serving behaviour of a fraudulent nature that have been very painful and costly.[303,304]

It is important to note here that approaches to address anxiety amongst nurses are sometimes a challenge to the relationship nursing that Saunders encouraged. An example of this can be seen in a report on a study of a nursing service in a general hospital and the subsequent discussion published in the *Nursing Times* in 1988.[305] Here defensive techniques to protect nurses from anxiety, as recommended by Menzies-Lyth, include splitting up the nurse-patient relationship to prevent a nurse “coming effectively into contact with the totality of any one patient and his illness”.[306] In a challenge to Menzies-Lyth’s recommendations by a registered nurse working in mental health, this technique is summarised as "preventing nurses becoming too intimate with any one patient".[307] In stark contrast, Saunders saw her nurses accompanying patients on a difficult journey and sharing their vulnerability,[57,195] saying:

> "Inevitably in this work we are made to face our own attitude to death, our emotions and fears … we cannot and should not avoid becoming personally involved at times … we will fail our dying patients if we always remain hidden behind our technical functions and avoid the true personal contact for which they so often are longing."[308]

The resilience that Saunders espouses for those working in the field comes through a search for meaning and the development of an individual and corporate philosophy that she knows is usually painful, hence her emphasis on teamwork, community, dedication and shared belief in their cause.[309]

Kubiac and Surikova also indicate tensions emerging through the development and institutionalisation of hospices.[88] They point to a shift in western societies from religion as the centre of social moral life to that of the individual in terms of plenitude, personal autonomy and personal expectation.[310] Kubiac argues that individuals only understand their significance and meaning in their broader social context rather than in isolation. This was recognised from the outset of modern hospices in, for example, Lamerton's story of Mrs N where the hospice enabled her to travel to her ancestral home in Grenada to resolve issues at the end of her life.[311] Thus, hospice colleagues carry an inherent tension trying to understand and recreate a patient's natural milieu especially if they are limited to providing care within a hospice building.[88] This is significant in this study because it points back to the importance that Saunders (and her predecessors) placed on the value of the philosophical, social and environmental elements of the hospice idea.[71,107] It also points forward to the rationale for public health approaches to death and dying where people have their family and friends around them and benefit from more personal control made possible by power shifts from professionals to community and individuals.[312,313] However, in practice, according to Whitelaw and Clark, there is an added complication, namely that public health approaches *within* palliative care are just that, one discipline embedded within another.[314] As with Baron, Hodges, McVey and Speck, Kubiac unpacks tensions and flux that exist within the make-up and landscape of hospices.[88]

2.4.3 The need for change

Moving forward in time past the millennium, following a population-based needs' assessment for palliative care in 2004 by Peter Tebbit[315,316] and Mike Richards' End of Life Care Strategy for the Department of Health in 2008,[317] Charles Leadbeater and Jake Garber at Demos, funded by HtH, published *Dying for Change* in 2010.[15] This was the outcome of work commissioned by HtH which had recognised the need for hospices to understand shifts in demography and disease, the changing health and social care landscape, the effects of austerity and, the twenty-first century case for finding the best ways to support people at the end of life.[16,318] Demos were asked to lay out the ground and the subsequent Commission into the Future of Hospice Care considered the role that hospices can play in the broadening context.

The book *Dying for Change* looked at how we die in Britain and how it could be better. Inspired, in part, by the deaths of Leadbeater's parents this was more than an academic exercise. Demos's main argument is that: "Most people want to die with family and friends nearby, cared for, free from pain with medical support available when needed"[319] and "Not everyone will want to talk about how they want to die. But everyone should be offered the opportunity to do so".[320] They commended going back to a pre-modern emphasis on family and community combined with the best support that modern professions and technology can provide. Getting people to talk about how they want to die is seen, by Demos, as critical, otherwise efforts to improve services will be, as they say, like groping in the dark especially when personal control and agency are seen as central to a dignified death (including the debate over euthanasia).[321]

In terms of hospices, Demos perceives them as one element in the end-of-life picture alongside hospitals and care homes and the 12,000 members of the Dying Matters Coalition.[322,323] Amongst Demos's ten recommendations is the creation of 'home hospices'[324] where people can die closer to home and medical support can be called quickly and easily if it is needed. However, Demos also issues a warning to hospices, saying that having started out as disruptive innovators challenging the medicalisation of death, "they are [now] in danger of becoming incorporated as niche providers of specialist services within the system they set out to change".[325,326] The conclusion to *Dying for Change* acknowledges that their recommendations will challenge entrenched interests and will need new ethical and legal frameworks but at the same time they make a salutary plea, saying “we are the first society in human history that can plan to honour people *while* they are dying not just *after* they are dead. That is why we need to find better ways to die”.[327]

When *Dying for Change* was presented to the annual HtH conference in 2010, Charles Leadbeater, alluding to the high quality but limited impact of hospices, summed up by saying that the hospice imperative is to address the paradox of “intimacy at scale”.[328,329] In other words hospices need to do more than provide a “bit of heaven for the few”[119] and find new ways to help more people end their days comfortably and meaningfully.

2.4.4 Preparing for change

The work of Leadbeater and Garber was well received by hospices, prompting questions about how hospices should move forward so, in 2011, HtH established a Commission into the Future of Hospice Care.[16] For context, this was at a time when a Palliative Care Funding Review, that included hospices, had been undertaken in England. It reported to the Secretary of State for Health in 2011.[330] However, apart from some pilot projects that ran over the next few years, the Review did not result in long-term funding improvements for hospices serving adults.

Dame Clare Tickell chaired the Commission, supported by Professor Barbara Munroe, CEO of St Christopher’s Hospice. Many contend that this is the most comprehensive series of reports carried out under the title of ‘hospice care’ since the millennium with its messages continuing to be echoed today,[331,332] including from respondents in this study. Hence the detailed attention afforded to its findings in this literature review. The Commission set out to inform hospices’ strategic position and support them in addressing significantly changing and growing needs at the end of life.[16,18] Over two years, it produced a large volume of work through 18 formal documents under themes set out below, followed by its final report.[18,333]

Here I summarise salient points in relation to the strategic focus of this study:

(1) The unique contribution of hospice care

This work area involved responses from 700 users and many members of the public. Feedback in 2013 chronicled terrible times made easier through the passion, love, comfort, care and security of hospices.[334] Hospice care is described as being about more than buildings and patients. Hence, respondents talk about support from staff, the friendship of others in similar situations and the value of the hospice atmosphere and environment, saying "it feels like a big family home with friendly and happy people ready to welcome us in … it feels like being wrapped in a big comfort blanket"[334] (echoing the meaning of palliative).[63,71] Hospice care is described as the gold standard and people trust hospices to help them in dark times.[334]

However, respondents to the Commission say they want to be heard more and that hospices should include patients, carers and families constantly as partners.[335] As Parkinson, a senior hospice nurse explained more recently, maintaining these vital relationships is a challenge for hospices in a world of increasing bureaucratic accountability.[336] Participants also comment that hospice staff can be poor at receiving negative feedback (which is an aspect of chronic-niceness;[296] note also the Commission's final report comment that some believe hospices are "insufficiently self-critical").[337] Respondents also speak of hospice availability and quality being patchy, the need for care in frailty and dementia, that they want to be more in control (with some including ending life as a choice) and that hospices have a role in creating a more death-literate society.[335]

(2) Future needs and preferences for hospice care

The 2013 report on current and future needs examines data which include population changes, mortality trends, preferred place of death and experiences and outcomes of hospice care. It confirms, for example, that the UK population continues to age and that 50% of people still die in hospital although the majority say they would prefer to die elsewhere[338] but that "dying well, regardless of where it happens, can be more important".[339] However, it does *not* discuss views about assisted dying. The report shows high levels of satisfaction for hospices.[338]

(3) Operating principles for development

This theme considers principles to guide the future development of hospices.[340] These are on leadership, workforce, data, reconceptualising hospice care, reaching out, marketing, and facilitating conversations in society. The report says, “shifting perceptions … requires … a coherent awareness and understanding of what hospices do”.[341] Amongst the strengths of hospices, this report refers to fleetness of foot and hospices being *more* than providers. Whilst amongst weaknesses, a lack of horizon-scanning and thinking beyond buildings are mentioned.

The 2012 report on preparing for the future identifies four areas of performance: outcomes; fairness; choice; and sustainability, stating that, “hospices need to start articulating a clearer narrative … about (1) what we are and (2) what we offer”.[329] The authors also speak of hospices needing to be more “geographically promiscuous [and] to provide care to people who need it regardless of location”.[342] What they do not do is discuss hospice (as opposed to hospice care) and what the ‘living idea’ means today.

(4) New models and approaches to hospice care

This 2013 report on future needs and preferences[343] also looks to the future, highlighting data from previous reports and the issue of hospices becoming specialist niche providers only, thus echoing comments in *Dying for Change*.[343] Opportunities emphasised include supported beds in other settings, halfway-house models, more advanced care planning and improved data. Hospice strengths include their scope of services, being at the heart of communities, their volunteer base and the capability to build on trusted expertise. Stronger business acumen is also seen as vital for economic survival. In addition to hospices being providers, the report mentions roles of empowerer, educator, innovator, collaborator, coordinator and data collector but not disrupter. It speaks about being more open about the concept of death as a social process, that hospices do not always know best and need to listen more but, again, there is little, if any, reference to the ‘bigger idea’ of hospice, as Lamerton called it.[134,343]

(5) Workforce requirements for the future

This theme includes reports on voluntary and paid colleagues in hospices published in 2012.[344,345] They stress the importance of volunteers, potential volunteer-led services and a more extensive deployment of volunteers.[344] Scenario planning looks at future skills in the context of health and social care moving from industrial age to information age healthcare. Thus, alongside skills focused on patients and families, they include: business management; brokering; navigating; customer relationships; outreach; education and information technology but not lobbying or campaigning.[345]

(6) Funding opportunities

This 2013 report considers voluntary income for hospices.[346] It recognises opportunities for increasing income through improved marketing, use of databases, learning from other hospices and charities, improved communications and branding, and working nationally.[346] However, there is little mention of income through the development of businesses other than retail and lotteries. Statutory income is beyond its remit because of the Palliative Care Funding Review.[347]

(7) Partnerships and collaborations

The Commission developed a toolkit to help identify potential partnerships to enhance hospice care.[348] The Commission says that hospice care is integrated and that hospices must use their independence to challenge and campaign for high quality care to meet unmet need[16] and advocate on behalf of unheard voices.

In 2009, Help the Hospices said: “A hospice is not just a building, it is a way of caring for people. Hospice Care aims to improve the lives of people whose illness may not be curable”.[349] In 2012, Help the Hospices describes hospice care as “community engaged palliative and end of life care in all settings for patients, families and carers”.[350] In supporting that definition, the Commission recognises the reciprocal relationship between hospices and local communities and the risks of hospices becoming too insular. It says that hospices can also be integrated with the NHS, care homes, local authorities, social care and others to maximise resources which also offers a platform for hospices to share their expertise, find collaborative solutions and influence future direction. This works both ways where hospices recognise that they have much to learn from other providers, communities, families and patients. Hospices are one participant in a large field of endeavour.[16]

The toolkit[348] refers to eight forms of collaboration: inspiring others; ‘stealing’ best practice; sharing skills; licensing products; commercial agreements; shared product development; joint ventures and acquisitions. They cite good practice and urge hospices to think about what they are good at in terms of *head* (critical thinking), *heart* (hospice philosophy) and *hand* (operational elements).[348]

Summing collaboration up in its final report, the Commission talks about:

> "a shift from a top down model of health care driven by medicine to a bottom up, co-created model in which individuals and networks of users are at the forefront of caring, supported by information. In this new model, professionals move into a position of facilitation and partnership".[351]

Inevitable tensions require hospices to adopt roles of advocacy, diplomacy and facilitation which in turn demand new approaches to leadership,[16] thus echoing Greiner,[154] Parry[152] and Watson[275] discussed earlier.

(8) Education and training

The Commission sees the picture of end of life characterised by old age and chronic illness. It sees current hospice care as largely reactive and suggests the addition of proactive and preventative components. Some participants in this workshop point to the importance of the underpinning philosophy and approach of hospice care but it is not followed up in this 2013 report.[352]

In terms of control and risk, the Commission notes that participants believe that professionals often feel protective of patients and are risk averse but a better approach would be for patients and hospice staff to agree acceptable levels of risk together. As one participant says, "the issue of the expert consumer is important to consider – we are not used to working with these users in hospice care".[353] The report concludes that education and training are important components of high quality hospice care,[352] as indeed they were for Saunders.[192]

(9) Research

At the beginning of the Commission's report, Commission member Murtagh speaks of four hallmarks in Saunders' vision for St Christopher's: expert pain and symptom control; compassionate care; teaching and research.[354] However, Murtagh says: "we find ourselves in a situation today where … research is not universally welcomed, encouraged and embedded within hospice care".[354] Recommendations include: developing a culture of inquiry; communicating the value of research; hospice research networks; partnerships with universities and national organisations assisting with funding.[355]

(10) Conclusion

Summarising the Commission's work, the chair states: "How we care for the most vulnerable at the most vulnerable of times is a measure of our compassion as a society".[356] They also say that hospices will need an unrelenting focus on the needs of all those living with life-shortening illness and that they must be advocates for those less visible.[356] The vice-chair points to the place of hospices in the wider system, proactively engaging others, finding ways to deliver services to populations, holding fast to the disadvantaged and not becoming "ossified and irrelevant",[357] adding that "a home death is not a guarantee of a good death".[357] The final report says there is a compelling case for hospices to adapt and reinvent their contribution to care through five key steps: preparing for significant change; strengthening understanding of hospice care's contribution; establishing hospice care as a solution to future challenges; strengthening collaboration and leadership.[16]

A review in 2016, conducted by Heather Richardson (who had also been a member of the Commission Support Team in 2011-13)[358] working as an independent consultant,[18] identified mainly positive responses from hospices to the Commission.[18] However, the Review also included criticisms, for example: "the usual suspects were involved"[359] making the findings the "same old by the same old";[359] it was "an intellectual adventure for a few"[359] and it was not representative of hospice diversity because "one size does not fit all".[19] In this regard, one person describes the sector as "a 'loose and baggy monster' in which there are more differences than commonalities".[359] A further criticism is of imbalances such as detailed attention to medicine but little to social care although the chair and vice-chair both emphasised the needs of the most vulnerable in society.[16] Gale, a hospice CEO, also questioned the Commission's formalising approach to volunteering as a negative constraint.[360] Finally, one critic says the Commission "identified nothing new and hospices have limited resources available [to enact recommendations]".[359]

Comparing the Commission to the Hospice Conference of 1980 there is an obvious contrast in titles and subject material with the latter written up as "Hospice: the living idea"[26] and the Commission being about the future of "Hospice Care".[16] Thus, whilst careful attention is given by the Commission to why hospices are here and how they might develop, less is given to what hospices are and the guiding concept or 'living idea' that underpins them. That is not to say this was entirely absent because the Commission does call, for example, for hospices to reconceptualise hospice care[340] but as critics point out, the inherent tensions and differences between hospices are perhaps underplayed.[18]

2.4.5 Reinvention

In 2017, when nothing significant had come from the Palliative Care Funding Review and hospices were experiencing growing financial pressure, HUK produced *Peering over the Precipice: a toolkit for hospices to survive and thrive.*[361] Following the Commission's lead, this pamphlet points to organisation life-cycle theory and Handy's second curve mentioned earlier in this chapter.[40] The toolkit's key words were "explore, adapt and change".[362]

At the 2018 HUK conference, Tracey Bleakley, the new CEO of HUK, said: "it's not just about hospice anymore"[10] as she talked about hospices working in different settings. This begs questions about what is meant by 'hospice'. However, the main thrust of the speech was "preservation, evolution and revolution".[10] Bleakley argued that whilst there is a legitimacy to what hospices do currently, they are not meeting more need. Hence, she argued that there needed to be revolutionary thinking through joint ventures to meet, for example, the dementia and frailty agenda. This is reflected in 'A five-year strategy for the hospice movement 2017 to 2022'[332] produced by HUK that carried forward principles from the Commission (which is why it is not given detailed consideration here since that ground has already been covered). Its four strategic goals are: "extend our reach to enable hospice care to be delivered in any setting; tackle inequality and widen access to hospice care; work with communities to build capacity and resilience; and empower a strong dynamic and responsive hospice sector".[332] Aware of multiple definitions for palliative care, end-of-life care and supportive care,[258,363,364] the strategy included a definition of hospice care that emphasises working with and within local communities.

Immediately after Bleakley's speech, the joint CEOs of St Christopher's Hospice, Richardson and O'Leary, made a presentation entitled, 'Reinvention of hospices:

Of course, but how do we do it?'[11] picking up the term 'reinvention' used by the Commission. They explained why hospices are here in terms of a changing picture of dying, population ageing, increasing isolation and social death, desire for personal control and public involvement and an NHS under stress. In short, suffering at the end of life continues. To address this, Richardson and O'Leary said in their presentation that hospices must: "keep the essence of personalised, holistic, relational care that is enabling; be fundamentally connected to communities; be prepared to work in opposition to the mainstream; be committed to pioneering; be focused on practice, education and research; and draw on people's personal, vocational desire to be compassionate".[11] Their perspective on reinvention is about becoming change-agents in terms of recognising "what is important to the system and what is important to people and communities".[11] This, they said: "will hold the tensions inherent in these questions and the space for radical transformation around end of life, strengthening the voice and contribution of people and communities in it".[11] Reinvention means stop treating palliative care like a very special speciality and acknowledge that the majority of end-of-life care does not need intervention with 95% of care at the end of life being undertaken by informal carers.[11,191]

Richardson and O'Leary also referred to Handy's second curve and its message "before you reach your peak start something new"[40] because, they said, the current hospice model is almost exhausted. In practical terms, the form of reinvention that Richardson and O'Leary espouse is hospices supporting a societal shift to less 'doctor knows best', to more meaningful personalisation and community action which "would likely mean buildings and beds were less important. Families and communities would instead have centre stage".[11] This, in turn, hints at their approach to sustainability.

Interestingly, a year earlier, the CEO of Earl Mountbatten Hospice, Nigel Hartley, gave a presentation[209] (that he refreshed in 2019)[365] about a new hospice model. His ideas resonate with those of Richardson and O'Leary. Stepping back to look to the future, Hartley quotes Saunders who spoke about their work as: "a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring him hope and consolation to the end".[168] Hartley shares the same start point,[209] refers to messages from the Commission[16] but adds that not all hospices are the same, echoing the ‘one size does not fit all’[19] criticism.

Looking ahead, Hartley recognises that innovation is by its nature poorly packaged with rough edges, born through inspiration and imagination. This is a call for colleagues to take risks when pushing on.[209] His reinvention sees hospices moving from being the ‘place to be afraid of’ to the ‘go-to’ place for those needing care near the end of life and also for the curious and the inquisitive.[209] Thus, he says, rather than cosseting the few, hospices should focus on how to enable people to live.[365] Hartley sees this requiring collaboration in all directions with a maturity to give away power and agree who leads on what. At the same time, quoting Twycross’s concern about the danger of “moving from the creative and disruptive influence of charisma to the cosy ambiance of routinization”,[366] Hartley pleads for boldness, disruption, values and social justice which includes being “in sync with our community and engaging in everyday conversations – assisted dying; dementia; loneliness; old age and frailty”.[365] Following these presentations from Bleakley, O’Leary, Richardson and Hartley, I note that HUK returned to the title *Dying for Change* for their annual conference in 2019.[367]

2.4.6 Power and practice diversity

At the same time as these calls for reinvention, issues of power and practice diversity are raised. Power in end-of-life care is one that Sallnow gives attention to when she examines the impact of a new public health approach to end-of-life care in St Joseph’s Hospice, Hackney.[313] Her study “situates reciprocal relationships as its foundation and forces an assessment of the nature of power and agency in all interactions”.[368] As the hospice hands over power it changes attitudes through reciprocity making the hospice a more accessible and responsive community resource to be shaped as local people see fit. The impacts of this include reduced loneliness, improved well-being and changed attitudes of local communities to the hospice. Sallnow describes moving beyond a one-way relationship where communities draw on resources from hospices, to collective social capital where there is more two-way permeability between a hospice and its surrounding communities enabling both to learn more from each other. This in turn allows “more people to consider and reflect on the issues of death and dying, meaning more engage with it as a universal issue”.[369] In short, the project creates space in which people can share and change their own experiences and, through agency, influence wider issues for end of life in society.

Gale's study of community hospice volunteers uncovers power being held back through a preference for applying professional rules rigidly that has a detrimental impact on the work of volunteers.[360] Gale points to examples where volunteers are not part of what she calls a rigid hospice system and therefore have more flexibility and less constraints than those in her study.[370,371] This lack of space to function, which at its roots is about professional control, stops clinicians seeing the value of friendship that volunteers create which is so beneficial to patients. Hence, Gale not only points to weaknesses in hospice approaches to volunteering but also to the importance of power shifts that the likes of Sallnow, Richardson, Hartley and Kellehear stress as critical in terms of population-wide improvement to end of life.[372,373] This is emphasised in the Lancet Commission Report on the Value of Death: "power resides within systems and the systems often maintain the interests of those holding power".[374] Hence, new developments like the Death Doula movement challenge professional approaches and strengthen the role of family members and companions[375,376] alongside other approaches such as compassionate communities.[377,378]

In a literature review of new public health approaches to palliative care, Sawyer et al. see them as a brave new horizon that view death not just from one constituent component but "from the perspective of the whole … a greater breadth of creative source including, but not limited to communities".[378] They see models like compassionate communities being showcased and evaluated or used less rigidly in a framework through which people can determine their own approach. Of particular interest to this study is their conclusion that in a field of diverse philosophies there are many tensions and complexities that have to be worked with: "We must also not fail to accept that such tensions are indeed the essence of what gives life to a situation [and] if we take a reductionist approach and ignore them in our quest for an idealized perfect system we will soon return to the place where we began".[379]

As with Death Doulas a lack of singularity can be seen as confusion[375] but it can also be celebrated as practice diversity.[376] This is perhaps one of the main reasons why the efficacy of approaches emanating from communities continues to be challenged[372,380,381] i.e. because communities are rarely unanimous in their aspirations and development.[196] Looking backwards Sawyer et al.'s embracing of diverse philosophies echoes Saunders' coexistence of opposites[1] and the flux in Baron's river.[61] Looking forwards, it relates to Schneiberg's heterogeneity[268] and figuratively, to the dynamic map of an end-of-life system in the Lancet Commission Report that vividly displays the intricacies, tensions and dynamics that hospices operate with and respond to in the field.[382]

2.4.7 Ambitions and definitions

Following the work of the Commission, the National Palliative and End of Life Care Partnership, of which HUK is one of the 27 members, produced a document (seen as significant by respondents in this study) entitled *Ambitions for Palliative and End of Life Care, 2015-2020.*[383,384] Here an integrated approach was called for through local leadership. The six ambitions are: each person seen as an individual; each person gets fair access to care; maximising comfort and well-being; care is coordinated; all staff are prepared to care and each community is prepared to help.

In 2021, the second iteration, this time with 35 members, pointed to building on lessons from Covid-19, emphasising again the importance of collaboration and the aspiration that "access to good palliative care should be seen as an essential human right".[385] The Partnership seeks to break the cycle of papers calling for change listing the same ambitions as those in the first edition.[386] These *Ambitions'* documents lay out the needs that the end-of-life care sector aim to meet and, as such, are another important identifier of why hospices are here today.

As in the HUK strategy, the *Ambitions'* documents append definitions for palliative and end-of-life care. Clark discusses recent controversies describing how 'palliative care' grew out of the achievements of the modern hospice movement and became a term that could be used without the historic association with hospices.[258] He moves through World Health Organisation definitions of 1990, 2002 and the disagreements of 2018, saying, "the conceit may simply be in the notion that there can even be a universal definition of something that is so multi-faceted, global in reach, and still in a phase of rapid evolution".[258]

Issues in the development of definitions include incorporating public health approaches, moving beyond people with a very limited remaining life-span,[387] how and when palliative care is implemented, responses to acute epidemics and humanitarian emergencies, and incorporating serious health-related suffering (SHS).[364] In particular, broadening the concept upstream beyond end of life is seen as proving difficult because of palliative care's well-known roots in care of the dying.[24] Whilst in one way this is not surprising, in another way it is, because as far back as 1981, Klagsbrun said that "hospice care is a misnomer when applied only to the dying patient [because all treatment of illness can benefit from the hospice approach]".[388] So here again, in relation to this study, there are many multifaceted rapidly evolving ideas and tensions for hospices to orientate and draw energy from.

2.4.8 Sustainability

In July 2020, following issues of sustainability raised in preceding years, the failed funding review and the first wave of Covid-19, HUK sent a survey to all hospices as part of its Future Vision Programme[389] that aimed to "strengthen the sustainability of palliative and end of life care for the future".[390] The Programme focused on integration and merger in the context of a new NHS plan with hospices seen as providers of services. The Programme set out nine principles for sustainability with "negotiate a new deal with commissioners" centre stage and integration and collaboration seen in relation to mainstream services and other hospices. It highlighted using hospices' local influence, digital working, effectiveness, deploying the right people and competitive career pathways. Commercial revenue generation is understood in terms of diversifying income.[391] However, many respondents felt that in the central component of the discovery phase of the Programme: "the survey questions could lead to foregone conclusions".[392] So, whilst the Programme creates suggestions for hospices in relation to economic development and sustainability, questions remain about how representative the findings were.

In June 2022, the Director of Finance and Interim CEO of HUK, Craig Duncan, published lessons from his hospice Financial Sustainability Index.[331,393,394] The index examined hospices' audited annual financial statements and its basis included reserves' levels, surpluses or deficits and the size of the hospice. Duncan described a quarter of hospices being in a strong financial position and a quarter being under severe financial stress, saying: “The generous support the government provided during the pandemic relieved the immediate pressure … but the worry is that this will soon return unless there is a fundamental change in the way hospices are funded”.[331] Through feedback from hospices, Duncan explained that older hospices often have a better legacy pipeline and smaller hospices find it disproportionately harder, in financial terms, to fulfil escalating regulatory requirements. Other difficulties included poor leadership appointments, overreliance on specific income streams, such as legacies, and adverse publicity from regulators. Further feedback highlighted poor investment in income generation and business efficiency but few geographical fluctuations in England.[394] The closure of St Clare’s Hospice, Jarrow, in 2019 and reductions in reserves for half the hospices in the country shown in published accounts for 2020 signal ongoing financial challenges for many hospices.[4]

National restrictions for the Covid-19 pandemic in England began in March 2020 when half of the interviews for this study had been completed. Because of this, reports for that period, which were necessarily limited in scope, are not covered in depth by this literature search. However, for context, I make reference to a HUK and the Nuffield Trust report on the role of hospice services across the UK during the pandemic, published in May 2022. Its key findings were that hospices supported an estimated 300,000 people in 2020/21, more care was delivered at home, the complexity of patients’ needs probably increased, virtual contacting grew significantly and, despite the restrictions, the number of people supported during 2020/21 only reduced slightly. The main criticism from the researchers was the limited data available.[5]

The HUK and Nuffield Trust study did not cover issues of financial sustainability but others did. For example, the University of Warwick’s qualitative interviews with 13 senior hospice managers of the impact of Covid-19 on hospices does include issues of sustainability, pointing to the need for a “long-term, sustainable and resilient funding settlement, with additional statutory funding that recognises hospices as a core part of the health and care system”.[395] From a business model perspective, another study looking at four hospices in the Midlands, revised in 2017, identified that the dynamics of the funding model, scarcity of skilled staff in fund-raising and an extended demand for care were key issues affecting sustainability. The authors concluded that the hospice model was becoming more businesslike but more complex and under pressure too, resulting in more hospices drawing on reserves.[396,397]

Finally, in the context of why hospices are here today, a Marie Curie report about the Covid-19 pandemic describes how extreme pressure on the NHS adversely affected end-of-life care.[398,399] Since pressure on the NHS has not eased subsequently, some argue that this has resulted in more deaths,[400,401] making the continued need for hospices all the more apparent considering the scale of their work.[5,402] Nonetheless, Stephen Kirkham a former consultant in palliative medicine argues that whilst the work of hospices is needed they would be more cost-effective if they were incorporated into publicly funded services.[12]

2.4.9 Living the idea

In concluding this review of the landscape around the purpose, concepts and development of hospices in England, I refer briefly to a new living history project entitled *Back to the Future* produced by St Christopher's Hospice in 2023.[192] Triggered by hospice pioneer Mary Baines,[197] the project reflects on the life of the hospice from its inception to today in order to help shape its future. Its headings point to the roles of the hospice, for example, in responding to the experience of suffering, in being prepared to be radical and in supporting innovation. 'Hospice', as a concept, is described in the stories as a way of life and what emerges is "a new ecological map that describes the relationship between the hospice and people's physical, interpersonal, health and wellbeing".[403] *Back to the Future* reveals philosophical and social foundations that profoundly affect attitudes to life and interactions with death. In this regard the work concludes by saying: "What is clear is that the organisation's value and impact lies in the people who have participated in its life".[404] In other words, the hospice with its underlying concept embodies a developing philosophy, a dynamic community and an organic resource through which people live their lives and serve others.

2.5 Summary

This chapter describes the landscape through which hospices emerge, their purpose, concepts and development, and it draws on reference points from organisation, business and leadership studies, some of which are prompted by respondents in the study.

The literature shows the developing purpose of hospices in their changing contexts, an organic multifaceted concept described by their modern founder as a ‘living idea’ that in its application sees hospices taking on many more roles than providers of care. The breadth of hospice work is seen no more clearly than in the outputs of the Commission, and yet its critics argue that it did not give enough attention to the kaleidoscopic differences between hospices, in their concept and application, that have emerged since their twentieth-century proliferation. Thus, whilst there have been numerous calls in the twenty-first century for hospice reinvention and integration *en bloc*, and considerable attention is given to hospice care, palliative care and end-of-life care, less has been afforded to hospices’ conceptual foundations and their developing heterogeneity. This project addresses these issues by exploring and visualising the purpose, concepts and development of English hospices through the rarely used lens of today’s CEOs. From an organisation studies’ perspective, I am investigating the ‘why-when-where’ and ‘what-who-how’ of hospices, and from an epistemological perspective I am exploring their ‘social construction’ that I will now explain.

Chapter Three: Methodology and Methods

3.1 Introduction

In this chapter I explain the philosophical basis of the study, the qualitative methodology and the methods that I adopted to conduct the research. I also describe how I adapted within the remit approved by the Ethics Committee when pandemic restrictions were introduced in March 2020.

3.2 Methodology

3.2.1 Social Construction

In social research, ontological and epistemological issues tend to arise together, albeit with different terminology.[405] The three major epistemological schools of thought are objective, subjective and constructive.[405] Whilst recognising, as Denzin and Lincoln state, that no single paradigm holds a monopoly on truth,[406] for the purpose of this study I adopt a social construction perspective.

Social construction has roots in philosophy, sociology and linguistics. It is concerned with how meaning is socially constructed between people and within communities and societies.[407] Unsurprisingly, these ideas emerge from a process of dialogue that dates back to the sixteenth century.[408,409] Consequently, there is “no single description of social constructionism”.[410] However, there is a “family resemblance”[410] that accepts that our knowledge of our environment is not drawn from the objects or individuals around us but from what people construct between them in social interaction. Constructionists see meaning in relationships when people and consciousness have an encounter, relate to each other, interact and construct shared ‘intelligibilities’ or ‘intelligibility nuclei’.[408] For Kenneth Gergen, a social psychologist who developed views on socially constructed knowledge, an intelligibility nuclei is a community that shares a set of interrelated propositions.[411] (In *Realities and Relationships,* Gergen sometimes refers to intelligibility nuclei as clusters of intelligibility or simply, intelligibilities.)[412] In arguing this position, Gergen draws on Martin Buber’s ‘I-it’ and ‘I-thou’ discourse that looked beyond the sick society of the Third Reich to a world of more meaningful relationships.[413,414] As his starting point, he quotes Buber who says: “In the beginning is the relationship”.[415] Similarly, he cites George Herbert Mead, who says: “Selves can only exist in relationship to other selves”,[416,417] and therefore, any sense of ‘self’ is developed by our *interaction* with the social relationships that flow around us.[416]

In explaining social construction, Vivien Burr, a social psychologist, says: “As a culture or society we construct our own versions of reality between us”[418] and consequently, different social constructions can result in various social responses. For example, in terms of death and dying, social action may give primacy to treatment of the medical condition, to improving the experience of the subject or to both. Thus, in social construction how we perceive the world affects how we build our shared existence within it.[408] Considering hospices from the perspective of social construction, relationships are central to their development and this is borne out by the historical literature. For example, Saunders’ concept of hospice germinates in the relationships between clinicians, patients and families; hence she calls it a ‘living idea’.[26] Similarly, Lamerton and Klagsbrun emphasise the critical importance of ‘interaction’ in their new approach to care of the dying, and more recently St Christopher’s living history project describes the continued importance of ‘hospice’ as a community whose value and impact lies in the people who participate in its life.[30,192]

Thus, within this paradigm, I am seeking to understand the social constructs, social development and social actions of hospices. To do so I focus on Gergen who poses a question that is pertinent to this study: “How are we to understand stability and change in the theoretical perspectives occurring in knowledge-generating communities?”[412] In answering the question, as I have stated, Gergen describes an intelligibility (nucleus) as a group of people that share a common understanding. [419] He also says: “Society is, in effect held together through common participation in a system of signification [and] we may view social understanding as a by-product of participation within the common system”.[420] Then considering how intelligibilities develop, Gergen draws on Immanuel Kant, one of the central Enlightenment thinkers and his epistemological consideration of “what one ought to do”.[421] Gergen reflects on this in the context of “doing otherwise” or “acting in contradiction to ought”.[422,423] Similarly he refers to Hegel, a nineteenth-century German philosopher who contrasts being, non-being and absence,[44,424] and therefore argues that “up” is understood in relation to “down” and “emotion” contrasts with “reason”. Saying that words on their own carry no meaning and only do so in the realm of human interaction in and between intelligibilities,[420] Gergen posits the idea that communities' perspectives are not only understood but also shaped by "signifiers of what they are not" and he describes this as "implicit negation".[422] Consequently, citing the French philosopher Michel Foucault, Gergen sees knowledge and power interacting[425] as individuals within an intelligibility nuclei use informal and formal power to challenge those who do not follow the "right thinking" of their group.[425] This is significant because, unlike Karl Marx, the revolutionary socialist, Foucault did *not* see power residing in capitalist employers because "power is not a property of any person or group, but is something that in theory anybody can exercise through discourse".[426] As such, Foucault sees Marx's view masking "the vast array of differences between people and their situations and the many different kinds of power relations in which they are caught up".[426]

Relating this to hospices, their *modus operandi* involves relationships within their organisations, their communities and with the broader landscape in which they operate. Thus, following Gergen's argument, to understand their social construction it is important to consider the "implicit negation" within and around them. These contrasts show what hospices are *not* and that hospices, and the intelligibilities that are in proximity with them, have the power to reshape each other. Thus Gergen observes that there is more than a "binary tension between a unity and an opposition"; he sees multiple negations and interactions taking place between intelligibilities.[422] For social constructionists, this is the 'reality' of social construction.[427] To visualise these dynamic interactions and tensions, Gergen turns to Algirdas Julien Greimas, a Lithuanian literary scientist and prominent member of the Parisian school of semiotics.[428]

3.2.2 Semiotics

Semiotics is a field in itself reaching back to Augustine of Hippo, a theologian and philosopher from the fourth and fifth centuries.[421] It has roots in logic and linguistics in the search for meaning in language systems and signs common to individual cultures. Greimas was a significant proponent of the European tradition in the twentieth century.[428] Its philosophical application is concerned with how: "reality is represented and … constructed [through signs and symbols]".[429] As in social construction, values and meaning are understood in relation to logic or value opposites with Greimas arguing that 'love' has no meaning without 'hate' in a similar way to Hegel who contextualised 'being' with 'absence'.[430] For Greimas, the study of semiotics enables a visualisation of these tensions, negations, contrasts and opposites.

The semiotic square is designed to be a visual representation of conceptual networks.[428] It is derived from Aristotle's 'square of opposition' where, in terms of logic, he describes a series of contraries and contradictories that were subsequently drawn in diagrams by Apuleius and Boethius.[431] Following a similar approach, Greimas's semiotic square displays 'concepts of opposition' as a fundamental structure of meaning. His squares show contrasts and differences between elements in the diagram and these can be layered on top of one another to enhance understanding.[428,432] Semiotic squares look more like rectangles with various arrangements of four, six or eight boxes within them. As I show in Figure 2, Gergen applies this to social construction by creating an example of a semiotic square to demonstrate the multiple interactions within and between intelligibilities.[25,425] He presents a diagram with vertical, horizontal and diagonal contrasts between two polar differences and four contrasting internal boxes. Using the centuries-old empiricist-rationalist debate that Kant eventually drew together (by saying: "All our knowledge begins with experience … [but] it does not follow that it all arises out of experience")[433] Gergen depicts the intelligibility nuclei of 'empiricists' (Box 2) and the intelligibility nuclei of 'rationalists' (3) in opposition.

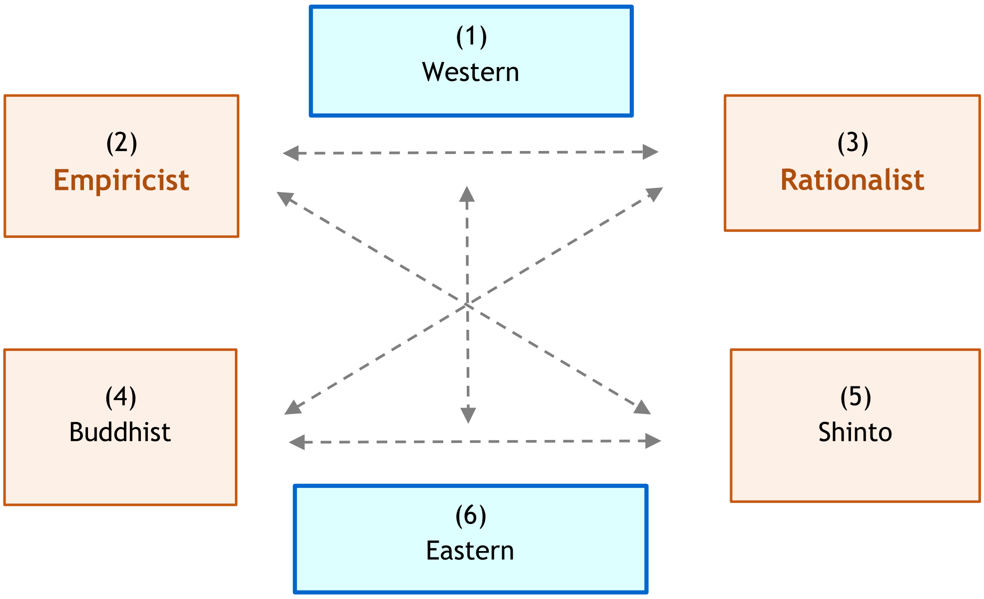

Figure 2 *- Gergen's semiotic*[425]

The purpose of his semiotic is to show that there are more tensions around these intelligibilities than the historical binary discourse that they became locked into. To demonstrate this Gergen contrasts Buddhism, an existential philosophy underpinned by elaborate theory (4), with the Japanese native belief system Shinto which is founded on myth, ritual and oneness with nature (5).[434] Then, displaying an even wider context, he shows empiricists, rationalists, Buddhism and Shinto sitting between the polarity of Western (1) and Eastern (6) thought.[425]

Thus, as one would expect from a social construction perspective, Gergen argues that, “The elaboration of any given nucleus of intelligibility depends for its meaning and significance on that which it is *not* – including its contraries, its absences, and those positions made possible from its various pairings”.[425] Accordingly, what makes up a given position (adopted by an intelligibility) comes from opposition, contrasts and distinctions that Gergen visualises using Greimas’s semiotic construction.[435] For hospices these positions could be various perspectives and sub-cultures[274] *internally* or between different hospices and other organisations *externally*.

Gergen then says: “To return to the alternatives laid out in the semiotic squares, we find that effective counters to any given nucleus of intelligibility must optimally rely on suppositions contained within alternative nuclei”.[435] Continuing his argument using the language of semioticians, Gergen states: “The fundamental unit of meaning is contained *in the relationship* between signifier and signified … within the linkage between the two … [and consequently] meaning is not born of action and reaction but of *joint action*”.[436] Gergen explains that in the social realm an individual’s actions are a primitive ‘signifier’ while the responses of another person are the ‘signified’.[436] However, for Gergen, this interaction only has meaning in the context of other signifiers in society and the intricate relationships or joint actions that take place amongst them.[436] Gergen’s semiotic displays a panorama that reaches beyond the insularity of the empiricist-rationalist discourse to the horizon of Eastern and Western thought. Extrapolating from Gergen’s thinking in relation to hospice development in the twentieth century, the NHS *action* was to neglect death, the hospice *reaction* was to focus on the care of the dying and the higher-level significance or meaning that emerged *from this relationship* was that dying and death gained greater prominence nationally and internationally.[437]

Incorporating or adopting a social constructionist multi-layered perspective of social ontology in this way opens up: “a whole complex of meaning possibilities”[438] when considering why hospices are here, what they are and how they have developed and might develop going forward. Hospices are places of contradiction, ambivalence, tension, paradox and multiplicity. As intelligibilities, hospices are not monochrome or one-dimensional but multifaceted social constructs sitting amongst a myriad of others in what could be envisaged as a multi-dimensional structure. Indeed, from this perspective, a criticism of the Commission into the Future of Hospice Care of “one size does not fit all”,[19] i.e. of hospices being viewed with singularity, can be appreciated whether or not the criticism is justified. Furthermore, this links with Schneiberg and Lounsbury commending a focus on social movements in institutional analysis that is less on “singularity” and more on fields that are “multiple, fragmented and contested”.[268] This then raises the question of how hospices as intelligibilities and social constructions might be described. Having seen the value of Gergen’s approach, I have chosen to follow his portrayal of Greimas’s semiotic square. As such, when I explain my approach to the analysis I will describe how I have applied semiotics to the study of hospices.

3.2.3 Qualitative approaches

This research study brings new insights to our understanding of the purpose, concepts and development of hospices in England. Figure 3 shows the research process and how I began with the development of my research questions, considered what kind of knowledge I was looking for and established my epistemological position. I then determined a suitable methodology and methods consistent with that approach. Following approval from the Ethics Committee, I proceeded with sample selection, pilot interviews, the two main tranches of interviews, transcription and analysis. I also arranged to be interviewed myself by a PhD colleague using the same framework for the research interviews. This was purely as an aid to reflexivity (See also Section 3.5.3) and was *not* included in the research data.

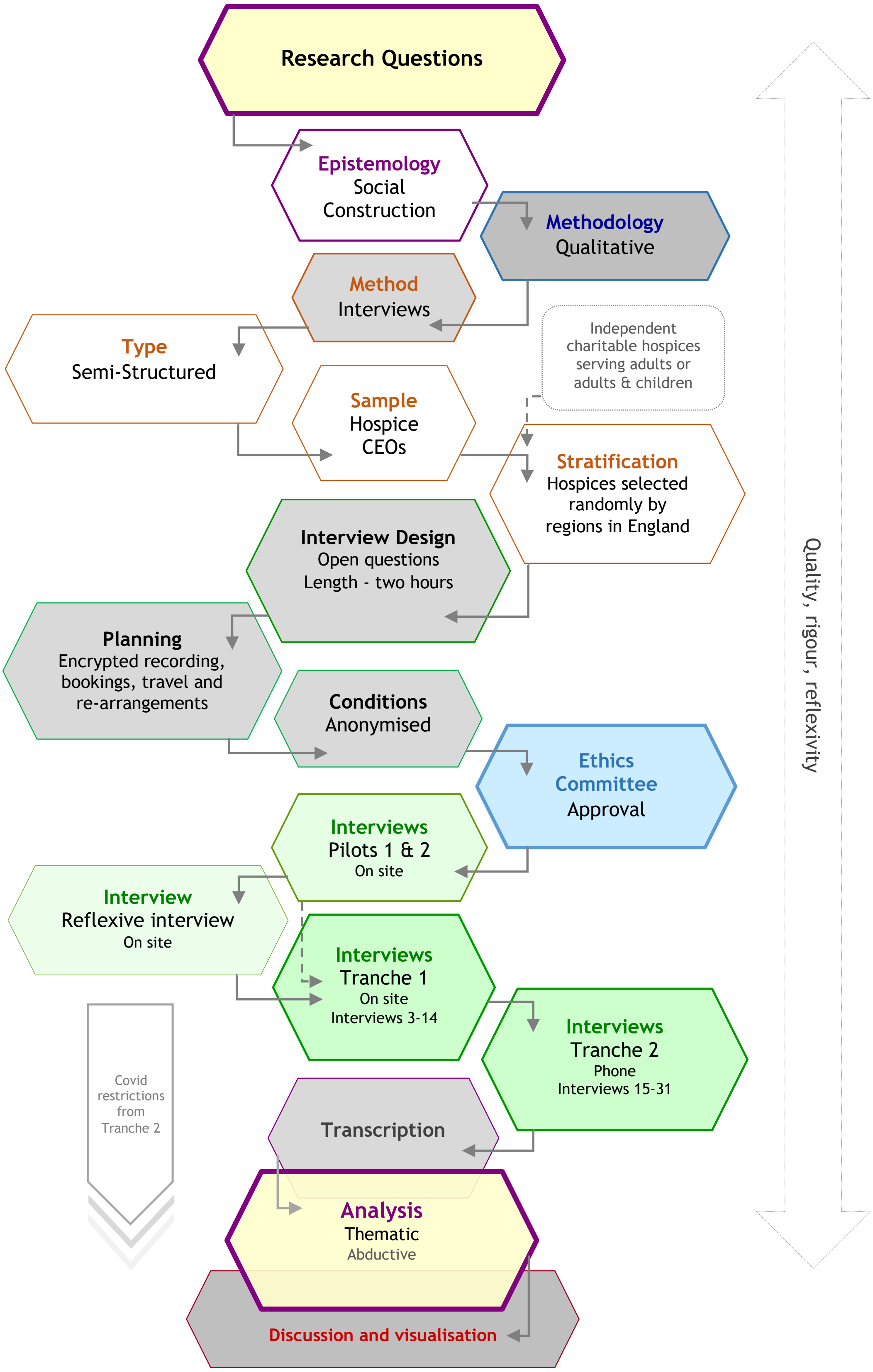

***Figure 3:** The research process*

In studies of health, palliative care and hospices, qualitative methods are used frequently,[439] such as, for example, in Baron et al.[273] and Sallnow,[313] cited in the literature, who both conducted studies in hospices. As I show in Figure 3, research begins with a problem to be addressed and questions to be asked within the context in which they exist.[440] Qualitative data collection, often used by researchers with a constructionist perspective,[440] has its roots in Weber's concept of 'Verstehen', a German term meaning to 'understand' social phenomena considering that "in much qualitative study the perspectives of those one is studying are the empirical point of departure".[441] This method offers rich, deep data,[440,442] and based on the understanding that hospices are 'intelligibilities' and social phenomenon, [61,443] a qualitative approach is the best fit for this study. At the same time its strengths and challenges like those of any research methodology have to be understood and where possible mitigated against.[440] Having considered the methodologies that researchers use in the field of health and social care, I chose to adopt a qualitative methodology because of its effectiveness in examining social phenomena and producing rich data.

3.3 Methods

3.3.1 Introduction

Having explained my epistemological position and my rationale for the selection of a qualitative approach, I now describe methods employed in this study. Figure 4 shows the six-year timeline. For the first three years I was working full-time as the CEO of St Catherine's Hospice, Lancashire, whilst working part-time on my PhD. When I had gained approval from the Ethics Committee and commenced the interviews Covid-19 and its associated restrictions came into force. The next significant landmark was September 2020 when I retired from St Catherine's and my lead supervisor Professor Clark retired at the end of the same month. My new supervisors were Dr Whitelaw and Dr Krawczyk.

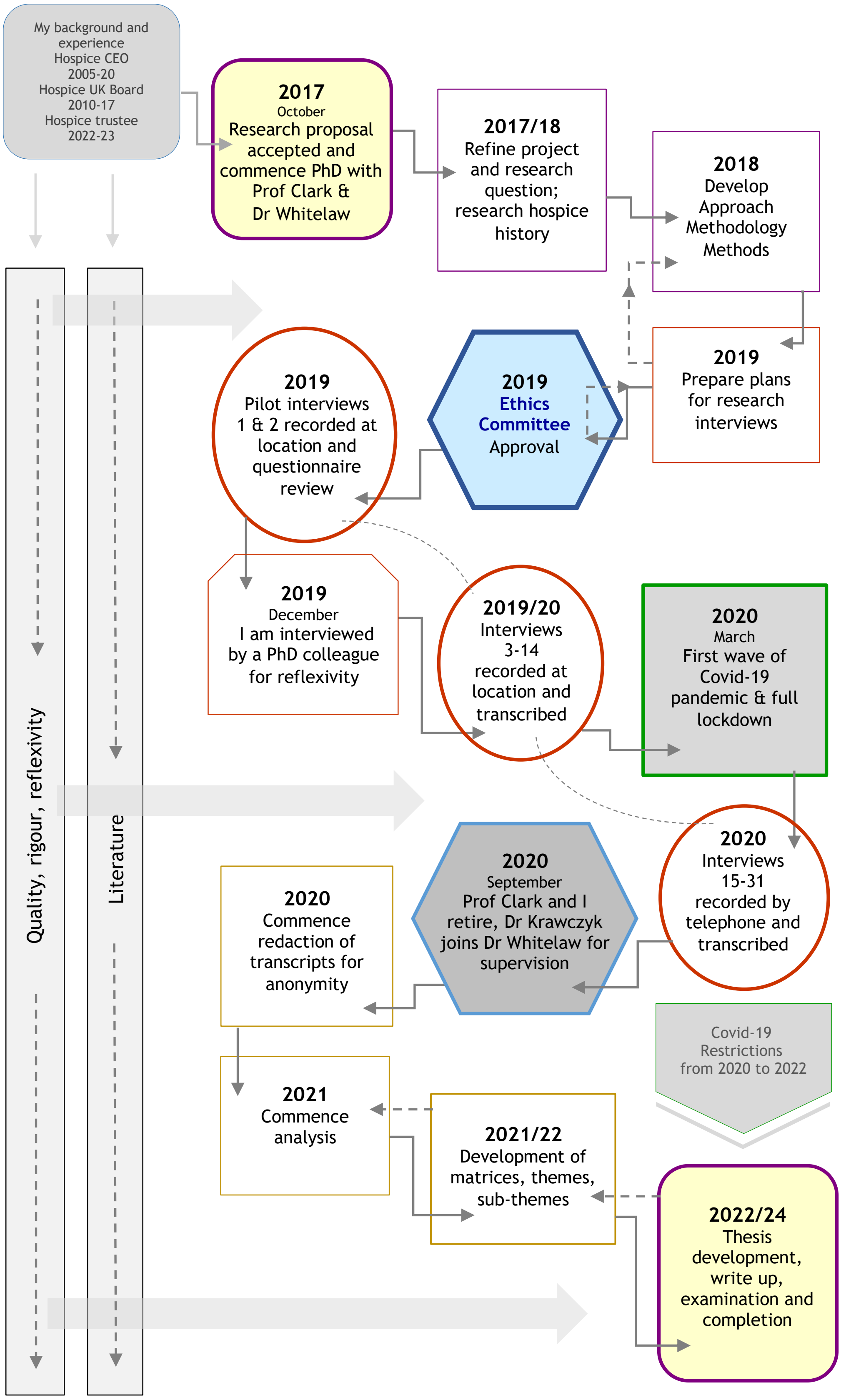

***Figure 4** - Study Timeline*

3.3.2 Interviews

Having considered suitable methods for a qualitative study, I chose one-to-one semi-structured interviews. They offer greater flexibility than structured interviews[444] and allow respondents to express themselves whilst at the same time avoiding the serendipitous nature of open interviews.[444] In designing the semi-structured framework (Appendix 1), I wanted respondents to speak within the remit of the research area but in their own way. The format had three main headings: Yesterday, Today and Tomorrow. These offered a historical timeline to enable the research questions to be answered which I matched in my review of hospice literature. The two pilot interviews enabled the interview framework to be assessed and respondents found the format logical and helpful. Interviews lasted approximately two hours. They were audio-recorded through two security coded smartphones with Lexicom dictation software that is used for recording confidential patient records from which they were transcribed securely.[445]

3.3.3 Sampling: hospices

Since this study is about hospices, viewed through the lens of chief executives, I sought a representative sample of hospices to produce data from across the country. In this regard, there is a lack of clarity in determining scale in qualitative studies compared to quantitative ones. However, I noted that Hagaman and Wutich considered that in a multi-site examination of meta-themes, 20 to 40 interviews across research sites would achieve saturation.[446] Whilst this was by no means definitive and each study is different, it offered a guide with the keyword being ‘saturation’ in terms of sufficient information power.[447] In the next sections, I will explain the rationale behind my sample selection.

3.3.3.1 Hospices in England

The number of hospices in the UK and England requires detailed explanation to clarify the focus of the study. The following information was provided by the Director of Finance at HUK, Craig Duncan. First, there are issues of definition. Membership of HUK is open to organisations whose primary purpose is to provide and support hospice care alongside other criteria set by the Board of HUK (listed below). Each organisation is required to confirm that they continue to meet these criteria when they renew their annual membership. To be eligible, hospices must confirm that:

a. Their primary purpose is to provide hospice care as defined by HUK
b. The hospice is registered with the Care Quality Commission (or country equivalent)
c. They submit an annual return to the Charity Commission, or country equivalent, or comply with 'Community Interest' regulation requirements.
d. Their accounts are subject to independent scrutiny as required by law in the jurisdiction in which the charity is registered.

Second, in counting the number of hospices, one considers whether to count an institution or the number of its facilities. The national charity Sue Ryder (named after the volunteer who worked in the Special Operations Executive in WW2[448] and founded Sue Ryder Care),[449] operates a number of hospices in, for example, Keighley, Peterborough, Henley-on-Thames and Leckhampton. Similarly, the national charity, Marie Curie[254] (named after the French-Polish scientist) operates nine hospices in, for example, Belfast, Glasgow and Liverpool. In the HUK list of member hospices, hospices are listed by institution. Thus, Sue Ryder and Marie Curie are each listed separately as one hospice.

Third, not all hospices are charities. Some hospices are funded and managed by the NHS. These used to be eligible for membership of HtH but are not eligible to be members of its successor, HUK, unless they have an associated charitable group that provides added support (similar to parent support groups for schools). Fourth, whilst the vast majority of hospices are members of HUK there are a small number that choose not to be and may be omitted from some hospice lists. Fifth, sometimes hospices close or merge and some organisations become new members of HUK, so numbers change over time. Sixth, there is the issue of whom hospices serve. This is principally adults or children but some hospices serve both. Seventh, one hospice is a community interest company rather than a company limited by guarantee. Eighth, many institutions such as care homes or hospitals provide palliative care but it is not their primary purpose.

As of 2019 when I began interview preparation, and as advised by Craig Duncan, there were 210 institutions eligible for membership of HUK and 208 registered members across the four nations. Of these, 15 were affiliated to the NHS. According to the HUK/Haysmacintyre Hospice Accounts,[450] there were 193 independent charitable hospices in the UK (of which 180 were in England) plus two national charities, Marie Curie and Sue Ryder. Due to the constraints of the study, I could not interview CEOs in every hospice in the UK so I selected in the following ways:

- **Hospices in England**. Hospices in the four nations have different NHS funding arrangements. In England, whilst NHS funding approaches have local variations they work to the same overall funding framework. By selecting from England only I removed the variable of different public funding regimes.
- **Independent charitable hospices**. This is by far the majority of hospices as the HUK/Haysmacintyre figures show.[450] By selecting only from this group, I removed the variable of those hospices that operate on a different financial and organisational basis such as, for example, NHS Hospices or national charities.
- **Hospices serving adults or adults and children**. I did not select from hospices that care for children. This is because hospices serving children have different funding arrangements, work to different clinical models and some operate regionally rather than locally.[451]

I therefore chose to interview CEOs working in independent charitable hospices in England serving adults or adults and children because: they represent the vast majority of hospices; they face similar clinical and social challenges; they operate within the same public funding framework; and they generate the majority of their income through charitable means and for a similar cause.

3.3.3.2 Hospices by region

In looking to stratify the sample, I elected to do so by geographical region to achieve a solid layer of evidence from hospices across England. This would potentially draw data from a mix of hospices.

Of the 144 independent charitable hospices caring for adults (or adults and children) in England, I had to select a useful sample size. This is not a quantitative study, so it was a matter of reasonable judgement. Following a number of deliberations with supervisors, I elected to interview approximately 20% of CEOs of independent charitable hospices serving adults (or adults and children) in England. This worked out at 28.8 rounded up to 29. In planning the research process in the summer of 2019, which was before Covid-19 arrived in England, I understood that the final number interviewed might be less if obtaining interviews proved difficult or, as discussed earlier, if responses reached saturation and were only producing more of the same. It could also be slightly more if there were delayed responses and backups had been selected or saturation had not been reached.

The next step was to stratify by geographical region within England. This could have been by a number of means, such as by county or electoral boundaries. At that time, there were 48 ceremonial counties, 82 metropolitan and non-metropolitan counties and 501 electoral constituencies in England. Another method would have been to use postcode areas: there were 121 in the UK, each of which had approximately 20 districts. The problem here was that there were so many and hospice footprints were spread across boundaries in terms of where a hospice is physically based and its population served, making it obvious that this option would be very complicated.

Another possibility was to consider where hospices leaders in England meet for quarterly meetings. In 2019, this was in ten geographical groups. I considered that selecting 20% of hospices from each regional cluster was manageable offering minimal confusion and optimal clarity. I selected interviewees from these regions because:

- CEOs are familiar with them and they are recognised by HUK
- They offer a geographical spread across England
- They include a mix of hospices, urban and rural, large and small etc.
- The number is manageable
- There are no difficulties with catchment areas or overlapping boundaries
- The weaknesses of this approach could be mitigated. For example, the number, size and age of hospices in each region vary but since CEOs were being selected from all regions of England there would still be a cross-section of hospices for a meaningful qualitative study.

I then had to consider how I would stratify within each regional cluster. Options included, for example: choosing a geographical spread across each region; selecting hospices by type, such as large or small, urban or rural, size of population, age of hospices; selecting by population mix in terms of demographics, ethnicity, poverty etc.; selecting on grounds of interviewee availability; selecting according to the number in each region; or random selection. Having considered all these, I decided that if I stratified too deeply, the stratification could quickly become unbalanced, confused and meaningless, especially if changes became necessary. So I selected 20% from each regional cluster randomly.

To remove bias, I used Excel's random number selector where one types in the action box =*randbetween (1,20)* and a random number appears. Repeated clicks provide more random numbers between those numbers. It is quick and easy to make the selections. The minor downside is that one cannot check original working because the system never repeats the same choice of number which is why it is random. I numbered each hospice in each region and using Excel made the selections with reserves in case of cancellations.

3.3.4 Sampling: CEOs

In addressing the research questions through interviews, my next obvious question was whom to interview. As I have explained, the majority of hospices in the UK are independent charities and they are also companies limited by guarantee.[4] Within these organisations, the CEO tends to be the only full-time member of staff with oversight of all aspects of the organisation. Roles such as medical director, directors of nursing, finance, education, communications, business development, people, engagement, income etc. carry responsibility for specific areas. The other main group of people who have complete oversight is the board of trustees. Whilst trustees are the highest level of executive they do not work at an operational level on a day-to-day basis.[452] Hence, CEOs offer a potentially helpful lens and, on a practical note, as a sitting CEO I had an excellent calling card that, as it happened, turned out to be vital during the Covid-19 pandemic when CEOs became extremely busy and hard to access.

Critical determinants for the success of the study were the availability and willingness of participants: some CEOs might not have wished to be interviewed; there could be an interregnum; a CEO might not like the researcher; a CEO might be desperately busy; a hospice might be in crisis and not want intrusion; a hospice board might forbid an interview; or, as things turned out, there might be a national health emergency. I decided that where it was not possible to gain an interview, I would simply go to the next CEO on the regional list that had been selected randomly. If I ran out of available CEOs in a region I would turn to the list of an adjoining region. There were no hospice CEOs that I did not wish to interview and I knew that I would find out during the research if any CEOs did not wish to be interviewed (which did not prove to be the case). A very small number of hospices do not have chief executives. If random selection resulted in a hospice being selected that did not have the post of chief executive, I would make another random selection. Again, this did not prove to be necessary.

Whilst many interviews had to be rearranged due to the Covid-19 emergency, there were only two that could not be conducted. One hospice had a senior vacancy which meant that the CEO was covering two key roles in the pandemic and did not have time to be interviewed. At the second hospice, the CEO was on extended leave. Table 1 shows the number of interviews conducted by region.

Hospice regions	Total number of hospices in each region in 2019	Number of independent charitable hospices serving adults (IHSA)	Number of interviews completed
North East	10	9	**2**
North West	31	28	**6**
Yorkshire and Humber	18	15	**3**
East Midlands	15	10	**2**
West Midlands	20	16	**3**
East of England	17	16	**5**
London	16	10	**2**
South East Coast	16	13	**3**
South Central	18	11	**2**
South West	19	16	**3**
Total in England	**180**	**144**	**31** (21.5%)

Table 1 *- Interviews by region*

Whilst it was a challenge conducting 31 interviews in all regions of the country with the added complication of Covid-19, the process ran relatively smoothly.

3.3.4.1 Respondent details

As described in Section 1.2, the aim of the study is to explore the purpose concepts and development of hospices through the eyes of hospice CEOs. In doing so I wanted CEOs to be candid in order that a picture of the inner workings of hospices could be seen. To achieve this, I set out to build trust and rapport with interviewees which included not asking personal questions that they might deem intrusive or unnecessary. I also wanted to understand the professional background through which they were looking because I knew that this would vary significantly. As such, at the commencement of each interview, I noted their presenting gender and asked brief questions about their professional experience. In providing this information I have been mindful to protect anonymity.

Of the 31 respondents in the study, 16 presented as female and 15 as male. All were working as hospice CEOs at the time of their interview. Their experience as a hospice CEO ranged from a few weeks to over 20 years with 18 having five or less years in their current role. Ten respondents said that they had held previous roles in a hospice before becoming a CEO and for five of these this was as a CEO in another hospice. Five respondents had over 30 years' experience working in end-of-life care that spanned back to the 1990s.

In terms of each CEO's professional background, 17 came into their hospice role from outside the health and social care sector and 14 from posts within it. Thirteen respondents described their professional background as clinical with the majority being nursing. A further thirteen respondents described their professional background as leadership and management. Three CEOs said that their professional background was in finance or economics. Some CEOs explained that they had a diverse professional background working in different sectors.

3.3.4.2 Respondent roles

In explaining the roles and responsibilities of a hospice CEO I have used the introduction to a job profile from an independent charitable hospice in England which I have anonymised. This post was advertised in 2020 i.e. during the interview period. Key points in the introductory summary stated that the post holder will:

- Be an inspirational leader, creating an environment and culture where best practice, governance, relationships and professional development flourish
- Be accountable to the Board of Trustees for the overall leadership, management, performance, governance and development of the Hospice organisation
- Build alliances and partnerships with other organisations including the NHS and act as an ambassador for the Hospice
- Work with the Board to develop and implement the strategic plan, ensuring alignment with Hospice objectives
- Lead all operational and business activities to ensure effective, efficient and safe running of the Hospice, meeting all clinical, statutory, financial, regulatory and legal requirements
- Work collaboratively with the Board of Trustees and senior team to continuously improve the experience of patients and their families, responding to changing community needs and patient requirements
- Develop and sustain income streams, financial controls and the ongoing financial security of the Hospice
- Have good knowledge of the hospice movement, charity sector and current issues in health and social care

I consider this to be a fair reflection of the role of respondents in the study. The bullet points show that the oversight held by a hospice CEO ranges from the provision of clinical and social care, to generating income and the safe and effective governance and management of a hospice as a business and charity. It should also be noted that whilst hospices are much smaller than hospitals they are inspected under the same regulatory regime and this level of accountability has become increasingly demanding for hospice leaders.

The job profile also recognises the importance of inspirational leadership that encourages colleagues to flourish and work effectively with others. In this regard, size matters. Whilst larger hospices bring the challenges of leading, motivating and managing a bigger team there are naturally more people to turn to and greater economies of scale to absorb the unexpected. In smaller hospices, CEOs have fewer people and lower economies of scale to call upon which can be critical when funds are stretched and savings have to be made.

Finally, what is not shown in the profile are the inherent tensions that CEOs have to navigate such as those between NHS strategies and community needs, and between service provision and local empowerment. Similarly, the profile does not show the varying emphases that different hospice leaders make and the conceptual perspectives that underpin hospice development which is the focus of this study.

3.3.5 Ethics

Approval was received from the College of Social Sciences, Research Ethics Committee to commence on 1 July 2019 (Reference 400180173). My application included the facts that interviews were anonymised as much as possible and that respondents were being asked to respond with their professional view rather than that of the organisation where they worked. The Ethics Committee reminded me to be careful as an insider interviewer. The degree to which I am or am not an insider is worth mentioning. I was an insider in that, at the time of interviewing, I was also a hospice CEO but I was an outsider in relation to the organisation in which the interviewed hospice CEOs worked, and for the latter part of the study I have been retired. Nonetheless I have been mindful of this issue throughout the study and discuss it in Section 3.5.3 on reflexivity.

3.3.6 Covid-19

Having received approval from the Ethics Committee, I developed the semi-structured framework, arranged the recording equipment and planned the pilot interviews. I decided that the major task of transcription would be carried out within two weeks of each interview and this was achieved in all but two cases which took a week longer.

The purpose of the two pilot interviews was to create the opportunity to adjust the semi-structure and to allow familiarisation with practical matters such as recording and timing. Since there were no radical changes following the pilots, data from them is included in the results. The first pilot interview took place on 15 October 2019 and the second on 1 November 2019. My own interview was on 13 December 2019 and was conducted by a student colleague using the same framework as the pilots.

The 14th interview took place on 26 February 2020. Interviews 1-14 were face to face, with 12 of them taking place in the hospice where the CEO worked and two at an agreed location. At this point, I had completed 48% of my target. On 5 March 2020, the first death from Covid-19 occurred in the UK and on 23 March the Prime Minister announced a national lockdown.[453] Hospices were immediately involved in supporting the NHS, with some admitting patients with Covid-19. Income from charitable sources for hospices is on average 70% of their total income[4] and swathes of this stopped at that time, for example, through cancelled fund-raising events, closed charity shops and cafés, cessation of lottery collection, cancelled education and training sessions, conferences and room bookings.

Hospices had to enhance controls for Covid-19 infection prevention, move as many staff as possible out of buildings, limit footfall (and in relation to visitors this presented significant ethical issues), access sufficient personal protective equipment (PPE), introduce new protocols for handling the deceased,[454] manage staff sickness and protection (including those who were in designated at-risk groups),[455] manage volunteers, maintain good communication and coordination and deal with all manner of other unexpected issues. There were deep emotional and moral issues for CEOs, including concerns for colleagues' lives, especially after a nurse from one hospice died of Covid-19 in April 2020.[456,457]

This meant that hospice CEOs (including me) became extremely busy and the availability of time for conducting or participating in research all but disappeared. It was also the case that the March 2020 lockdown was severe, with movement more heavily restricted than at any other time in the pandemic. This was a concern because I was halfway through data collection and at one of the most critical points in the study. I did not wish to lose momentum and, at that time, no one had any idea how the pandemic would unfold. To maintain progress, I began interviewing CEOs by recording telephone calls because this had been included as an option in the approval from the Ethics Committee. This meant that all the interviews were conducted and recorded on a one-to-one basis either face to face or by telephone.

Making appointments was a significant challenge. However, I managed to make headway and by October 2020 I had completed 31 interviews. The 31st occurred when a respondent unexpectedly contacted me after a long delay. By this time, I had achieved a sufficient level of saturation. There are obvious differences conducting interviews in person and by telephone because one does not have the same breadth of communication over the phone. However, the data is rich in all the interviews which can be seen in the results.

3.4 Analysis

In this section, I describe the processes of transcription, redaction and the thematic approach to analysis. I also explain my application of semiotics and criteria used for theme selection.

3.4.1 Transcription and redaction

To access the data, the audio-recorded interviews were transcribed. It was important to do so quickly to minimise uncertainty where there were muffled words because I would be able to recall the interview. The transcripts are on average 16,128 words in length each and together come to 516,091 words. To give this a sense of scale, J.R.R. Tolkien's trilogy *Lord of the Rings* is 481,103 words.

Redaction to protect anonymity commenced following transcription. Prior to each interview I explained to CEOs that the interview would be as anonymous as it reasonably could be and that they were being asked for their individual views and not those of the hospice where they worked. The reason for this was to encourage candour. This meant that I had to redact names and identification from the transcripts. This was by no means foolproof because even a turn of phrase could reveal an identity and respondents knew this. It is for reasons of anonymity that the interviews cannot be made available and why the first person plural is sometimes used for quotes in the thesis to mask gender.

3.4.2 Thematic analysis

In terms of methodology, the first step was to select an approach to the analysis that could answer the research questions and was congruent with my epistemological perspective and qualitative methodology. The second step was to understand the amount of data.[440] Miles describes qualitative data as "an attractive nuisance"[458] because finding a path "through the thicket of prose"[459] can be difficult and I had a considerable quantity to assess. Taking a more positive view, my third step was therefore to find a suitable way to explore this attractive untouched terrain.[460]

Bryman describes thematic analysis as: “a term used in connection with the analysis of qualitative data to refer to the extraction of key themes in one’s data”. It is, he says: “a rather diffuse approach with few generally agreed principles for defining themes in data”.[461] Similarly, Braun and Clark describe thematic analysis as poorly demarcated.[462] However, they say that it is one of the most common approaches to qualitative data analysis and they set out helpful steps that I followed. These include becoming familiar with the data, generating initial codes, searching for themes, reviewing and refining themes, as well as employing reflexive practice because this is vital to understand assumptions.[463]

In terms of the analytical process, my familiarisation with the data began in the interviews. I made a concerted effort to immerse myself in each interview, which meant limiting note-taking until afterwards.[464] When all the interviews had been transcribed, in order to re-familiarise myself with half a million words of transcripts, I began reading through each one quickly but it felt like driving a car at speed through the country and missing most of the scenery along the way. Further, this approach denied the opportunity to redact which had to be deliberate. So I had to retrench and start again.

Annotation or coding takes many forms and I wanted to stay immersed in the data and not lose sight of the interviews as a whole, which is a recognised risk in thematic analysis.[465] As a metaphor, a car manufacturer can become so absorbed in the examination of components that they forget what the car looked and felt like on the road. I found St Pierre interesting in this regard. As a professor of both qualitative research and women’s studies, she encourages her students not to code data because of the risk of becoming lost in low-level detail and missing deeper meaning.[466] St Pierre also points to a weakness in emphasising the number of occurrences of codes because the most significant datum might only occur once. However, in this study, I felt that I did need a method of coding to order the material but, at the same time, I did not want to become lost in a maze of analytical technicalities. So, in carefully considering coding options,[462,467] I sought to keep a balance between ordering the material and staying in touch with what the participants said verbatim. Bryman suggests that a useful strategy for assisting analysis involves creating a framework or matrix and says that this has been followed by the National Centre for Social Research in the UK.[468,469] So, having annotated the transcripts I created three large matrices. An example is shown in Table 2.

TODAY	Micro Patients / People	Meso Organisation / Charity / Business	Macro Local / Regional / National
Vision / Mission			
Philosophy / Approach			
What is hospice?			
Challenges			

Table 2 *– Example of a matrix*

Based on the interview questions and reflexive practice, the matrices were: (1) Yesterday; (2) Today; and (3) Tomorrow. The titles of the rows in each matrix relate to combinations of questions from the semi-structured interviews and issues raised. The column headings delineate individuals and small groups, organisations and then broader perspectives reflecting the micro-, meso- and macro-focus of respondents. This process of developing and populating the matrices took eight months but brought many benefits, including direct engagement with the data whilst maintaining a sense of its context and totality.

As I moved from the matrices to the creation of themes and sub-themes, selections had to be relevant to the focus of the research and they had to be justified.[470] I used two approaches to achieve this. First, in a general assessment, I considered repetitions, familiar and unfamiliar expressions, metaphors, similarities, differences, connections, what was missing and so on.[440,471] When deciding what warranted inclusion, I also considered the forcefulness of individual respondents and the power of a single statement.[472] I justify this through concepts of causal uniqueness, causal dispositionalism[473] and N-of-1.[474] In health research, the N-of-1 approach seeks to enhance medical treatment by looking beyond patients as a herd to recognising people as individuals and unique.[475] As Kerry puts it: “The greatest causal work can be seen in single instance cases” rather than in “statistical invariance in large groups”.[476]

Thus, in this study, alongside repetitions, a unique stand-out contribution from a single respondent has sometimes warranted discussion. This chimes with St Pierre's comment earlier. That said, the majority of points presented in the results are supported by multiple quotes from different respondents.

Second, in recognising the criticism that researchers can sometimes be unclear in the way that themes are chosen,[440,470] I identified a set of criteria that I applied to the method of selection and that encapsulated my initial assessment. These criteria were agreed in discussion with supervisors; the themes and sub-themes selected would need to align with at least two of the criteria. The first criterion was that themes worthy of examination in a doctoral thesis have to have depth, significance and present the potential for examination and interpretation. They need to be matters of fundamental, philosophical or strategic importance. From issues of this order I could hypothesise in theoretical terms and potentially draw inference.

The second criterion was that they should be themes raised by a large number of respondents in the study. My purpose was not to rank issues in terms of how often they were mentioned but to raise issues that were obviously of high importance to hospice chief executives in relation to the research questions. The third criterion was that they should include less frequently discussed issues. These could be a statement from a small number or, as described above, from just one person that fitted with at least one other of these criteria. This could include the unexpected. When I undertook the interviews and subsequently examined the data, there were a number of statements or issues that, despite my knowledge of the sector, were genuinely surprising and unimagined. An example of this is two CEOs describing death threats that they had experienced in relation to their work. My final criterion was to include issues that are not easily observed and are less commonly talked about.

By its nature, the process of selecting, interpreting and justifying themes for inclusion was a circular process where I went sideways, forwards and backwards many times over a period of months.[477] In practice this involved making numerous handwritten lists and diagrams. Some of this involved illuminating, elaborating and highlighting what had been described to display its significance[478] and some involved uncovering issues through reflection and consideration of theoretical perspectives.[478] Whilst I was driven by the research question, the process was abductive because I worked from the empirical data without having preconceived notions or theories in mind.[441,479] As Bryman puts it: "[Abduction is] a form of reasoning … that grounds social scientific accounts of social worlds in the perspectives and meanings of participants in those social worlds".[480] Having painstakingly selected themes and sub-themes in this way, I then considered how they related to each other and to the literature, and their implications. I hypothesised about their strategic importance and relevance within and beyond the hospice sector. An element in this process was the application of semiotics to which I now turn.

3.4.3 Semiotic application

As I explained at the beginning of this chapter, one of the original contributions of this study is the application of semiotics to visualise and discuss the empirical results. In the development of semiotics there are different theoretical families and numerous semiotic tools of which Hebert and Tabler present nineteen.[428] As such, when semiotics are used it is important to clarify how they are being applied. Sections 3.2.1-2, show that I am pursuing a social construction paradigm and adopting a similar approach to Gergen's application of a semiotic square that he described in *Realities and Relationships.*[425]

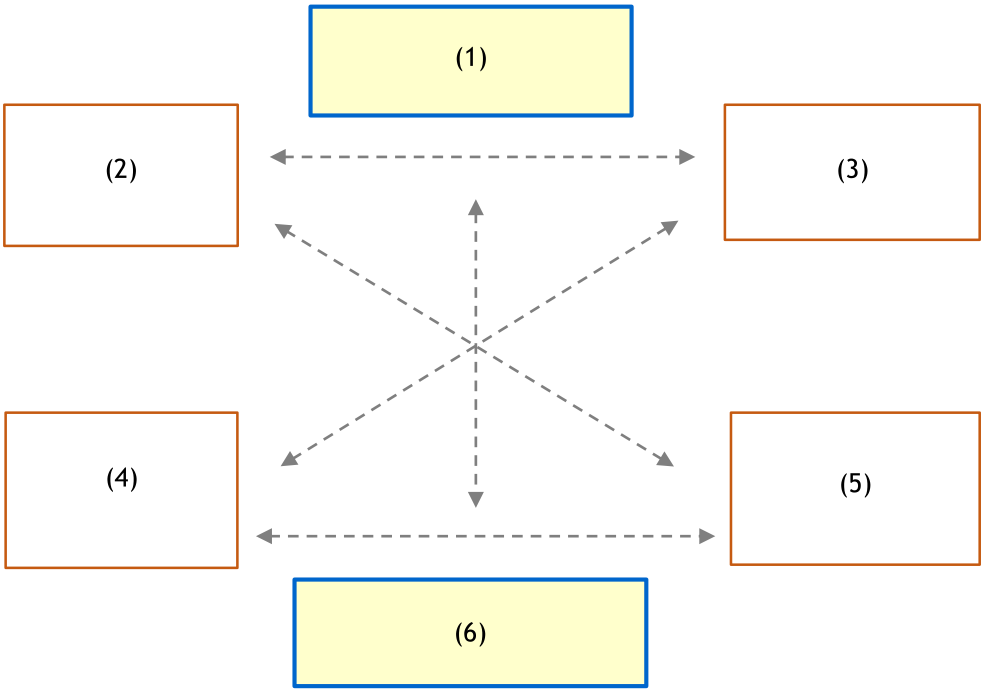

Figure 5 *– Semiotic example*

In this study the purpose of the semiotics is to be descriptive. They provide a visual representation of hospices' social construction. The semiotics show contrasts and tensions that hospices and networks of hospices consist of and work with. In the discussion chapter my semiotic squares follow the principles that Gergen describes and that Hebert and Tabler discuss,[425,481] and I use the semiotic example in Figure 5 to explain this in more detail.

In the polar meridian, Boxes 1 and 6 show strong contrasts in the subject of the semiotic at a level that helps the reader to contextualise and understand the diagram as a whole. (This is similar to Gergen's diagram [Figure 2] where Box 1 is 'Western thought' and Box 2 is 'Eastern thought'.) Similarly, my Boxes 2 and 3 and, 4 and 5 follow Gergen's 'empiricist–rationalist', 'Buddhist-Shinto' differentiations.[428] From some perspectives these may appear to be 'opposites', as depicted in Hebert and Tabler's example.[482] However, since that is a matter of interpretation (and the purpose of the semiotic is to encourage discussion and interpretation), it is more accurate to say that the boxes show 'contrasts' within the subject field under consideration. For Gergen, his use of the semiotic, in *Realities and Relationships,* does two things: first, it shows more than binary contrasts; and second, it opens up a wider aperture to reveal a fuller picture. My semiotics seek to achieve a similar outcome in relation to the intelligibilities of hospices.[425] In that regard, rather than being a linguistic tool (as they are in some semiotics)[428] they are illustrative, portraying aspects of the social construction of hospices and the 'implicit negations' that they experience. As with all semiotics, the ultimate purpose of this visualisation is to convey *meaning* by encouraging the reader to look beyond the constituent parts of the diagram to consider what they signify "within the process of relationship".[436]

Finally, to understand a semiotic, Jean Marie Floch, a consultant who applied semiotics to marketing and communication, argues that what matters most in semiotic application is coherence, clarification and commentary, and that without these the criticism that semiotics can be reductionist is justified.[481,483-486] Since there are so many semiotic applications this makes sense. Hence, when I present my semiotics, I make it clear that whilst I am following a similar line to Gergen's approach,[425] I provide a detailed commentary of each semiotic so that the reader understands what they consist of. My intention, following Floch's argument, is not only to explain the dynamics of my semiotics but also to offer a route for others to follow and improve upon, which may or may not involve a different application.

3.4.4 Themes in the study

There are three main themes in the study: Theme One, Why hospices are here; Theme Two, What and who hospices are; and Theme Three, How hospices are developing. These themes address the research questions laid out in Chapter One and flow naturally from the data. They relate to the literature that emphasises the importance of understanding why organisations are there in their where-when context, who they consist of and what they are capable of, as well as how they are developing. Similarly, in hospice history, Saunders, for example, writes in great detail about why hospices came into being and what they were conceptually as well as about how they were developing. As in the literature, the main themes are interconnected, flowing naturally from ‘why to what to how’ and along a timeline of ‘past, present and future’.

In Theme One (Chapter Four) ‘Why hospices are here’, I describe CEOs’ views about why hospices were established and why they are here today. CEOs describe pioneers’ recognition of suffering at the end of life, for example, dying patients being ignored. Then they describe pioneers’ identification of needs to be met that can alleviate their suffering, for example, the development of better pain relief, humane environments and intimate care on the last journey of life. Respondents also describe the motivation and inspiration of pioneers who, having recognised the misery that people were experiencing and the needs that could be met to relieve that suffering, then turned their awareness and theoretical knowledge into practice and established hospices. In a similar way, CEOs describe suffering and need at the end of life in the twenty-first century and, like that of the pioneers, their personal motivation for doing something about it.

I conclude the chapter by summarising respondents’ views in relation to the importance of context. This includes ‘where’ hospices are and also ‘when’ they are operating which, during the period of the interviews, included the first wave of the Covid-19 pandemic. Theme One emerged partly because respondents were asked questions about why hospices are here and partly because the breadth and depth of the answers showed that the issue was clearly significant to them and their comments could be grouped naturally into the sub-themes. These felt strategically important to me as indeed they are shown to be in the literature.

In Theme Two (Chapter Five) I describe CEOs' views about 'what and who hospices are'. This theme is primarily about the present i.e. what hospices are today in the twenty-first century, albeit with historic comparisons. 'What and who hospices are' is considered in terms of the hospice concept or idea and its application in strategic roles, foci and outlooks. As with Theme One, the literature describes changing emphases in terms of the hospice concept to make life better at the end of life and its outworking in the roles and activity of hospices. Similarly, in organisation studies, what organisations are and who is or is not 'on the bus', as Collins puts it, is significant.[487]

In Theme Three (Chapter Six) 'How hospices are developing', I look forward, describing a subject that was prominent in the interviews and that has a major influence on where hospices are heading. Economic development and financial sustainability is a key strategic issue for respondents in the study. I begin by describing its significance and respondents' approaches to development as a charity and a business. I go on to consider obstructions to development and how development relates back to a hospice's purpose. I conclude the chapter by explaining how respondents feel about the future of hospices. Again, Themes Two and Three were developed in response to the research questions and because the issues were important to respondents.

3.5 Strengths and challenges

In this section I look at strengths and challenges of interviews. I then consider more broadly issues of quality criteria, rigour and reflexivity.

3.5.1 Interviews

A strength of interviews is that they are an established method in social research, including within the field of health sciences and palliative care.[439] They are also one of the most common.[488] However, interviews have not been without their critics.[488-490] Whether they are structured, semi-structured or open there can be many influences on the evidence that is drawn from them such as, for example, power imbalances.[491,492] So although I was working with a cadre of people who were confident enough to be running hospices there were still dynamics that I had to be aware of including the facts that I had prepared the questions and they did not know what they were and, for some of them, I had more experience in the sector.[493] Knowing that there are some potentially unwanted dynamics, one of the challenges was to enable participants to feel as relaxed and comfortable as possible throughout each interview which in turn could encourage candour and openness.

To achieve this, I explained in advance to each CEO that the interviews were being undertaken anonymously and that they were being asked to give their professional opinion and not that of the organisation that they represented. I also said that they did not have to answer particular questions if they chose not to. During the interviews I set out to show empathy, congruence and positive regard (the three pillars of humanistic counselling established by Carl Rogers)[494] in order to give each interviewee confidence in the process and the opportunity to speak freely. Ways in which I did this were to limit my interruptions, ensure sufficient time to cover the subjects and offering a break during each interview. Giving sufficient time was important to limit the risk of oversimplifying the subjects under discussion[495] which is why two hours was allowed. The last two questions were 'How are you feeling?' and 'Is there anything else that you wish to say?'[488,496] The purpose of these was to receive feedback about how the interview had gone and to make sure that respondents had the opportunity to say all that they wished to. I also recorded details of time and place showing that interviews were where respondents felt comfortable and that intrusions could be kept to a minimum. Looking at the interviews as a whole, an indicator of rapport[497] being established is the preparedness of participants to open up about deeply sensitive experiences along with the overall richness of the data.[498] These can be seen in the results chapters.

3.5.2 Quality and rigour

Through consideration of Charmaz,[477] Mays and Pope,[499] Ritchie and Lewis,[500] Morse[501] and Bryman,[440] I summarise my approach to ensure quality and rigour in the research as follows: the study has been undertaken with sufficient knowledge of the context and setting through my long association with hospices and knowledge of the literature; interview responses are rich, showing resonance with practice; the research questions have been consistent within the semi-structured framework and accurately transcribed; the philosophical basis, methodology and research methods are explained in detail, along with consideration of strengths and weaknesses here and in the concluding chapter. I quote CEOs extensively so that their voices are heard directly. I have not altered quotations, removed repetition or colloquial expression. In doing so I show references to the relevant transcript using square brackets, e.g. [20]. Finally, a strength of conducting the study over six years has been that it has created time for ongoing observation and opportunities to debrief, reflect and discuss issues with supervisors and stakeholders over a prolonged period.

3.5.3 Reflexivity

In seeking to understand the social phenomenon and intelligibilities of hospices, I have needed to understand my position or place in the study. The American philosopher Thomas Kuhn says that what we see depends on what we have learned from experience[439,502] and recognising that is a step towards transparency.[503] Similarly, Berger and Luckmann who influenced the establishment of the field of social constructionism, state, "My here is their there. My now does not fully overlap with theirs".[61,504] In that regard, the phenomenological approach of Husserl[505,506] and the hermeneutic phenomenology of Heidegger[507] and Gadamer[497] helped me to consider what form my 'now' might take. Husserl wrote about researchers bracketing out the outer world and personal biases to achieve what he described as "contact with essences".[508] However, Heidegger, and subsequently Gadamer, point to co-creation or dialectical interaction between researcher and participant because it is the interaction that leads to new knowledge[508,509] and a person cannot simply put their persona to one side and choose to adopt a neutral attitude.[508,510] Hence, Kvale writes of the research process being like that of a traveller sharing a journey with others.[511] The traveller reflects and suggests but needs to carefully consider the nature of their interaction.

As such, when reading the literature, taking part in supervision, conducting the interviews and writing up this study, I have sought to do so as a researcher with awareness of my experience as a CEO. So, whilst I might have had background knowledge and empathy with the roles of interviewees, I set out to be an independent seeker of knowledge, actively listening and gleaning as much as I could from the thoughts and feelings of participants during the journey of the research. In this respect, papers on insider-researchers have been helpful,[512] such as Costley et al. who make important points about the anonymity of participants, ethics and morality, power dynamics, obligation, reciprocity and trust[513] and the researcher articulating their own position through reflexivity.[513,514] Respondents in this study knew that I was a fellow CEO with insider relationships and knowledge, and some might even have been suspicious that I might break our agreed basis of anonymity, although none gave me that impression. Dynamics in research interviews work both ways[515] so whilst I recognise this as a potential bias or limitation in the project, the overwhelming bonus has been the benefit of respondents' willingness to be candid and to be available during a health emergency. I have sought to mitigate these issues through, for example, being candid about anonymity, being clear to respondents about their place in the study and that the project has *not* been funded by an influential body such as HUK or the NHS. I also made it clear to participants that I was retiring in 2020.

Of course, none of us can comprehend fully our own contribution, which is why supervision, peer review and reflexivity are so important. This study is not just about the voices of CEOs; it is about my voice too and, of course, that of those who influenced me through discussion, supervision and literature. So it was vital that I critiqued my own contribution. My aids to reflexivity have included:

1. Monthly supervision and detailed typed supervision notes throughout the six years of the study, annual assessment and examination
2. Journals of thoughts, reflections and ideas over the life of the PhD
3. Being interviewed myself using the same framework, with the interviewer being a fellow doctoral student
4. Personal notes made during and immediately after the interviews
5. Discussions, in confidence (protecting the anonymity of respondents), with a small number of colleagues over the six years of the study

An important aspect of this has been the identification of my own biases. This has been aided by the length of the research and the fact that my perspectives have developed over that period. For example, in the second half of the study I became more aware that I was gradually walking away from the role of a hospice CEO that I had been in for 15 years. As I have said, I have sought from the outset to function as a researcher but it has been important to explore the limits or edge of my awareness. For me, probably one of the most important actions in this regard has been participating in my own interview in December 2019 and returning to read it later. In Chapter Eight I explain how my understanding of the concept of ‘hospice’ (that I described in the interview) changed over the course of the study.

It is in these ways that I have sought to conduct the research in a reliable and trustworthy manner. I will return to some of these issues in the concluding chapter.

3.6 Summary

This study asks the question: “What do chief executives of hospices say about the purpose, concepts and development of independent charitable hospices serving adults in England?”

In Chapter Three, I began by describing my epistemological position in social construction and in particular Gergen’s depiction of intelligibilities and their implicit negation. I have explained Gergen’s application of Greimas’s semiotic square and how he offers a means of visualising similarities, tensions and ambivalences between and within social groups. In doing so, I offer a diagrammatic way of visualising the social construction of today’s hospices in order to understand more deeply their heterogeneity and the multi-dimensional structure that they consist of and work amongst.

In terms of the research process, I have demonstrated the congruence of my qualitative methodology and its application in semi-structured interviews with CEOs of charitable hospices serving adults or adults and children in all regions of England. I have explained the rationale for my methods of research and analysis that are consistent with my methodology. My approach has been rigorous, involving a detailed rationale for the options chosen, the application of ethical and quality considerations and my use of detailed aids to reflexivity. I now present the findings of the study under the three main themes that I have outlined.

Chapter Four: Theme One - Why hospices are here

4.1 Introduction

In this chapter I consider what CEOs say about why hospices were established in the latter part of the twentieth century. In this regard, most respondents displayed some knowledge of the Saunders' era. I do so in terms of the suffering that the pioneers recognised for people at the end of life, how that motivated them and their identification of the needs that, if met, could bring comfort, relief and meaning. Following that, I move forward in time, to explain CEOs' understanding of why hospices are here today in the twenty-first century using the same pattern. The themes and sub-themes were worked up after the matrices had been created in the process that I described in Chapter Three. As I explained, the numbers in square brackets, i.e. [19] [20], indicate the interview from which a point or quote emanates.

4.2 Recognition of suffering in the twentieth century

4.2.1 Horrific deaths, brutal treatment, neglect and fear

In the twentieth century, as one respondent puts it: "The starting-point was the alleviation of suffering and a belief that people deserved better than they were getting" [1]. Many CEOs speak about people experiencing, "horrific deaths" [19], "terminal restlessness" [8] and dying in great pain [31]. Respondents believe that, at that time, people were particularly afraid of suffering a painful death through cancer because: "There was definitely … a feeling of cancer equals death" [2]. Another CEO says: "You know people would whisper the word 'cancer'. It was seen as a dirty word" [12]. One CEO describes their grandmother's experience: "I've heard the stories all my life about my grandmother - this must have been about 1948 - dying of ovarian cancer and dying at home and properly screaming in agony. She died screaming" [4].

Respondents report that, as a consequence, people were deeply afraid of the awful deaths that they were seeing: "people were really frightened" [15] and thought "that it was barbaric that people should have that suffering" [15]. The fear factor around dying and death in the twentieth century - "fear of the unknown" [21] and "the fear element" [24] - was significant and one that pioneers sought to address. That fear grew because, as one respondent puts it: "I don’t think people really talked about dying. They didn’t talk about cancer, so it was very much a mystique, held in mystique. And people weren’t talking about death and dying” [15].

A number of CEOs express an understanding that the NHS’s approach to caring for patients with incurable medical conditions exacerbated their suffering. One CEO explains this in terms of the NHS being focused on cure: “The modern hospice movement was a response to how the NHS was about cure and fix it …. it was a positive response to say: ‘Actually, you can’t make everything right and not everybody can be made better’” [21].

Another CEO describes this focus on cure in terms of the national euphoria and political optimism of a new society in a post-Victorian, post war Britain:

> “Cicely wanted to redress the very poor experience of dying and it was at a time when medicine, politics, the societal context, was one of optimism and cure and success and investment, and death and dying didn’t fit anywhere in that” [9].

This respondent refers to optimism for healthier lives arising through the new NHS, advancements in medical science (such as the advent of antibiotics, vaccinations and the discovery of DNA described in the literature)[81] and the social relief and optimism that followed two world wars leaving no place for dying and death. Some respondents describe the NHS’s approach in stark terms, speaking of “brutal chemotherapy” [9] and saying: “It was barbaric that people should have that suffering, especially watching it in acute care settings” [15]. Here participants do not simply see that the NHS was getting it wrong. They understand that people were treated inhumanely because they did not fit within the exciting image of the newly born national service. Putting it starkly, one CEO describes the NHS’s culture at that time thus: “If you can’t be cured, you’re an embarrassment. You’re a piece of darkness that we don’t need” [9].

Respondents say that not only did individual people not want to talk about dying but clinicians did not either. Thus, while some were being treated barbarically, interviewees say that at the opposite end of the spectrum, some patients were not even “identified as dying” [8] and often did not know they were dying, as

Pearce's textbook of nursing confirms.[96] One CEO talks of Saunders reaching out to "people who might find themselves otherwise forgotten or ignored or unimportant" [9]. Another says: "The consultant wouldn't even speak to someone who was dying; they would write TLC in the notes and they would just walk on" [12]. Using non-medical terminology, another CEO speaks of human separation, saying: "At the heart of her [Saunders'] story is one individual who wasn't, who didn't have his hand held at the right time" [11]. Respondents believe that what was going on was about far more than poor treatment on a hospital ward: it was also about dereliction and abandonment.

4.2.2 The motivation of hospice pioneers

In considering why hospices were established in the twentieth century, interviewees understand that pioneers like Saunders recognised the suffering around them which motivated them to act. This can perhaps be seen no more clearly than in Saunders' many papers and letters that I have referenced.[214,516]

4.2.2.1 Outrage, willingness and watching people die

CEOs speak about public reaction to these horrific deaths, with one respondent saying that these experiences of dying led to: "Outrage at the state of end-of-life care and [the] sort of quality of people's experiences" [30]. Another speaks of people coming together to do something about these appalling deaths and engaging with the idea of caring for people properly at the end of life which was the beginning of the hospice movement:

> "And local people started to engage with it, and this is the story of all hospices really isn't it? People all come across friends, family members who have died in appalling circumstances. Well, often, they have not been cared for properly, and this resonated with people" [2].

This public outrage and the desire for a new approach and solution to solve the problem of horrific deaths resonated within communities. Another participant speaks about small groups of people in a community seeing a need: "That's the one strong thing about hospices as they are very community focused. Often when you go back through the history, it's a very small group in a community who saw a need" [14] and, "[in this geographical area the hospice was] founded by really strong-minded women who had gone through an awful lot and fought an awful lot to get where they've got" [14]. Another speaks of, "A massive willingness for people to come together and build a hospice" [4] and says that that willingness had to withstand resistance from the mainstream: "There's some old newspaper articles where some consultants with the hospital, for example, were dead against it [and] without them being brave and having such a belief we wouldn't be here" [20]. As another participant puts it: "She [Saunders] probably felt a bit embattled and thought, you know what, I just think I can do it better" [22]. Likewise, a further CEO believes the biggest challenge for the pioneers was: "Trying to set up a charity and do that separate to the NHS … and convince funders … that this was needed and we could do things in a better way" [21]. One interviewee sums it up like this:

> "It's about somebody looking at the way things were done and saying this isn't good enough for my fellow citizens and fellow human beings … I love that approach of not sticking the plaster on but actually looking at the root cause of what's going on and then saying: 'Right. Let's do something about it. Let's change this'" [27].

The breadth and depth of change is not underestimated by participants in the study; it was a root-cause "rebellion" [13] that had to overcome sometimes hostile resistance from the establishment[517] but at the same time garner its support, as shown for example, in the speech by Sir George Young to the 1980 conference.[216] As I explained in the literature, that massive willingness, courage and determination of the pioneers led to the proliferation of over 200 hospices in the UK.[29]

Those respondents in the study with knowledge of hospice history explain that the pioneers felt this outrage personally and were motivated by their own first-hand experiences at the bedsides of people who were suffering. When asked about what motivated the pioneers, one CEO puts it succinctly, saying: "[It was] probably watching the way people died and the way doctors walked past the end of the bed" [12]. One interviewee speaks about their hospice founder, a local Christian minister, who, as part of his pastoral care, visited people at home: "[He] saw people in very difficult circumstances with no support, no pain control, in and out of hospital, dying, having awful deaths and thought there must be something better" [31]. This direct contact and proximity to people suffering awful deaths and seeing the inadequacy of mainstream provision, motivated hospice pioneers to act with dedication. One interviewee feels that it was: "[The] main driver for Cicely and her … cohort of people. They recognised and responded to suffering at an emotional and a spiritual level" [9]; and similarly, "Those pioneers wanted to hold the hands of as many people as possible" [15].

4.2.2.2 Inspiration

Some respondents describe the hospice pioneers as people who were not only motivated but also inspired, the distinction being that inspiration is a more powerful driving force. Here a CEO relates this to a sense of religious calling and something bigger than self: "Our heritage really, which is a very religious organisation but I do think vocation and that sense of something bigger than the self, stands out for me" [5]. That vocation is described by another respondent as "a life's work" [15]. One participant describes this inspiration as their "religious focus" [2], another as "a moral compulsion" [3] and another as "being called to a cause" [17]. Speaking philosophically another interviewee depicts the pioneers as: "All people who were inspired outside of their profession. Their profession was an enactment of something bigger and more important for them" [9]. These CEOs believe that this inspiration, that often involved self-sacrifice (one respondent speaks of a hospice founder, "who sold her family home [to fund a hospice building]" [14]) was "part of their resilience" [9] and "visionary energy" [17] that enabled them to succeed. This can be seen in Saunders' reference to Victor Frankl, mentioned earlier in the study, where she alludes to him rising above the terrible circumstances in Auschwitz and holding on to his beliefs,[109] quoting Nietzsche, who said: "He who has a *why* to live can bear with almost any *how*".[110,111] In the study, more than one participant refers to the inspiration of Frankl and their feeling that 'hospice' has a transcendent imperative [28] [12].

So, according to the transcripts, hospice pioneers recognised suffering through their proximity to it and were motivated to act through a belief in something greater than themselves. However, as I highlighted in the literature,[29,121] hospices did not come into being purely because groups of inspired people recognised human suffering at the end of life. They were established because pioneers, having seen what was going on, went on to identify the needs that, if met, could ease that suffering and make dying a more comfortable, compassionate and meaningful transition.

4.3 Identification of needs in the twentieth century

In this section, I explain respondents' statements about the needs that pioneers identified for people at the end of life. For example, pioneers recognised that people were experiencing horrific deaths but they also identified how meeting the need of pain relief could relieve some of their misery. Again, pioneers saw that patients suffered because they felt isolated; they identified, for example, that creating an environment where patients felt included and could have open conversations would meet their needs and therefore reduce their suffering.

4.3.1 Pain, holism and humanity

CEOs understand that hospice pioneers in the twentieth century identified, as a priority, the need to ease pain holistically. In answering a question about what stands out in the pioneering era, one respondent says: "I would say, first of all I think that it was all structured around a very simple concept which was the theory of pain … the four different pain elements" [28]. The same CEO goes on to say that the pioneers' theory of pain was like the "fundamental core of a stick of rock that goes through everything that hospices do" [28]. In other words, relieving pain is at the heart of all hospice activity. Similarly, other respondents understand that the pioneers identified, quite simply, that many "people die in pain" [4] unnecessarily and that pain is multifaceted and, therefore, more than medical. Another interviewee says: "They [hospice pioneers] felt passionately about finding a way to make people pain free or as pain free as possible" [17] and held the view "that pain wasn't just physical and that was the other part of Cicely's research that we all know about" [17].

Here, this participant and others [4] are referring to Saunders' concept of 'total pain' that I described in the literature (See Section 2.3.2).[23] One CEO goes on to say that pioneers, having identified that pain was holistic, realised that it required more than a medical perspective to treat it, hence the introduction of multi-disciplinary teams (MDT) that examined patients' physical, psychological, social and spiritual needs:

> "They were pioneers in recognising the pain, discomfort and symptom control needs that were lacking and my feeling is the same as Cicely

> Saunders' is, that she was the pioneer of our MDT equivalent, our multi-disciplinary team" [15].

Supporting this view, a respondent speaks of the heritage of multi-disciplinary teams as the "way we've always done it" [6] to meet the holistic needs of patients and families. Another says: "That really chimes for me … the hospice approach is that it looks at … the whole of their being" and "their family, however they define family" [27].

Some participants also understand that pioneers saw agonisingly deep unrelenting pain being experienced by patients at the end of their lives, so new scientific approaches were required. The newly-founded hospices offered multi-professional perspectives and new combinations of pain-relieving drugs in a humane environment. Thus, one interviewee speaks from their own experience as a young nurse in the second half of the twentieth century: "I remember that brown bottle (the Brompton Cocktail)[518,519] with that label … and I think of the science of understanding pain management, symptom management" [31]. Others speak of those early developments when mixtures of "morphine, cocaine and some sedatives" [12] and "the Brompton Cocktail" [12] were administered as pioneers recognised "the pain, discomfort and symptom control needs that were lacking" [15]. Here, these CEOs see a contrast with the NHS's scientific approach of "cure and fix it" [21] that I mentioned earlier in the chapter because they were focused on meeting an individual's need. One CEO speaks about hospices not "treating people as illnesses" [4] or having the negative attitude of "if I can't fix what's wrong with you, I'm not interested" [4]. These respondents understand that the pioneers' approach to science was different from that of the mainstream medical profession because it was "connected into people's humanity" [9]; they looked at the person first and worked outwards from there. In the literature this is one of the defining aspects of the approach adopted by the twentieth-century hospice pioneers.[204]

4.3.2 A good death

This focus that hospices have on a person's well-being includes the person's experience of death and whether it is good, bad or better than it might have been. Thus, a number of CEOs speak about the pioneers' concept of a good death and Saunders seeing death as part of a journey:

> "She [Saunders] was very much focused on this idea of a good death … because she thought it was a journey and you know, and that you will be supported to find peace with your Maker and … through that, the family themselves would find some comfort" [2].

Using non-theological language, another respondent believes that, for the pioneers, this meant "acknowledging death as a natural process … and giving life meaning" [12]. Looking at society as a whole, one participant says that for Saunders "dying in pain, terminal restlessness … isn't acceptable anymore because people should be having a good death" [8], and another speaks of Saunders adopting "a campaigning approach to the importance of giving people a good journey towards the end of life and a good death" [1]. Thus, some CEOs understand that, for Saunders, the work of the hospice was not just about making death humane and pain free. It was about bringing life to a purposeful conclusion through a meaningful death that had the potential to bring peace, comfort and hope to patients and families. Dying and death are part of life's journey and a new dimension.[520]

4.4 Recognition of suffering in the twenty-first century

I now move forward from the past to the present, to consider what respondents in the study say in response to questions about why hospices are here today. I have ordered the results in the same way that I did for the pioneers by, first, looking at the suffering that respondents recognise as being present in society, second, looking at their personal motivation to lead hospices and third, looking at the needs that have been identified to reduce discomfort and improve quality of life.

4.4.1 Suffering of all near the end of life

In terms of recognising suffering, one CEO speaks simply about the hospice's mission today being "to relieve suffering" [13] and another describes their mission as meeting "unmet need" [7]. Similarly, a further respondent recognises the huge breadth of suffering near the end of life and their responsibility to do something about it:

> "Our vision, which is very broad, is about a world in which everybody dying will have access to the care they need, whoever they are, wherever they

> are and whenever they need it. It's very inclusive but it is all about a better ending, for want of a better word" [9].

In other words, for these respondents, hospices are here because they are working in whatever way they can to reduce suffering for people near the end of life, whoever they are and wherever they are found in their locality. However, there are variations in focus and outlook and I describe these in Theme Two.

Looking more specifically, respondents say that, today, they recognise suffering within and beyond malignant medical conditions. For example:

> "The other thing obviously, is the fact that changes in the types of disease, and ours are 50% now non-cancer and again, you wouldn't have seen that. That's a massive change from when Cicely Saunders started to work with sort of cancer patients and we know that through the evidence" [19].

Similarly, another respondent says: "We are seeing 50% of people with non-cancer; it wouldn't have been heard of ten years ago" [8]. Despite this development since the pioneering era, respondents still recognise imbalance and unnecessary suffering for those with non-cancerous illnesses, especially the frail elderly. Putting it bluntly one CEO says: "If you have got cancer you are alright; if you have not got cancer and have dementia and frailty you are stuffed" [1].

A number of participants highlight suffering brought about by dementia and frailty. One respondent speaks of: "Hospice care and dementia … and that there's been quite an anxiety about what to do … and how it is going to change the organisation" [3]. Another speaks of provoking debate nationally about "the role of hospices in looking after people who are living into late old age with frailty" [9]. This CEO sees "parallels between the experience of dying with frailty now, like it was dying of cancer in the 1960s and that will be our new top priority" [9]. In a similar vein, another respondent speaks about poverty and the very old saying: "There's another moral imperative that's as strong as the first founding fathers, for older people dying at home alone often, sometimes still in pain and often in poverty and we're not there for them" [29]. Another participant says, with feeling: "Dying from old age is horrible, a horrible way to die … and they are disenfranchised because it's not ticking any kind of box" [12].

One CEO referred to the importance of identifying the suffering of patients earlier in their illness, seeing this as significant for hospices: “So it's about that whole health and well-being of somebody's life and having a bigger impact earlier on in somebody who's got more complex symptoms … and I think that's the point, the tipping point we're standing at” [21]. So whilst some CEOs emphasise the suffering of patients with a broader range of medical conditions i.e. not just cancer, this respondent also points to experiences of suffering before patients currently receive palliation. Similarly, other participants speak of the importance of “earlier intervention” [22] and of “reaching people much earlier in their pathway or journey” [23]. It is in this regard that one respondent thinks that: “Hospice is transitioning; the use of the word is transitioning, into something different [from its twentieth-century meaning]” [21], the transition referred to being end-of-life *living* in addition to dying and death.

Many CEOs express concern about hidden suffering. Speaking broadly, one respondent says: “The vision would be that we look after more people that need our support. I think what really concerns me is the people that don’t get our support” [8]. This points to an awareness amongst CEOs that there is still much suffering and unmet need out there, some of which is hidden. Thus, one respondent speaks of “known unmet need” and about how to “uncover unknown unmet need” [7]. Another says: “It’s not the needs of the people that come; it’s the people out there” [12] that keeps them awake at night.

Another respondent speaks boldly of not turning anyone away who approaches their hospice:

> “So we’re just launching a new strategy in April and we are absolutely saying we are not, in the next five years, going to ignore anyone who needs us. I mean that’s a big statement. But actually quite a lot of people don’t need very much from us” [17].

In doing so, this respondent recognises that, whilst there is plenty of suffering out there, it does not necessarily require a demanding response. Another respondent speaks of suffering that is hidden away:

> “I do worry for … the amount of people that are probably hidden away in communities, suffering on a daily basis because nobody knows they even exist anymore and they’re not getting the support that they need and that really concerns me” [13].

Finally, one respondent seemingly goes further, from a hospice perspective, recognising suffering that is broader than end of life: “Our mission is to relieve suffering and people suffer from lots of other things …. to me it’s not just about dying people” [13].

4.4.2 Society is still not doing death very well

In terms of recognising suffering, one CEO offers a helpful society-wide perspective that draws together a number of key strands:

> “I think society is not doing death very well at the moment, whether that be kind of systemic health systems or whether it be national, local conversations, whether that be support to people, support to families, support available to groups, it just doesn’t do it very well. I don’t think hospice is about trying to fill that whole vacuum although I know some people do” [16].

Thus, over 50 years on from the advent of the modern hospice movement in England, this respondent considers that society still does not handle end-of-life living, dying and death very well and, consequently, from this perspective, hospices still have a purpose in making things better. People are still suffering; health systems are not getting it right and there are not enough conversations and support groups available. This echoes with the literature and, for example, with a recent Marie Curie report[398] describing how end-of-life care was adversely affected in the pandemic and that this has continued, with reports from the University of Hull, *The Guardian* and the BBC supporting their assertion.[399-401] Just as the pioneers asked in the twentieth century, the respondent above [16] asks hospices in the twenty-first century what they should be doing to fill the gap of unnecessary suffering at the end of life and, therefore, what kind of hospice they want to be.

From that interview as a whole, it is clear that the respondent is not saying that hospices have failed over the last 50 years but simply and obviously that a vacuum persists today and dying and death in this country is often not good. The respondent understands that some CEOs think hospices should be filling all of that vacuum but this respondent does not. Another respondent shares a similar view, talking about "only doing the things that we can do" [22]. Whilst noting these differences in outlook, I will consider them in more detail in Theme Two. For the moment, the point here from respondents is that hospices today have much work to do. Society is still not doing death well and hospice CEOs recognise the ongoing unnecessary suffering and misery that needs to be addressed for all at the end of life, including the frail elderly. This can be seen in the literature, perhaps no more clearly than in *Dying for Change*,[328] the Commission reports[*16*] and calls for hospice reinvention[209] (Sections 2.2.3-5) predicated on the fact that there is still so much unnecessary suffering in England at the end of life.[11]

4.4.3 The motivation of hospice CEOs today

Earlier in this theme I described respondents' understanding of the motivation and inspiration of the twentieth-century pioneers which drove them to establish hospices. I now consider respondents' descriptions of their own motivation for dedicating themselves to keeping hospices operating today.

4.4.3.1 Experiences of dying

A number of CEOs speak of witnessing inadequate care and poor experiences of dying and death first-hand and that this motivated them to want to do something. For example, one CEO talks about their mother near the end of her life: her lips were cracked and her mouth was terribly dry and the nurse asked them to keep re-using the same sponge sticks because they did not have any more. The CEO says: "That was the only comfort my mother was getting was from the moisture from the sponge sticks to make her mouth comfortable and you just think, this is not how it should be" [6]. The respondent goes on to say how they knew that their mother's death could have been "so different" [6] but this and the poor death of another close relative motivated them to become involved in hospices. Similarly, it was the intimate details of caring for dying patients, such as these, that prompted Saunders to act as she did.[521]

Another CEO describes poor care for a sister, saying that "homecare from a hospice in xxxxx … was awful" [29] but from experience as a volunteer they knew "the potential of the difference hospices could make" [29]. Another participant describes experiences with mainstream services as woeful in relation to their brother's death and says that the attraction of the hospice approach motivated them to become involved, "I think that whole holistic approach of hospices, particularly for families as well as patients, was really important to me" [4]. Finally, a respondent says of their father, that after five years struggling with cancer "the end when it came was horrific" [5]. They said to themselves: "I'm going to find a way to make this work and it was weird but I'd just, I was reading *The Guardian* and the advert for my first hospice job was there" [5].

4.4.3.2 The attractiveness of hospices

Whilst some CEOs talk of being motivated through their direct experience of poor deaths, other respondents describe being drawn, through their nursing experience, to the hospice clinical environment, with one saying: "I think the way people die matters enormously" [12]. Others make comparisons with the NHS, with one saying there was less "pomposity" [31] in hospices, and another commenting:

> "In the NHS, a doctor would come to see a patient and say right, this is what you've got, this is the treatment we are going to give you and this is what's going to happen. In hospices it's about, this is your problem, this is your situation, how would you like us to deal with that and what is important to you in the way that we deal with that. That's the difference, that's what inspires me" [13].

The difference between beginning with the *person* rather than the *illness* clearly inspires this respondent as it did for Young when he spoke at the hospice conference in 1980.[216] Others are excited about opportunities to be creative: "You could make decisions, you could have an influence on what happened" [8]; and: "There was plenty of scope to do some interesting things" [18]. One CEO speaks about wanting to be in a "value-driven organisation" [22] and another says: "The ethos … the values really attracted me to hospice care … it's a brilliant sector to work in" [23]. Again, at the end of the twentieth century these attributes of hospices were recognised by national political leaders such as Margaret Thatcher,[238] Neil Kinnock,[239] Paddy Ashdown[240] and David Owen.[241]

A number of CEOs describe an aspiration to “make a difference” [6] [10] [27] in terms of excitement and a desire to benefit humanity. Examples are: “I was excited absolutely by the hospice and being able to make a difference” [21] and “I was passionate that everyone in our community should have access to a dignified pain-free death and for me that’s the very least that we as a human race can offer” [26]. Another says, quite simply: “[I was] wowed by the feel of the place” [27].

4.4.3.3 Inspiration

Like respondent [13] quoted earlier, others speak of inspiration, with one CEO saying that, although they had known very little about hospices beforehand it was clear that they were a really important part of society and that from the perspective of their personal faith: “It sort of pressed a button because there is a biblical phrase that I relate to about defending the orphan and the widow and all that sort of stuff from Isaiah” [1]. Another interviewee points to something within or beyond, expressing this in terms of being and destiny: “I think I’ve always been there Stephen. At 18, I went to the bedside of somebody dying and I stayed there. That’s just … it’s not what I do; it’s who I am really” [12].

Whilst there is broad commonality in respondents’ views about the motivation of hospice pioneers and leaders of today, there were nevertheless indications of some differences. For example, many CEOs mention with fondness the work of pioneers and founders, such as “Mary Aikenhead” [9] [25], “Douglas Macmillan” [4] [18], “Robert Twycross and Christopher Spence” [17]. Cicely Saunders was mentioned by every respondent and many also referred to local founders [10] [14] [20] [31]. However, comparing these pioneers with hospice leaders today, one CEO laments the loss of their determination and self-sacrifice. Speaking candidly, the respondent talked about a “second generation of hospice leaders [being] too precious” [17] saying:

> “This kind of self-preservation and we must all not do too much and get drawn into the needs of other people too much because it’s detrimental to

> keeping ourselves well, all of that kind of culture I find really, really difficult to stomach" [17].

Similarly, other respondents hint at the dangers of losing rich elements from the pioneering era, saying that it was really important for hospices "[to keep the] timeless values" [5] of the pioneers and not "lose … the philosophical part of what Cicely Saunders was driving at" [6]. Similarly, speaking metaphorically, Baron et al. depict a fast-flowing stream (the pioneering era) turning into a river (today) that has naturally slowed down and in doing so dropped some of its valuable minerals (original hospice values and ideas) that, they say, may go unnoticed by today's hospice leaders.[273]

4.5 Identification of needs in the twenty-first century

Having described respondents' descriptions of the suffering that they recognise in society today and their reasons for becoming involved in the work of hospices, I move on to explain some of the needs that, if met, they believe could ameliorate that suffering.

4.5.1 To celebrate life and dignify death

Offering an overarching perspective, respondents speak about the need to "celebrate life and dignify death" [29], for example: "Finding meaning in death and being able to celebrate your life before you die is a very important component of the therapeutic support that we offer" [15]. Another says that it is important that "life has been celebrated in death" [4], and stresses the value for society of "being more open about death" [4]. Experiencing the benefit of this, one participant speaks of families saying: "[Thank you for making] those last weeks so wonderful for us as a family … that has given us great memories to hold onto rather than the trauma that people sadly go through" [27]. Thus, respondents give voice to the need for and benefit of celebration and openness.

4.5.2 Comfort, safety, intimacy and love

Pointing to more specific patient and family needs, respondents' comments are wide-ranging. CEOs talk of comfort and safety: "My vision for the patient is that our input provides them with a degree of comfort and safety and security and confidence that they have not experienced anywhere else" [2]. Similarly, another says: "We don't have to be doing intrathecal lines; we don't have to have one of the top consultants; we can just provide the comfort measures and a comfortable safe place to die with your family" [12]. With obvious reference to medicalisation, concern is expressed that this important principle of feeling safe may be being overlooked: "That very basic just 'being with' somebody as they die, perhaps that has had to be diminished … has something been lost there?" [12]. This relates to the emphasis on 'being' as well as 'doing' in the Saunders' era and the importance of proximity - of 'heart' as well as 'mind'[112] – that they saw as part of being fully human.[187,188]

In this regard, one CEO speaks of patients needing an "experience of being loved" and expresses concern that "this whole notion of intimacy is completely undervalued in our health system today" [9]. Another respondent sees that this is sometimes the result of "disjointed care, or a professional doing their bit and then someone else doing their bit and sometimes those two things don't work together" [2]. As I said earlier, this lack of intimacy is also an issue that respondents describe as existing in the pioneering era, where dying patients were neglected and "doctors walked past the end of the bed" [12]. Another respondent connects intimacy, comfort and safety at the point of death saying: "Go and sit with them, hold their hand. You know, I don't think anybody should die on their own, unless they want to" [13]. Again, this cross-references with the importance given to "hand-holding" stated by interviewees [2] and [11]. This also points back to where Saunders came in and her intimate relationship with David Tasma that inspired the development of St Christopher's Hospice,[1] along with the stress that she laid on clinicians being prepared to be vulnerable as they joined the journeys of their patients,[308] describing it as: "a special kind of living and … travelling".[522] However, as Clark points out, this was a complicated area for Saunders, saying: "She [Saunders] got into situations where the boundaries between her personal and professional life were seriously blurred".[523]

Respondents recognise that patients need understanding and a humane, personal and compassionate care environment in order to cope with their situation. That environment needs to understand their pain intimately, whatever it is. Having described the concept of 'total pain' in the pioneering era, one respondent also mentions the need today for patients to: "Still have a sense of purpose and to share special things for their families to demonstrate that their life hasn't been a waste of time" [15]. Another CEO describes this as patients being enabled: "To celebrate a life well lived” [11]. In other words, understanding is not only needed, with pain relief, for medical, psychological and social pain, but also in relation to biographical experiences[23] and how patients assess their life as it reaches its conclusion which, in turn, brings a spiritual dimension. In that regard, one participant expresses concern that in today’s society, which is more secular than in the twentieth century: “[staff are] abdicating responsibility to a chaplain [or in other places] they don’t have a chaplain [so, from] the combination of the two, I think we’re losing our way here about helping people with the mystery of death” [29].

4.5.3 Power and personal control

In terms of personal control, CEOs understand that patients have a need to be “confidently active” [1] whilst “managing clinical uncertainty” [9], and to be “at peace and more able to cope with their impending death” [2]. Thus, some respondents emphasise the need for enablement and empowerment so that patients and their families feel more in control. One respondent sees this as a sign of the times: “We have seen society wanting to take more personal control” [1]. However, the same respondent speaks of creating a balance because “the average person has a fear of death and dying because it is the big unknown [1] [and] so it is about enabling people to have confidence … to do a little bit more themselves” [1]. This contrasts with paternalism, as one respondent puts it, saying: “[end-of-life care] is really paternalistic and that’s one of the struggles … It’s so engrained in that we are providing ‘to’ you” [4]. Another says that there is “a lot of paternalism in the hospice world [but] hospices are there to *enable* patients to have a quality of life” [8].

In this regard, another CEO asks the penetrating question: “Who owns death?” Moving from the past to the present, they say:

> “People avoided talking about death because, historically with death, the church owned it … and then the doctors and the hospitals took ownership of death … but it was medicalised; it was paternalistic, and death was owned by the doctors and the hospitals, and that was the biggest challenge to try and see this as a life event and a very important event … and it’s only now you are seeing the paradigm shift where it’s swinging back to the people who are starting to make their own choices” [12].

This important notion about power is clear in the literature with the same question of who owns death being asked by Ros Taylor, a physician and former hospice CEO, in a BMJ blog.[300] The need and desire for personal control requires a change in attitude and role for those who support end-of-life care, whether they be relatives, professionals or organisations.[313] As one participant puts it: "Death doesn't belong to hospices; death belongs to all of us" [31]. Another CEO says that "we're going to *give* you palliative care" displays an attitude of ownership and asks: "How do you turn that on the head so that people … can actually say what they want?" [8] Another says: "The biggest challenge for me about death and dying, it's the focus of clinicians on keeping people alive … we need to actually recognise what people want" [4].

Hypothesising, one respondent comments that after two world wars where people experienced so much death, they probably did not want to talk about it but: "That generation is leaving us and we now have a new generation that are talking about it, preparing for it, want control, even want assisted dying (AD)" [31]. So, naturally, the issue of power and personal control relates to the issue of AD. Expressing concern that hospices make judgements and statements about AD, one CEO says that: "This reinforces our sense that we own the agenda. We know what is right for society" [9]. Similarly, another interviewee says: "I think it's not for us to, or the law to actually say, what's right for us because life and death is our choice … a lot of people disagree with me but I just think it should be choice" [22] and, "It's just we all should have the right to die in a way that allows us to die how we want to die" [13]. Another respondent not only says: "I think the patient should have a choice" [26] but also that these conversations should be much earlier during "some sort of health check when you're forty" [26] and that this should be part of a "more proactive approach to death and dying" [26]. Thus, these CEOs say that a primary driver for AD should be personal autonomy rather than institutional control (including that of hospices). The last respondent [26] suggests a proactive approach much earlier in life than current advanced care planning (ACP) which more commonly takes place after people have been diagnosed with a serious illness.[524,525]

However, because this section is about power, autonomy and personal control, it is important to state that there is a range of views about AD in the study. For example, one participant says: “I think patients are already confused about whether hospices bump you off”. They add that if AD becomes law we could still say “it’s not something that we do” [4]. Others comment: “It’s a bit like Brexit … all the people on the inside thought they were having one conversation … but the wider populous was thinking something quite different and I don’t think you can ignore that” [5]; “we have to be part of the conversation” [17]; “ethically, morally I’m not for it” [23]; “I’m really conflicted about it … my worry is about the potential abuse” [27]; “the best legislation in the world would have tons of unintended consequences … I’m against it but I believe society wants it” [29]; “[AD] will be a huge platform for raising the profile of sort of hospice and end-of-life care … I think public opinion is overwhelmingly in favour” [30]; and “I don’t agree with it because I think you then put all your energy in that rather than helping people to live when they die” [31]. Interestingly, one respondent gives a historical reflection, saying that Saunders may have had quite a battle on her hands because some people may have thought that: “Not treating them to try and make them better [was a form of assisted suicide]” [13]. In the literature, this discussion has continued from the Saunders’ era and debates about voluntary euthanasia[62,91,118] to those of assisted dying today.[526,527]

Explaining the issue of personal control further, one respondent sums the matter up by saying: “There’s a lot of contemporary suffering about no longer being able to be autonomous … to control your life and we ignore that at our peril [and our language does not help] calling people ‘patients’ now feels very outdated to me … it’s certainly kind of positioned them in a place of dependency and ownership” [9]. This wide-ranging discussion about power also relates to comments made by respondents elsewhere in this study about the medicalisation of death, enablement and empowerment. This issue unveils lines of demarcation between the power of authorities and individuals that, as a consequence, challenges where those lines should be. In this study, respondents’ comments are on both sides of those lines.

4.5.4 Support for all

For respondents, a supportive and empowering environment may be in a hospital, a hospice or at home (including in a care home). Thus, one CEO talks about personal support which they set up with patients and hospice staff and also between patients as mutual support in the community:

> "There was something about having that peer support but also they used to get a courtesy call on an evening, just a couple of minutes: 'How are you? Have you got any problems?' and that constant reassurance that somebody was there prevented them from getting anxious, prevented them from going to A & E" [13].

For patients at home, a number of respondents articulate the need for community support and how it is important for "community to remain resilient beyond death" [5]. Thus, in one hospice locality, they set out to "achieve normalising death and dying in the community and making it … part of normal life" [5]. Some CEOs speak of 'community engagement' meeting previously unmet needs by opening up new channels of communication and conversations. For example, one says: "[it] has enabled people who would never have been able to have any conversation with our hospice whatsoever to have a connection" [3]. As I mentioned earlier, in relation to "known and unknown unmet need" [7], this is seen as particularly relevant for those who are lonely and isolated through frailty, extreme old age and poverty (see earlier quotes from interviews [9] and [29]).

For respondents it is also about: "How are the homeless working this?" [7]; "people with palliative needs in prisons?" [11]; and "those groups who are socially disadvantaged … LGBTQ-plus community and others?" [11]. As one respondent puts it: "You only have to walk around the town and see the numbers of homeless people and knowing how many people are lonely and isolated, how many people are frail and thinking there's got to be a better way" [13]. Another participant expresses it like this: "Unmet need isn't distributed evenly; it's focused in particular communities … that are least empowered" [30]. Thus, respondents are clear that there is a need for improved connections, communications and conversations in the communities that they serve and not least amongst those who are isolated, abandoned by the system and forgotten because all should be supported as the end of their lives approaches.

4.6 The context of hospices

As I explained when examining the literature, context plays a key role in the establishment and development of any business or organisation and hospices are no exception. Here I understand context as everything that is around and within an organisation. The context of time (‘when’) and the context of space (‘where’) affect why people do things, such as the development of hospices in England during the twentieth century. They also affect what organisations consist of and how they develop, such as the establishment of different types of hospices in Kerala in India[528] compared to those in England and other forms of end-of-life care around the world.[529] Similarly, the contextual ‘when and where’ has influenced the establishment and development of different health systems across the globe.[530] Here I summarise briefly evidence from the transcripts to establish the significance of context in terms of why hospices are here and how they are developing.

4.6.1 When

In terms of the relevance of time, differences that have already been described in Theme One between why hospices were established half a century ago and why they are here today include, for example, the twenty-first century aspiration to ‘celebrate life and exercise more personal control’. Looking broadly at the time-context, one respondent says: “Flexibility is for me the most important thing … to see what’s changing; what do we need to do to stay in the best position for our patients?” [25]. Here the CEO recognises the importance of keeping up with developing context because, as time moves on, so do needs and the ways in which they can be met. As another participant puts it:

> “I think the hospices are at a crossroads because the world outside is changing … if we don’t change and adapt, then we won’t survive … people living with a cancer diagnosis are living longer … so do we use the model we used ten years ago? No, it would be completely wrong” [8].

Similarly, another CEO speaks of connecting with the changing perspective of new generations: “They want to look after the planet, so therefore they want to look after the people on the planet … if that means a really futuristic approach then we have to move with that” [13]. Put simply, hospices need to keep up with the times and all that goes on around them. In other words, according to these respondents, hospices must stay relevant.

An example of context changing over time is the Covid-19 pandemic which began in England during the period of this study. As one respondent says: “[Here, in

March 2020] this is one of those events that … could completely change the whole picture" [16] and a couple of months later, another says: "This pandemic … has caused us to think and work differently … and to me the priority for our organisation is to make sure we don't look back" [23]. A month later another CEO says:

> "This current situation is a golden opportunity … it's awful but it means people are talking about dying much more and we need to … say to people: 'This is our role, this is how we can help you think about that, plan for it, prepare for it' … It must be the start of a national conversation" [27].

Similarly, another interviewee says: "If we can't do something now then we're, we've lost our moment haven't we?" [28]. Whether that opportunity has been, and is being taken up is another matter, the point here is that times change and sometimes dramatically. The Covid-19 pandemic also created many challenges, with one respondent saying: "Fear caused a reaction of people moving to what they could control and in the beginning we weren't strong enough against the fear; we were too strict restricting visitors but learnt and managed things more flexibly" [31]. In direct contrast, another CEO speaks of: "[Carrying on] as much as normal as we could … with some visitors saying 'it is just like normal here'" [17]. Again, this is a reminder of the importance of context as a key factor in determining why hospices do what they do.

Naturally, opportunities that arise over time need careful consideration. One respondent talks about being approached by their CCG: "The clinical commissioning group want us to run *all* end-of-life services and coordinate it across the whole system and that's the thing we're struggling with" [16]. Their struggle is about "becoming part of the system" [16] and therefore not being able to "stand out as a place that does death properly" [16]. In terms of context, the issue here is that at different times opportunities open up for hospices but measured thought is needed about whether to take them up or not. In this case the hospice's reticence was in relation to what the hospice considered itself to be in terms of its purpose and concept. In stark contrast, another CEO speaking of future possibilities says: "I would like that we're the hub [for end-of-life care in our area]" [6]. In other words, the exact opposite is desired. Clearly, in both cases the relevance of time is obvious with the added point that wisdom is needed in determining whether opportunities should be taken up or not.

4.6.2 Where

Respondents in the study also talk about the importance of the context of place or geography. For example, one CEO speaks about "being reactive to the specific nature of the locality that is responsible for the funding of the organisation" [18], and another about "being able to be what people need from us" [17]. Here, local knowledge is seen as critical to hospice development.

Interestingly, one CEO posited the thought that context was critical to the inception of the modern hospice movement and that, without the context in which Saunders lived, it may never have happened:

> "It's an interesting thought actually, if Cicely hadn't been from a wealthy family with contacts in London, and this was some sort of idea that had been established by a doctor in, say, Barnsley, who was a working-class doctor, would it have taken off in the same way? I don't know, it may have done but it probably wouldn't" [2].

Hence, this respondent recognises the significance of both the historical and geographical context that brought the modern hospice movement into existence. This can, of course, be seen in Saunders' biographies. The opportunities that she had, including to train as a physician,[112] and the contacts she made were critical to her success as her own correspondence shows.[107,214,260]

In a final example, two respondents describe the significance of their rural context. One says: "It's very leafy and small in conservative XXXX which means that any project and any change we want to do is met with howls of dismay" [22]. So here the CEO recognises the local culture and the importance of working within the grain of it, so to speak. Another participant talks of the challenge of operating in a deeply rural area. On arrival in post, this respondent was often told at events "don't mention so and so here" [14] which at the time seemed ridiculous but proved to be good advice because the challenge of serving a very wide rural area is people thinking that: "All the money goes to one place [even though] … that's not the case" [14]. In fact, the CEO suggests that because this particular criticism is so strong it would be better to: "Build an empty building in the middle of nowhere because actually everyone would see it as the middle of nowhere [and not in one village or another]" [14]. This parochialism is exacerbated by the: "Lack of funding … because it is so rural; the larger amount of money [state funding] goes to the highly populated [parts] of the region" [14].

I include these issues here because geographical challenges for charity leaders are more commonly mentioned, as the respondent suggests, in the context of areas of population density and disadvantage[531] rather than rural areas. For example, speaking about research one respondent says: "Some hospices … are much more cash rich than others and … can push … innovation forward" [23]. In that case, the reference is to hospices that benefit from wealth in their areas and also to those which cover higher population levels. For example, one hospice in the study covers a population of 78,000, another has a population of a million and another a population of one and a half million. The latter obviously has a greater capacity to generate income by charitable means.

This short section provides an indication of the importance of the time-space context in terms of why hospices are here and how they develop. There are many references across all three themes that affirm this. Thus, *why* hospices are here is affected by *when* they are operating and *where* they are located; in turn context also shapes *what* and *who* they are as well as *how* they develop going forward.

4.7 Summary

Participants in the study describe the horrific deaths that people experienced in the twentieth century and the poor response of mainstream services that led to public outrage and hospice pioneers recognising that something had to be done. They explain the motivation and inspiration of people like Saunders and the needs of people near the end of life that Saunders and other founders identified. Similarly, CEOs describe the suffering of people in the twenty-first century and that society is still not doing death very well. They explain their personal motivations for helping hospices to be here and both the needs and unmet needs that they believe people face today. In considering why hospices were established and are here today the relevance of context can be seen throughout Theme One. It is also an important factor that influences what and who hospices are and how they develop.

CEOs’ understanding of why hospices were formed and are here today shows detailed knowledge that reflects descriptions in the literature. This includes some respondents displaying awareness of the historic roots of hospices and their origins in offering ‘hospitality’ to those in need. As one might expect, some respondents had more in-depth knowledge than others. In considering why hospices are here, there are not many differences in perception amongst participants or indeed between participants and the conclusions of the literature.

Chapter Five: Theme Two – What and who hospices are

5.1 Introduction

Moving forward to the present, I now consider what and who hospices are. By considering this from the perspectives of social construction, organisation and business studies, 'what' hospices are naturally includes 'who' they are as Gergen and Collins would argue.[411,532] For the pioneers, hospice is a 'living idea' with philosophical, scientific and social dimensions.[26] Many tensions can be seen as hospices grow into a 'Movement'[34] and the pioneers sought to use that energy positively. They also recognised a tendency to oversimplify the hospice idea,[1,21] and as time moves forwards, issues continue to be raised about the roles, foci and outlooks of hospices.[16] The literature also shows a shifting emphasis in terminology from hospice[26] to hospice care[16] and palliative care.[37,258] The results in Theme Two portray a very wide variety of views amongst respondents.

5.2 The concepts of hospice

When a problem has been recognised, there has to be an idea about how to overcome that problem and the conversion of that idea into practical activity.[26] The problem can be multifaceted and may require more than one concept or idea to address it. In this section, I consider interviewees' understanding of 'hospice' i.e. the hospice idea or concept. As will become obvious, there are many different perspectives amongst CEOs. As one participant puts it: "When you talk about the word 'hospice' what is it? It's different to different people and I think it's different to different people at different times and we're not one size fits all; I think that's the thing" [23]. Those different people can be those who work in hospices, those who benefit from them, supporters, local people, NHS commissioners, mainstream health professionals, academics, the media and so on. In fact, one of the main findings of this project is the kaleidoscope of understanding of 'hospice' and hospices amongst participants in the study. As a respondent says: "When you've seen *one* hospice, you've seen *one* hospice" [9].

5.2.1 A place

As I discussed in the literature, hospice leaders recognised that, as a concept, hospice is sometimes understood as a 'place' or 'space' which may or may not be a building. This can be seen in Saunders' *The Scheme* that outlined her plans for St Christopher's which she described as a 'place' with a feeling of belonging, permanence and security underpinned by a founding philosophy.[163] A few years later, Lamerton talked about making a patient's body a comfortable enough 'place' to live in.[134] Similarly, for most respondents, where hospice is described as a 'place' it is seen as more than bricks and mortar which Young emphasised at the 1980 hospice conference.[216]

5.2.1.1 A building

Considering the concept of place as a building, there is a wide variety of views. Referring to the early days, one respondent says that, for Saunders, a hospice was "an alternative to a hospital", albeit one that treated patients and their loved ones very differently from the NHS [9]. So whilst the hospice idea was originally partly about a building, hence the construction of St Christopher's Hospice in 1967, as one respondent explains it was much more than that:

> "It [hospice] was a building and I think in the beginning hospices were buildings and lots of people still talk about this hospice as a building … it is that whole wider … it's all the care provision wherever it may be but it's also all of that influence and the shaping of the future" [4].

Another CEO agrees that some people originally understood hospice as a building and goes on to say that this early perception: "Shifted in its institutional journey … [as the years progressed, from humble beginnings to] big, big, statement buildings" [3]. The interviewee quotes Clark referring to hospice buildings as "citadels",[71] describing this development as "the darker bit" [3] because some hospice leaders began to make statements through how big or impressive their hospice buildings were.

Another respondent speaks about this understanding of hospice that "drifted into being about a building because that's what the public could understand" [29]. In other words, local people could campaign for something tangible like a building more easily than they could for a new concept of caring for people who were dying and, of course, as history shows they did so with great success. This is still the case today, as the earlier respondent points out: "Lots of people still talk about this hospice as a building" [4]. Similarly, another CEO says: "They see this lovely building and that's what they support" [18]. However, some respondents also explain that: "People see a hospice as a place to go and die" [23]; this is a problem because “it’s really hard to get away from that stigma, isn’t it, that hospices are places where people go to die” [13].

The concept of hospice involving buildings brought a range of contrasting views with one interviewee feeling that moving into buildings was “the one bit that Cicely Saunders got wrong [and] haunts hospices [to this day] I think that is now a millstone around our necks, that people are still aspiring to, still building rather than thinking to improve everyone’s experience of dying and grief” [31]. This a little unfair on Saunders because, although she built St Christopher’s, she also said, “We want to spread care and too many buildings might stand in the way of doing that”.[250] The emphasis from this interviewee is that reaching out to everyone rather than being limited to those who can be cared for in a building is important. However, another CEO proffers an opposing view, suggesting that recent HUK workshops had inferred that if hospices were starting from scratch they would not have in-patient units. This participant did not agree, saying:

> “I do not think that is true because I think you have got to look at the needs of the potential beneficiaries and there is still a level of complexity that cannot be served in someone’s home nor is it economically manageable” [1].

Similarly, another participant supports the need for in-patient units, saying: “People still need acute care and we still need specialist palliative care beds” [15]. Another endorses the value of hospice buildings, saying: “Hospice beds are really special to us … and as we’ve seen … in XXXXX … hospice beds are what people think about what the hospice is” [2]. Thus, the participant believes that, conceptually, this is what people sometimes understand hospice to be.

One CEO holds a position between those of the last two respondents, explaining that buildings neatly hide away the problem of death: “One of Cicely’s downfalls was she created this place that people can put death into and forget about it. So it has this place in the community that everyone loves but they don’t really have to go there, so it’s fine” [17]. However, this participant offers a solution through changing the setting of hospice buildings and, consequently, people’s perceptions: “So it’s just trying to say, well actually it is a hospice, but also it’s a café and also it’s an art gallery and also it’s a concert venue that just happens to have within it a place where people have services who are dying" [17]. In other words, in "the public psyche" [17] such a setting normalises and integrates rather than isolates.

Thinking on similar lines, another CEO talks about introducing a "nursery which gives us a good blend on site" [25] and another about working with others to build "a village on the land that addresses our needs" [13] (where 'our needs' means the community's needs which include those of the hospice). In the literature, the Review of the Commission referred to one hospice's long-term project, The Mill, St Catherine's Park.[533] This project in Lancashire involved a strategy to open up the grounds of the hospice to the general public in a new way. Hospice gardens were connected to local council land that was re-designated as a park. Within it, where an old mill used to stand, an old barn was converted into a large café with rooms for public hire and a shop. Along with communications' and knowledge exchange programmes their approach was to open up 'hospice', and ultimately dying and death, in order to make them more familiar and normal to local people.[534,535]

In terms of finance and sustainability, one CEO explains the draw and drain that buildings can create in terms of hospice income and expenditure, saying:

> "I've got one million pounds' worth of nursing costs on there, half a million pounds' worth of medical costs … and that's before you turn the heating or lights on. Well, that's the dilemma isn't it? That's the gamble. If you didn't have a building, what would the hospice mean to people?" [5].

Here again, this interviewee sees the public associating hospice conceptually with a building. Similarly, another respondent feels that hospice buildings, despite their costs, are a critical element in income generation: "I've often had the thought that the majority of the support we get from local people probably comes from people who have been on our in-patient unit" [2]. (As I explain in the Explanatory Notes [Appendix 3] it is important to remember that not all hospices in England have buildings in which overnight care is provided.)[4,536,537]

5.2.1.2 A place to do things differently

Looking beyond buildings and more broadly, many CEOs embrace the concept of hospice as a place to be creative. Thus, one says that from the beginning hospices: “Created a little bubble in which they could devise, test, experiment, perfect ways of caring” [9]; and another says: “For me it's [hospice] a place where we strive to provide the best possible care that we can give with the limitations that we have” [25]. For both, hospice is a place to improve upon existing models of care. Similarly, others speak of hospice as a place without the constraints of mainstream institutions that are “very siloed” [1], of one which offers the potential to develop “one’s perspectives and ideas, philosophy and expertise” [1], a place “where you could offer that holistic care to people in a different way than was being offered in the NHS” [21] and where “we can deliver this [care] absolutely properly” [31].

In setting out to achieve this, CEOs understand that doing things differently was and is a challenge: “We still have that challenge to a certain extent today” [1]. One respondent says: “[That this is] because we felt obliged to be delivering what they [NHS commissioners] wanted us to deliver” [15]. Similarly, another speaks: “[Of the] governmental narrative that you then absorb as a clinician, especially when you work in the NHS that you realise is only a narrative … to make you work in that way rather than actually thinking about death” [31].

Thus, respondents see hospice conceptually as a place to step away from siloed or narrative thinking, to develop ideas philosophically and practically, to remove limitations, to think and do things differently and to strive to produce the best ways of caring for people.

5.2.1.3 Welcoming and safe

Quite naturally, having already heard CEOs speak about the fear and suffering that people experience, it comes as no surprise that their concept of hospice includes the idea of a welcoming, safe place for people to live until they die. Thus, one respondent speaks of hospice as: “The right place for someone to live well right to the end” [5]; others of “somewhere that’s a safe place” [19]; “that place of refuge” [21]; of “shelter” [11]; saying that “hospice is shelter” [12]. Thus, creating places of safety is not just something that hospices do, it is what they are. Hospice *is* shelter and it is not necessarily shelter in a hospice building.

Interestingly, one CEO proffers a historical example from the earliest known days of hospices and one that reaches beyond dying and death. This respondent talks about the word “hospitile, from hospitalia in Latin”[538] [11] that was the name for a place of welcome and hospitality at the front of a monastery where all “wayward people who had lost their way … or who were hungry and tired and sick” [11] could enter for rest, food and shelter. This respondent identifies the fact that the origin of hospice was about open access, welcome, hospitality, care and safety; it involved more than care of the dying. Moreover, this concept is still relevant today because hospices seek to offer “what it is you need at that point and it happens” [11]. Interestingly, this broad outlook of offering hospitality and shelter links to a comment from a CEO mentioned in Chapter Four: “I do believe that the hospice has a place in other aspects of health and social care in the town. To me it’s not just about dying people” [13]. This understanding of the first hospices following the ancient belief of offering hospitality to weary pilgrims, that came from the teaching of Jesus of Nazareth, matches with the literature (See Section 2.2.1).[63,134]

5.2.2 A quality of care

As I have shown in the literature, hospice as a concept is often understood to be a quality of care, hence the commonly used phrase, ‘hospice care’.[16,363] Hospice is also described as a philosophy of care.[105] Both include the concept of ‘total pain’.[23] Respondents referred to each of them and whilst they overlap they also have distinct features. I begin with quality of care.

To give this context, CEOs understand that from the outset of the modern hospice movement, hospice care was different from the mainstream medical services, including in the administration of pain-relieving medication. For example, reflecting on being a young hospice nurse, one interviewee speaks about normal dosage and whether it was working or not:

> “I had support from other doctors behind me and he [a doctor] was saying, ‘What do we go up to?’ And I said, ‘We go up by a third, that’s what we do’. He said, ‘but that’s enormous’. I said, ‘but it’s not working, I’ll go in twice a day and monitor’” [31].

In that new world of hospice care, the pioneers looked at recommended doses, actual patient experiences and how comfortable they were. As other respondents put it, they saw what was wanted: “They were pioneers in recognising the pain, discomfort and symptom control needs that were lacking” [15], easing a patient’s discomfort through proximity, “intimacy” [9] and “holding a person’s hand” [11]. As another CEO explains: “Our patients are seen as people, not as somebody who needs to be repaired or cured” [13].

Participants describe hospice care as “personalised care” [3], care that is “encompassing of all the aspects of pain that someone suffers” [2], “holistic” [3] and “around the whole person” [4]. This notion of intimacy, personalised and person-centred care is seen by one participant as a determining factor of quality and value: “It’s what makes the difference for me between care that’s either adequate or good in a very sort of superficial way and care that really has value and that people remember” [9].

According to these interviewees in the study, the lack of intimacy and person-centred care of the dying was where the pioneers came in and its high importance continues today. Intimacy was a key issue when the Covid-19 pandemic arrived:

> “It's quite hard for staff because you've got the dynamic of no visitors, so staff are having to take on a different role in the caring aspect because they're trying to support the family at arm's length and bring succour to the patient at the same time at a very difficult time … the last three or four days of life in Covid has not been very pleasant for many people” [25].

In hospices during the pandemic, the transcripts show that there were varying levels of social/visiting restrictions imposed by hospices ranging from the “no visitors” [25] described above to carrying on “as much as normal as we could … with some visitors saying: ‘It is just like normal here’” [17].

In relation to the identified needs of patients described in Chapter Four, hospice quality care is described by some participants as being for more than the last few days of life: “It isn’t just about coming towards the end of your life; it is about those people with a long-term condition who can be supported in some way by this all-encompassing care” [2]. Similarly, another CEO says: “I don’t just see it about the end of life … [it] is about providing care from the point where a patient is diagnosed" [8]. As one respondent describes it:

> "Our patients have a longer trajectory. They live longer and it's more about actually their bucket list and making sure that they can actually be symptom-controlled in order to enable them to live to the very last moment" [15].

Another CEO reinforces this point, emphasising the importance of excellence of care "over a sustained period of time and being reactive to the specific nature of the locality" [18]. Thus, hospice care is about end-of-life *living* as well as dying, death and bereavement. In that respect one CEO believes that hospices should help people 'earlier in life' to think about how they can make 'later life' better [18]. This of course is reflected in the literature in recent debates about definitions of palliative care, where it is argued that care should be made available 'upstream', which means earlier in a patient's experience.[24] Other respondents speak of an "individual's family" [10], seeing it as "a whole family situation not just the person themselves" [24] and how care is "multifactorial" [24] and must relate to community need, local culture and understanding [10]. Hence the need for the multi-disciplinary approaches that were mentioned previously and in the literature.[539]

Hospice care is also described as specialist care. For example, one respondent says: "I would say it is the provision of specialist end-of-life care for those … well in most discomfort at end of life, across a range of conditions, diseases [and it is] … free of charge at the point of delivery" [10]. Others talk of their mission to be: "The provider of specialist palliative care" [15] [4], alongside being a local voice and helping to coordinate care. The last respondent identifies different views in hospices with some saying they should just care for the most complex cases. However, their opinion is that they should take a more inclusive view because from the outset Saunders would look after dying people whoever they were [4]. In the literature, this relates to a concern expressed in *Dying for Change* and the work of the Commission that some hospices run the risk of being reduced to specialist providers within the system they set out to change.[325]

One CEO describes delivering specialist palliative care as the “core *raison d’être* of the organisation” [10]. In other words, conceptually, hospice quality care is the heart of what hospices are about. However, one respondent also says that hospices do not always provide good care. On more than one occasion during the interview this CEO says that whilst hospices claim their care is high quality, it is not always so. These comments are based on personal experience with family members:

> “I think some of them [hospices] are atrocious. I think ‘atrocious’ is a strong word but I say that because as well my sister had some offers of home care from a hospice … which was awful” [29].

The same CEO describes hospice care provided for their mother-in-law as “garbage, really awful, terrible, terrible” [29] and feels that the quality standard can be a false assumption and is an important strategic issue for hospices nationally:

> “I do think we within the hospice movement feel that the quality is good and we think the challenge is quantity which may dilute the quality. I would suggest to you that sometimes the quality isn’t very good” [29].

This CEO, who was not alone in their views, explains that gratitude towards hospices is sometimes because people have nothing to compare hospice care with. Likewise, another respondent says: “So many people … just accepted their sort of sub-standard experience because they don’t know any better” [30]. In less vivid tones a further respondent stresses “the importance of challenging” the quality assumption saying: “We think we are patient and family centred [but] actually are we?” [1]. Thus, here concern and challenge are expressed about the very core of what hospices are about and a concept upon which, many CEOs believe, everything stands.

5.2.3 A philosophy and belief

Closely aligned with the concept of hospice as a quality of care is hospice as a “philosophy of care” [29] or “ethos” [19]. The following quotation shows that this concept of a philosophy of care incorporates quality of care but is also about something much broader:

> “The reality I think is that it’s [hospice] a type of organisation that delivers a particular type of care and service …. So, a bit of the history and the heritage and the ethos and where it comes from and what personalised care truly is within the hospice ethos” [3].

One CEO describes the hospice philosophy as being beyond walls: “And we’re not a building; we’re a hospice without walls; we’re practising a philosophy of hospice care” [15]. For others, this philosophy is more than a quality of care because: “Hospice is a way of life … it's all about people” [24]. It involves openness, communication and meaning: “If they ask what hospice is for me, it’s a philosophy of care that lets us talk about death and dying, lets us talk about that philosophy of care and what that care means” [29].

From a similar perspective, one respondent describes hospice as a belief system, “I think it's [hospice] about a belief system around living well to the end. It is a, it's a verb; it's a doing word. ‘We're going to Hospice you’ is a sort of cultural belief” [5]. This understanding of hospice as a belief system is of something active and dynamic, a positive culture which chimes with Saunders oft-quoted words that every individual matters and must be helped to live until they die.[516] Similarly, others speak of proximity, of “seeing the total person and being in that space with that person and making sure that person knows they matter” [12] and of “empowering people to make their choices and live their life” [19]. Talking about the biggest challenges for the pioneers, one CEO says simply that a difficulty was in “convincing people that it was important … getting people to believe” [15]. Similarly, another says: “Without them [the pioneers] being brave and having such belief, we wouldn’t be here” [20]. Hence, the philosophy described here includes courage.

Some respondents describe ‘hospice’ as a feeling or emotion that “you have to experience” [4]. So, whilst a feeling is not a concept, it is an outcome of a way of being and working. For example, one CEO talks about the “idea of caring hands”, saying that the experience “is really very emotive actually, and that’s what it’s about” [2] because it symbolises what hospices do and the feelings they create:

> "It could be where somebody is producing something memorable to leave behind … It's a spiritual thing that idea of feeling safe, feeling able to say what you feel, feeling that you are dealing with a professional that knows what they are doing, who communicates properly" [2].

Here these feelings have a meaningful and transcendent quality for those who experience them, and for this respondent they are "what hospice is about" [2]. Another CEO ascribes the special feeling to their team of hospice colleagues, their united approach and the atmosphere that they create together: "I don't think hospice exists without a team of people who have a united approach to delivering that better quality of life … It's a sense and a feeling … It's a community; it's a place of life and of people enjoying life" [28].

Another respondent believes that the source of this feeling, the "philosophical part of what Cicely Saunders was driving at" [4], makes a significant difference. It is much more than a superficial feel-good factor: "It's always hard to describe what is hospice and what's different about it and often I have to say to people, 'you have to feel it, you can't describe it'. You have to experience it and feel it to know what difference it makes" [4]. Similarly, another participant speaks about "atmosphere being the fundamental importance of hospiceness" [5] and how watching the hospice team separate during the Covid-19 pandemic was extremely difficult.

Following a similar train of thought, one participant in the study believes: "Hospice is a behaviour" [31]. When asked to describe the hospice difference, this participant says: "It was about our behaviour, how we treated people, not what we did to them or where we looked after them; it was what we were like" [31]. Consequently, it is not surprising that another CEO says: "I think people see it [hospice] as a good neighbour" [23]. This, in turn, intersects with a point made earlier about love and compassion: "People still talk to us about feeling loved … it's an experience of intimacy that people have and it's often very healing after a very brutal time" [9]. Finally, one participant sums up this concept by saying: "We're here because something sings to us" [5]. Hence the philosophy described here is not just about a type of care; it is also about caregivers, care-receivers and an organic interactive community of 'being and doing'. It is about love which is multidimensional, encompassing and transcendent. This, of course, correlates with Saunders' living idea,[26] Lamerton's big idea[134] and Klagsbrun's "the care of the dying is the care of all of us … it is the dying who are giving us a much better awareness of the gift of life".[218] Clark describes this as "a matter of 'being' rather than 'doing' … the task is to alter the character of this stage, to see it as a positive achievement in dying itself".[188]

In considering the relationship between the concept of hospice as a quality of care and that of a philosophy, belief system, feeling and behaviour, the key point that I draw from these descriptions is that the hospice philosophy signifies something much deeper than quality standards or professional practice because it is about a way of life, human value and belief.

5.2.4 A vehicle

In sharp contrast to hospice as a philosophy, 'hospice' is described much more simply and pragmatically as, "a vehicle for delivering the best possible end-of-life care for the population" [30], and this respondent is also clear about what it is not: "That's all it is in my mind … the hospice isn't the building or a philosophy of care; the hospice is the entity that has that purpose and basically anything goes to deliver that purpose" [30].

In contrast to others, this CEO appears to hold a reductionist view of hospice, seeing the hospice idea as simply a coach that drives from one destination to another carrying its passengers. Another respondent appears to share this view, saying: "Hospice is about the delivery of an outstanding level of palliative care" [18]. However, when describing 'hospice' as a 'vehicle', participants usually add something more, for example: "It's a body of people delivering services" but also "It's a movement … it is the facilitator of a good death" [26]. Naturally this concept of hospice as a vehicle asks the question: "What kind of vehicle?"

5.2.5 A community resource

One CEO describes the concept of hospice as a repository within the community that is available and enabling for everyone. This could be understood as a function of hospice, like education, but for this CEO it is much more than that; it is conceptual: "So my view is that hospices should be almost a repository within the community of everything around death, dying and bereavement" [17].

The respondent explains that if people are having anxiety around death, if they have watched an upsetting film, experienced a bereavement, seen friends or neighbours dying or are themselves bereaved then: “Hospices should be the place that people come to for support and help and to ask questions” [17]. Consequently, this CEO believes that hospices should be there for everyone:

> “Creating communities that are a lot more comfortable with death, dying and bereavement … making sure that people can talk about the things that they really want to talk about and plan for the things that they’re afraid of and do things in their own way” [17].

Whilst this concept shares common ground with that of those respondents who talk about reaching everyone or everybody, it is unique in the use of the term ‘repository’ and the meaning that is applied to it. From the interview, that meaning goes far beyond the idea of hospice as, for example, a traditional high street library or information centre. It feels more like a vibrant, community resource of life, a living hub in and amongst local communities, an organic repository that all can be part of, one that imbues comfort and confidence, dissolves fear through openness, inclusiveness and accessibility and is relevant to all through its own regenerative activity.

Whilst no other respondents describe hospice as a repository, others share common ground with the concept. For example, one CEO speaks of hospice as a community resource saying: “[It is] for the community, by the community, of the community and I think that’s something that’s really unique and … mess with that at your peril” [6]. Another talks of “social value within our community” and “a community development component right from the beginning” [3]. Another says: “We’re a community service and we’re embedded in the community” [13]. One participant describes being “really ambitious about the amount of change that we can make by empowering others to change as well” [4], and others talk about the importance of “the education offer” [27] and how education is so important “if you’re going to remain relevant” [28]. Another interviewee describes learning to “work through other people and you were the resource they called upon” [31]. In other words, the community resource or repository concept is about people sharing experiences and knowledge together. It is about social value and resonates with community-engagement approaches to equip and empower communities to help themselves in an organic and vibrant way because, as Deliens and Cohen state: “It is unlikely that good dying for all will be attained by limiting our societal efforts to the improvement of palliative medicine or palliative nursing”.[540] The next concept adds to this in terms of broader social change.

5.2.6 A social movement

The concept of hospice as a social movement relates to the concepts of hospice as a philosophy and belief system, and a community resource. In the literature, the concept of social movement is described as the application of a belief in social value by a group of people who champion that cause[541] which, as one might expect, is a view shared by Neil Kinnock, former leader of the Labour Party. In a letter commending the values of hospices he says: “Hospices represent the highest ideals of our community … they have taken the medical and moral offensive against death … [liberating] the humanity and the skill of the whole community”.[239]

Here a CEO describes belief in the hospice movement as a social movement: “And so my mission and vision is to continue being part and true to, at least in this area, a social movement which is the hospice movement which champions what I believe in, which is original and still valid” [29]. At the same time, this interviewee also says: “I do think it was … a social movement. I do think it was [but] … I’m sad to say, that I don’t believe the hospice movement is a social movement any longer” [29] and that as a consequence hospices miss out on “what is unique and precious about the hospice movement” and its ability “to face the challenges that are coming to society” [29]. Likewise, another CEO says: “I don’t think there’s a [hospice] movement anymore … there’s no call to arms … I don’t think we ever sit down and have a grown-up conversation” [17], and another comments: “It would feel nice to be a movement again” [3]. However, in this regard, a further participant in the study suggests that “hospices overstate their claim about a national hospice culture” [16], but by contrast another believes that ‘hospice’ is “a movement. It’s a body of people … It is the facilitator of a good death” [26].

Amidst these contrasts and concerns, some respondents espouse the social movement concept locally, saying: “It’s around an ethos that we have in the community [and] … embracing the community” [19]. Another says forcefully: “This hospice is here because the community built it not because somebody might have decided this was a good place for it" [11]. In other words, local people appreciate the broader social value that hospices bring. For example, the CEO says: "They appreciate what we're doing as a part of, in their view, a much broader contribution to society, because we're not just the people with the dead bodies in the back" [11].

So here, hospice is not viewed simply as a vehicle to deliver end-of-life care; it is also about shared values in society. Historically, social movements are described as "social relations that link social action events by circulating meaning through these relations"[542] and Klagsbrun emphasises this symbiosis in hospices.[218] In the end-of-life context, social meaning and value are ascribed to individuals, especially in their last days, and hospices are a reminder to society that this matters. As one respondent puts it: "Hospice exists to provide a haven, remind society of value. Life has its greatest value when it's going to end" [9]. For this CEO, all hospices have a responsibility to remind society of human worth, especially at its conclusion. Similarly, another respondent talks of the importance of asking: "What does add value to society these days?" [13]. Here one sees a link to Gergen's application of semiotics in order to visualise a bigger picture and to consider what the actions, reactions and joint actions of intelligibilities signify and *mean*.[436]

One participant believes that today, these "benefits to society [from hospices are] … part of the check for the over-medicalisation" [7], and another says that hospices have a key role because "the way society responds to death and dying will change" [12]. One interviewee believes that: "There needs to be a rebalance … the hospice movement as it stands shows a humanity and morality to the world" [24]. Thus, the concept of social movement emphasises the wider role that hospices have in local and national life. In Gergen's terms of intelligibility nuclei, it begs questions about where hospices sit in relation to the intelligibilities of, for example, governments, public services, communities and society and, consequently, whose values they share, broker or represent.

5.2.7 The colour grey

One CEO answered the question "What is hospice?" in a way that surprised me, saying: "I best describe hospice as grey. So we're not black and we're not white; we're the bit in the middle and people sometimes struggle with the bit in the middle" [14]. For the proponent of this idea, it is not about "the new innovative system to management, let's throw everything at it. It's not healthcare with a red line around it" [14].

I find the idea of hospice as a colour interesting. This CEO describes the concept in relation to a freer, more open and less rigid form of working compared to the mainstream: "We've had a horse in the unit, a dog on the bed … it's about being really, really person-centred … [and] if you're a diabetic and you want full-fat sugared custard because you are going to die in the next three, four, five days who are we to say … [and] we've done Christmas in the middle of summer" [14]. Contrasting this approach with the mainstream, this CEO says: "Acute hospitals struggle to be person-focused because they do things *en masse*" [14]. This approach that seeks to truly care for people individually links to the idea of N of 1 mentioned in the methodology[476] (see Section 3.4.2) and to Saunders saying: "What dying people need most of all is a doctor who will see them as another person".[204]

Whilst no other respondents describe hospice as the colour grey, many talk about the value that they place on 'different' and making a difference. For example, as one CEO puts it: "[You value] the difference that you are making" [28], and others understand that hospices are only here "because those pioneers really made a difference" [25], because they were different. In this respondent's explanation of the concept of grey, those differences are often in contrast to mainstream approaches. Thus, one respondent says: "The main difference down here is between us and the CCG [Clinical Commissioning Group]" [16]. Likewise, as discussed earlier, another speaks of the challenge of not being caught up in a "governmental narrative" [31] that makes you work in a particular way.

Thinking about this concept metaphorically for a moment, one could think about a boundary or coast. The coastal boundary, or grey zone, creates opportunities and challenges that are different from those faced by those who are operating inland or at the centre of meta-organisations.[543] Thus hospices, unlike hospitals for example, do not operate within the mainland of public services and central funding and consequently, this presents opportunities and challenges for hospice leaders to take and address.

In considering what hospices are, I have explained seven hospice concepts that CEOs describe: a place; a quality of care; a philosophy and belief system; a community resource; a vehicle; a social movement and the colour grey. I now move on to CEOs' views about how these concepts are put into practice through strategic roles, foci and outlooks.

5.3 The strategic roles of hospices

Respondents describe many strategic roles for hospices. In the literature, thinking at a national level, Owen speaks of hospices *not* being the NHS but having complementary roles.[241] In more detail, the Commission emphasises the strategic importance of hospices being collaborators, a role which can involve advocacy, diplomacy and facilitation. It also points to the risk of reducing their activity to being no more than specialist providers when hospices can have many strategic roles as, for example, empowerers, educators, innovators, researchers and coordinators.[343] This they say "will mean challenging some of our … orthodoxies [and being] champions of those in need".[357] Interestingly, more recent work by HUK says little about twenty-first century hospices being disrupters and campaigners that hold governments to account as hospices did before the millennium, where the likes of Twycross described their work as a protest against the way that people were cared for at the end of life,[120] and Lamerton spoke of hospices as a "corrective" to modern medicine.[204] Similarly, Saunders described a frequent lack of cooperation amongst those concerned with terminal care[544] and said that St Christopher's would not only provide care but that they wished to raise the standard everywhere in helping people at the end of life.[545] It is in this context that I present strategic roles of hospices described by respondents in the study. I group these under eight headings.

5.3.1 Provider

All respondents speak of a key role of hospices being to provide services and, at various points in their interview, each respondent talks about what they provide. For example, one says: "We provide four services: an in-patient ward; hospice at home; the clinical nurse specialist; and day support services" [5] and refers to "the education we provide" [5]. Another describes hospices as a "provider of health" and as a "palliative care and end-of-life provider" [18].

In terms of growth in provision, one CEO looks back, talking about hospices now being more than a provider, explaining a historical development in their hospice to incorporate enablement: “Our hospice started many years ago [and] … was more set up just to provide that peaceful end-of-life care” [8]. However, one of their frustrations, the CEO says, has been that, “[They] provide this absolutely platinum service for a few people” [8], so today we are seeking to help more people in a variety of ways [8]. Similarly, another participant says: “Our core business … is around our expertise in providing palliative care”, but looking ahead an option will be “to go big [through partnership working]” [1].

However, one CEO says that by seeking to extend reach: “There’s a real risk that hospices are setting themselves up as the main providers” [31] in contrast to the situation in earlier years where hospice nurses were “actually based in a district-nurse team” [31]. The respondent sees this as an issue because hospices do not have the resources to become the main provider. When discussing the role of HUK, the same CEO expresses concern that: “They’re still about *services* … thinking about a *service* organisation rather than an enabling charity” [31]. Unusually, compared to others in the study, whilst this participant recognises the importance of providing services, being a provider is not seen as the primary role.

There is universal agreement amongst interviewees that a key role of hospices is as a provider of services for people near the end of life. For many, this is seen as their primary role but it is not the only one.

5.3.2 Exemplar and standard-bearer

A key role that a number of CEOs point to is that of exemplar. Hence, one participant says: “I think hospice is, it’s both an exemplar and it’s a provider and by being both, it could, it could inspire others to want to do more and to do it differently” [9]. So here a hospice is a provider for others to emulate.

Another respondent describes exemplar as a function of hospices in terms of them being specialists: “They should be recognised as the specialists [and this specialism should be] … delivered through training, through research, change of practice” [24]. Another participant talks about reminding staff: “We’re an important part of the history of hospices so those standards have to be maintained” [25]. Similarly, another says: “I think we’ve got to stand out as a place that does death properly and is available to people and accessible" [16]. In other words, hospices should be standard-bearers.

In this role, one respondent explains that there is work to do in unexpected quarters because sometimes doctors do not know what hospices are: "I'm equally shocked when I talk to doctors at the hospital who don't really know what happens in a hospice. It's just like: 'How can you possibly not know what a hospice is or have never been to one?'" [6]. Another talks of how, in developing exemplars, it is sometimes clinicians who do not share the same priorities [9]. One participant says: "Doctors … debate about a patient, for example with motor neurone disease coming into the in-patient unit, but if you have a patient with breast cancer we'd find it [a bed] … and I've had to challenge that over time" [8]. Another interviewee says that, in terms of priorities: "We've over-medicalised death and … we are trying to unpick that" [29]. One CEO addresses this challenge through a compassionate neighbours' team saying: "For the first time ever I've got people that are the intellectual equivalent of our doctors who are going to stand their ground" [9]. So, a role of hospices is seen by a number of respondents as being that of an exemplar and standard-bearer for doing death properly.

5.3.3 Collaborator

All CEOs talk about hospices working as a collaborator with communities and other organisations such as the NHS, Adult Services and local councils. The words 'collaborate', 'partner' and 'integrate' are used widely in the interviews. These terms date back to 1980 when the Wilkes Report considered the organisation of terminal care services for cancer.[247] Since that time, hospice leaders have considered the issue of collaboration.[11]

One CEO speaks of the importance of hospices recognising that they are one part of a large field of work: "I'm going to leave an organisation that recognises that it is only a player in a much bigger world and that it's not centre stage and that it has got something to bring to the party, but … it's only one bit of that party" [9]. Others explain collaboration in terms of fulfilment and survival: "My belief has been strongly in terms of partnership as the only way that we are going to try and fulfil our mission" [1]. Another says: "We will not survive in the future as a hospice in isolation; we've got to work in partnership beyond the sector" [11]. Here CEOs are saying that partnership or collaboration is essential if hospices are going to be capable of fulfilling their mission and ensuring their own long-term survival.

Many give examples of good partnership working, such as “our partnership with Marie Curie which has worked really well actually” [5], and the “great opportunity of the XXXXXX Partnership” [2]. Many speak about “partnerships with schools” [10] and working “alongside the council” [28], which in this case was in a compassionate city project. Respondents give examples of opportunities to work with other hospices. One speaks of “three hospices serving a relatively small population” and that a challenge is “the way in which commissioners historically have funded services”. They add: “I think with that comes an opportunity to collaborate [and] that’s about trust … that we’ve built up over a period of time” [23].

Many CEOs say that collaborative working between hospices does not come easily, for example: “We’re [hospices] like tethered elephants … and we tie ourselves up … no one ever wants to work in partnership, no one is ever going to have a go” [5]; “I think we are poor at partnerships” [10]; “I find it very hard to do anything productive with nearby hospices”; and “getting agreement to joint collective action is blooming hard” [30]. One CEO puts it bluntly: “The starting place almost inevitably is how could we avoid a merge. The starting place isn’t: ‘how can we do what’s best for patients?’” [7]. Similarly, another interviewee says: “There’s a tension between hospices … anything that leads us to be more trusting of our peers within the hospice movement [is good] … even in the private sector, where it’s far more cut-throat, they tend to collaborate much better on some key issues” [25]. Being self-reflective, one CEO says:

> “I also wonder with the rest of the system how easy it is to work with hospices as partners because I think the arrogance, the sense that we have a bit more money … pisses our partners off quite a lot I think and makes it more difficult to work with them” [17].

Another participant speaks of the need for consistency in data provision because “that must be quite irritating to the NHS” [28]. In other words, hospices should think about how partnership feels on the other side, so to speak, and how they can make working together easier and more effective. So here, challenges of collaboration are found between hospices themselves and between hospices and other partners such as the mainstream organisations.

Another challenge in the function of collaboration is hospice development or lack of it, which in turn relates to viability and local identity. One CEO says: “There are hospices who are still moving, changing and making a significant impact … but if I’m completely honest, I think there are quite a lot of hospices that probably shouldn’t be here [and we end up] competing for territory” [4]. Similarly, another respondent says, “I still remain very interested in conversations with adjoining hospices” but, importantly, “without undermining the localism identity” [1]. At the same time another interviewee, who is relatively new in role, states that “my biggest surprise is how everybody’s just doing their own thing [and] we could be more efficient, more productive, more effective without threatening our local identities” [16]. Here participants believe that there are opportunities to collaborate, including between hospices, and that some partnerships work well. However, it was also felt that some hospices are too close together and need to merge but this must include protecting local identity.

At the same time, some CEOs call for discernment, warning of risks in getting swept into collaboration with poor partners even when they are major players. For example, one respondent speaks of colleagues:

> “Who feel they have to collaborate for the sake of collaborating … if we’re not prepared to say, ‘Do you know that what you’re doing is rubbish here? We’re not going to work with you to do that’. And they say, ‘But we’re the Community Foundation Trust you have to’, we go ‘yeah, it’s a bloody shame isn’t it’” [29].

Whilst this could appear to be negative, this respondent argues that collaboration has to “benefit patient care and families; otherwise we’re not collaborating” [29]. Likewise, another interviewee expresses concern about a nearby hospice that has “partnered up with the NHS and other providers”, who have “put their logo alongside the NHS logo which I think is fascinating but I also think it’s dangerous [because] you could easily lose your identity and your support” [16]. One CEO puts it more strongly, saying there is a danger “we’ve been consumed by the organisation we were trying to change" [31], echoing a similar comment in *Dying for Change*.[325]

There are sharp contrasts amongst CEOs about how hospices should collaborate or integrate. Thus, compared with those quoted in the last paragraph, one respondent wants to be working at the heart of mainstream services, saying: "The hospice can do most by actually bringing the system together to deliver better end-of-life care" [30]. Another says: "I would like that we're the hub" of local end-of-life services [6], whilst others see hospices being "distinct, on the edge" [16], as a "gap filler" and "enabling charity" [31] that supports, facilitates and innovates. In this regard, some CEOs express anxiety about HUK's views on collaboration, for example: "I worry more about their vision … when we are getting told about like getting rid of buildings and palliative care can be done on a hospital ward because I feel they are becoming part of the NHS then" [8]. Another CEO shares concern that HUK seems to be saying "the only way to survive is to merge" [21]. (This was mainly about hospices merging with each other and integrating with the NHS.)[37] They continue: "I was like, hang on a minute … who's saying that mergers is the right way forward?" and "Is that necessarily helping hospices think about how they are different in the future, because there's only one view being put forward?" [21]. In a similar vein another participant feels that HUK (at the time of the interview) is "focused on a mission of merger" [28]. From the literature, there was criticism that the HUK's Future Vision Programme[37] survey could lead to foregone conclusions in this regard.[392]

In terms of HUK's collaboration with hospices, one respondent says: "I felt more comfortable with Help the Hospices than … with Hospice UK" because "they were more collaborative and less directing" [3]. Others say: "Help the Hospices was a better organisation in its approach" [29] and, "There's a significant disconnect between the national body … wanting to be distanced from its membership status" [30]. However, by contrast, others say: "I believe in membership organisations" [27] and, "My experience to date [with HUK] is very positive" [25].

Thinking proactively about partners, another CEO talks about an energetic approach that reaches out, knocking on as many doors as possible to say, "not only, 'Can we come in?' We're not going in with a begging bowl; we're going in saying, 'this is what we can offer you and it's not just palliative care either'"

[11]. In other words, for this participant, hospices should not sit back and wait for opportunities to partner or integrate; they should seek out new ones by knocking doors down to offer solutions to problems. Likewise, another participant says: “We need to be fearless … passionate [and] … see ourselves, as hospices, as a significant integral part of the integrated care system … we are not the poor relative … and it is time we started acting like we were [a significant partner]” [26].

Another participant recognises that integration is not just about collaboration with mainstream services; looking forward this CEO says: “I hope they [hospices] will become seen as more and more an important part of life and more integrated into other parts of society and life” [22]. Similarly, another interviewee speaks about “things that really matter to me … our kind of genuine partnership and choice with people” [27]. This is significant because integration, collaboration and partnership are often talked about in relation to hospice mergers and working with the NHS, but here the emphasis is on integration with people, society and ‘life’. Finally, seeing hospices positioned between communities and the mainstream, one participant says:

> “The future of good end of life … sits in much stronger partnerships, much more equal relationships between community and the systems of health and social care and I think hospices are really ideally placed to broker that … around agency and power” [9].

This brokering role prompts questions about whom hospices represent and are agents of, which I will come to shortly.

5.3.4 Enabler and educator

All CEOs in the study consider that enablement and empowerment are important roles for hospices and that these include education. Speaking in overarching terms, one respondent says: “We are here to enable people to have really good end-of-life care and a good death, and the word ‘enable’ is a really important thing” [1]. Enabling is seen to be significant due to a lingering paternalism in hospices and hospitals:

> "There's a lot of paternalism in the hospice world isn't there? It's about doing to patients, so it's like, I think hospices are there to enable patients to have a quality of life …. it's very much that model about enabling rehabilitation, setting-goals type of model" [8].

This is interesting because, as I said earlier, one of the criticisms of the NHS when hospices emerged was its paternalistic attitude.[29,71] According to the transcript of this interview, some hospices have fallen into the same way of working because "It's so engrained … that we're providing care *to you*; you are receiving the care" [4]. So, empowering, enabling and helping people to have "more personal control" [1] are seen as important roles. However, whilst agreeing with the value of an enabling approach, the last participant also expresses a concern about motives. The interviewee says: "[If this is being driven by people saying] 'I want to take more control of my life' … this is a really potential positive opportunity, but if it is defaulting to that because the whole system is in total crisis then it is not" [1]. So, in the function of enablement and empowerment, underlying motives are seen as important.

For many, the roles of empowering and enabling include raising public awareness about end of life, encouraging advanced care planning and equipping people. For example, "You know I think to enable people to advance care-plan and to talk about their future starts at an early age, which is why the schools and colleges' work is so important" [19]. Another respondent says: "I feel very, very strongly about the intergenerational responsibility we have and for those who don't currently get access" [1], and, "If we were doing a good job everyone would be informed, equipped, enabled over dying, death and grief" [31].

Some CEOs describe enablement and empowerment in terms of facilitating and influencing. For example, one says: "So, you know, the … the growth of the organisation out of being a large hospice based in XXXXXX that people come to [is] increasingly [now] an organisation that facilitates care in the community" [10]. Others speak about influencing "other secondary care professionals" [1], and "increasing the influence of the organisation" [18]. One interviewee comments: "A huge change for me [is trying to] shape and influence the *whole* of care in the area" [4], and similarly another participant talks of "serving locally but provoking nationally, and kind of supporting internationally" [9]. Another CEO speaks about "being the organisation that supports and facilitates" [31], and gives an example:

> "I see our healthcare assistants rather than going, they might do a bit of sitting at some point to help, but I would see them going into almost being a 'death doula' to go in and facilitate … but it's not, we don't become a big sitting service type thing" [31].

Thus, many participants recognise the importance of influencing and facilitating as they seek to empower and enable. A key element in this role is education which includes information and knowledge-sharing with hospice colleagues, other professionals in the field, patients, families and communities. For example, respondents recognise that its provision of education was one of the hallmarks of St Christopher's when it opened in 1967, "I think you know, education and it has been right from the day Cicely opened St Christopher's, education has always been a strong thread running through the organisation, for us, but also for most hospices" [19]. Another CEO describes education as the biggest thing, "so the biggest thing going back to our roots with Dame Cicely Saunders is actually pushing on the education [and educating people] that we're not a building; we're a hospice without walls" [15]. ('Hospice without walls' is an established phrase in the literature.)[537]

Similarly, another CEO places very high importance on education, describing the broad range of what their hospice does:

> "And the education … I mean that has always been a huge part of what we do, so all the medical students in XXXXXX came here or to another hospice. We've managed to get more teaching days on palliative care at the university for medical students than anywhere else in the country … and all of the student placements and … district nurses, GPs etc., … and that feels like it's really embedded; it's really solid; it's there forever" [4].

Here education is a major hospice function that reaches deep into the NHS in terms of hospice and palliative care. Looking forward, participants say: "And the other area I really want to expand if we can, is our education offer" [27]; "reshaping the organisation to be fit for the future so we have a large education team" [10]; "one of the key lessons we've learnt … has been that we're not educating people enough … they have preconceived ideas" [15]; and "I don't know that we educate people or train people in what is hospice care in comparison to palliative care" [3]. Clearly, for some CEOs, education is an extremely important role for hospices as it was for St Christopher's from the outset.[195]

Education is described as taking place in many forms, including the exchange of knowledge. One respondent describes their approach as reciprocal in nature: "So really, what we're wanting to do is have the equivalent of almost like an ecosystem where we're working alongside and in partnership with others and education is a large part of that" [15]. Others describe knowledge exchange through community engagement and interaction, for example: "I think one of our legacies will have been about integrating community action and professionally led care and … primarily … through education and training, through teaching internally and externally" [9], and: "We've got an increased community engagement arm … they are supporting people differently … collaboration with groups" [3]. Another participant, as I described earlier, puts great emphasis on equipping:

> "Life is a life-threatening illness and … if our ambition is for everyone to be informed and equipped, then some people need direct support. A lot of people need teaching, a lot of people need training and it's again, it's not using death as an illness" [31].

This is also the case, as I described earlier, for one respondent who understands the concept of hospice in terms of "a repository within community of everything around dying, death and bereavement" [17]. Thus, education and information sharing are seen as central elements in the hospice roles of enabling and empowering.

5.3.5 Explorer, researcher, innovator

Many respondents speak about exploring unmet need and improving access. For example, one participant talks about "all people in the community having the right to specialist end-of-life care free of charge at the point of delivery to hmm, not just themselves, but … their family, their carers" [10]. Others express concern about, or mention, projects concerning specific groups that do not have access to good end-of-life care, for example, those who are “homeless” [7], “with a piece of newspaper over them” [9], “lonely and isolated” [13], “lots of hospices … working in prisons” [5]. Other comments are: “I’ve been studying around hospice care and dementia” [3]; “it’s had a massive positive impact … on residents with dementia” [28]; “old age with frailty” [9]; “elderly frail people” [29]; “the LGBT community” [22]; and “those who are “lost” [11]. Here, exploring unmet need and improving access are seen as important hospice roles: “Everybody should access a standard set of services … they should be open to everyone” [3], and “everyone in our area should access it [palliative care]” [1]. This links with a respondent’s description of the earliest concepts of hospice as a welcoming place where monks, through the “hospitile” [11] opened their doors to all to help them on their way.

In seeking out unmet need and exploring new ways forward, a number of CEOs explain the importance of research and innovation. For example, one says: “Research … has always been a huge part of what we do” [4] and “we spent two and a half years … creating a professional development and research centre” [10]. One participant talks of Saunders as a “pioneer in scientific experimentation around pain control” [13]. Another says that exploring new ways of relieving suffering and improving end-of-life living was where the twentieth-century pioneers came in, commenting that they “deliberately created a space” where they had “time and legitimacy and peer support, to think outside the box, to reconnect with their patients [and] focus on aspects of science that were, at that time, very uninteresting” [9] in a way that would have been discouraged if they had stayed in the system. This CEO sees their work as transformational:

> “We glide over it now but it was absolutely transformational in the way people experienced pain or not and there’s no way … that anybody would have allowed them the time or the opportunity to do that kind of research in a world that was just completely excited by surgery and macho-medicine” [9].

This of course matches with the literature and a hallmark of St Christopher’s being ‘practice, education and *research*’.[29,195] In considering research today, one interviewee says that, for them, research has to be practical and “not just doing research for research's sake" [24]. Another expresses concern thus, "[Whilst] it's really embedded [here] research still feels like it's very perilous [and hospices] need to come together more as a research community [rather than] doing it in these pockets" [4].

Whilst many respondents do not talk about having a research function themselves, there is a recognition of its valued role and in which hospices can participate. For example, one speaks about drawing on research, "some of the research that's coming out now that we're looking at" [21], and another expresses a research interest saying, "It would be a nice piece of research to do" [8]. One participant talks about a research role for HUK because for hospices, "it's quite hard to step out of your reactive framework" [1] and "having a facilitating body that can … encourage partnerships with universities … is a really good thing" [1].

Understandably, some CEOs talk about 'innovation', which is a popular word in health these days; there was even a recent World Health Innovation Summit.[546] This is not the place to discuss what is or is not innovation or research. However, for some participants, developing new approaches and methods is seen as an important function. For example, one respondent considers that "everything I've just outlined is innovative and creative" [18]. Another says that "innovation in theory is a really good thing and to challenge and play devil's advocate". They add, however, "I don't think that the hospice movement is at the extreme end of entrepreneurship and innovation [… because] it would be an interesting one to see how safe the patients would feel if we were at the extreme end of that". Nonetheless, this CEO says, "I think that we are arguably more … innovative than the average NHS institution" because in their view, hospices do not have the bureaucratic limitations of a mammoth organisation [1]. Finally, one participant points to financial resources as a factor that creates the opportunity for some hospices to innovate, saying, "some hospices … are much more cash rich than others and … can push … models of care and innovation forward a bit quicker" [23].

5.3.6 Voice, agent, broker

A number of CEOs see hospices as a voice of influence for local communities and a voice in the local health economy. Comments include, for example, "We don't want to go back to how it was and leave these people with no voice …. we have an influencing role in both the community development work and health economy" [3] and "Our vision and mission today is to be the voice … and the provider of specialist palliative care" [15]. Similarly, another says: "What I'm focusing on is the new health and social care system and making sure that we're a voice in the system" [6].

The interviews show that the hospice role as a voice both for and with local people operates in a variety of ways. Here it is suggested through what the respondent above [3] describes as an influencing role in community development.[377] Similarly, another participant speaks about a "voice group" [5] where people bring their friends together and discuss pertinent issues that is facilitated, but not led, by the hospice. Hence, it is the group's voices that becomes heard, rather than the hospice's. Another CEO talks about people "sleeping on the pavement … they talk a lot about dying but not being remembered … nobody coming to their funeral … the people you can't hear nobody remembers" and how hospices need to be like Saunders who "amplified those voices" [9]. One participant speaks passionately about being an advocate, a voice that defends the cause of those who are dying and not walking by on the other side of the road: "It's about advocating and fighting … and ensuring … that this really important issue about how we all live and die, is not kicked into touch" [1]. So here, the voice function is for the individual but it is also one that shouts out for social value and the wider cause of how we all end our days. Again, this resonates with the literature and Saunders' "voice for the voiceless" that perhaps emanated from her days as an Almoner and her Christian values.[200]

In an earlier section, a CEO speaks about hospices acting as "brokers" [9] between communities and mainstream services, in other words being a voice in both directions. Thinking about how that works in practice, one respondent talks about hospices as agents:

> "We have got agency theory, we are supposed to be the agents [of local communities] … but actually there is nobody who is a true agent … so, I don't think that the leadership in most hospices have been honest with themselves about the fact that they are not agents truly of their beneficiaries" [1].

Thus, reflecting on Agency Theory that I discussed in the literature,[140] I note that this CEO sees conflicts for hospices through their receipt of state or NHS funding, regulation and compliance and their function as a voice, advocate and defender for local people. Criticising a meta-organisation that might provide 30% of your funding or has the power to close your hospice down, inevitably creates conflicts of interest. The same respondent talks of hospices as “change agents” and “ambassadors” [1] and another of hospices “acting as an agent for change in the health system … and someone that brings the whole system together around a common vision” [3].

Rather than using the term ‘agent’, another participant in the study considers the function more broadly, speaking of hospices functioning as social ambassadors:

> “We are here also as social ambassadors … people give a lot to this hospice, money, time, commitment, and we need to invest back into our community. So, we need to create opportunities for people who want to work, you know, and cannot work and haven’t got the skills, so we offer volunteering opportunities, apprentice opportunities to enable them to become more skilled up and then go back into society. For me that’s a payback” [13].

For this respondent, the expansive role of social ambassador comes, in part, from the huge social capital that exists in hospices, that the Commission refers to,[16] and the potential and responsibility that presents. (Social capital here includes “networks, together with shared norms, values and understandings which facilitate cooperation within or among groups”.)[547] This links naturally to the concepts of hospice as a community resource and social movement. Hence, the CEO’s reference to the importance of social “payback” [13] that reaches beyond end-of-life care to wider social need. Here, of course, there is a link to pre-twentieth-century hospices that, whilst caring for those who were dying, also offered hospitality to those who were impoverished, weary and lost.[56,63]

5.3.7 Disrupter, campaigner, solver

A number of CEOs talk about the importance of disruption to drive change from the ways things are in order to relieve suffering at the end of life. One respondent sees disruption as a crucial role of the pioneers, saying: “I listened to a lot of those tapes of the founding people … being willing to disrupt the existing status quo of the NHS that was failing at the time" [29]. Likewise, another CEO describes the work of the pioneers as "a rebellion against what wasn't there" and "it must have been a bit like a revolution" [13]. This of course is borne out in the literature, for example where Twycross describes hospice as a protest to redress the balance in medicine[120] and how hospices sometimes had to withstand withering criticism.[217,517]

Moving on to today, the above participant [29] explains that, whilst disruption can be uncomfortable, where it is positive disruption for good reason it can be beneficial: "Disruption, it's not a comfortable place to be sometimes but it's okay … to say the emperor's wearing no clothes to some of our NHS colleagues and to each other" [29]. In other words, it is not easy telling someone that their organisation is getting things wrong but it is important to do so. The respondent is deeply concerned that this role has been lost over time: "I believe in the hospice movement. I do believe in it with a passion and the ability to disrupt in a positive way. But I think we've lost it. I do think we've lost it" [29]. The participant goes on to say that, following the Commission into the Future of Hospice Care,[16] they felt that they "failed miserably" to disrupt positively with colleagues to achieve better outcomes, believing that there was no external "critical evaluation" of the Commission and that the process was "nepotistic" [29]. This view echoes comments in the review of the Commission's work.[18]

Locally, this interviewee actively seeks entrepreneurs and "disrupters that understand 'hospice'" [29] as board members and wants the chair of HUK not to be an establishment figure but someone who will challenge the system. The respondent talks of "huge successes disrupting" [29] and cites a number of projects and initiatives and how difficult it had been to make them happen. Looking ahead, the participant says that "the challenge for the future of hospice is to become a disrupter again and an innovator and to challenge the systems which are letting people down that are dying" [29]. At the same time, the CEO recognises a need for balance saying, for example, that their consultant medical director is "risk averse" [29]. Maintaining balance is seen as important because hospices need to combine a steadiness that people can have confidence in whilst at the same time being prepared to disturb the status quo in order to reset priorities.

Another respondent links disruption to innovation. Thus, for their own hospice they say: "We may not be going as fast as Richard Branson … but we are trying to think that way … and it might likely be the case that someone will come up with something so disruptive … that in the medium term probably wouldn't work … but then if you look at Lidl, actually people seem quite happy" [1]. In other words, innovative disruption can seem as if it is *not* working at first but can do so eventually. The above respondents are not alone in speaking about the value of challenging. Another says, for example, "Cicely … was prepared to be counter-cultural … to fight for the underdog" [9] and that that was so important. Another respondent talks of agitation, saying that a function of hospices is "to recognise the inequities of care and advocate, shout, agitate, work with the health economy, get the data, the understanding, looking at lived experience" [3]. Similarly, a further participant speaks of holding powers to account and makes an interesting comparison between the beginning and end of life:

> "We have to take hold of the … nettle and hold the powers that influence our world to account … if there was as much reliance on the charity sector at the maternity end of life, there would be uproar. Society wouldn't accept it, and yet it seems to be accepted that society does not pay enough attention to … the end of the spectrum that we're looking at" [11].

Applying this theme of disruption and agitation, some CEOs talk about a role of hospices being to campaign. There are variations in views about what form a campaign should take and the risks involved, such as losing public funding if the campaign is aimed at government policy. Thus, some respondents feel comfortable about campaigning, for example: "We should be a campaigning organisation … and people get that we're fighting for a change in how people see that within their everyday lives. And that's where we need to be quite edgy, I think" [17]. Another says: "So when I think of campaign I think of an absolute massive campaign that you are going to hold … we've got a role to campaign as hospices for people that aren't accessing the right end-of-life care that they need" [8]. Another interviewee believes that campaigning is the hospice heritage, saying that Saunders introduced a "campaigning approach to the importance of giving people a good journey towards the end of life and death" [1]. However, this CEO recognises that campaigning is difficult for hospices saying, "I have always been a campaigner in my own way and it's hard to campaign in an argumentative fashion as a hospice in the way that 'Extinction Rebellion' is doing at the moment" [1]. Nonetheless, this participant speaks of doing so in a positive way which reflects the approach of Saunders. Saunders campaigned by demonstrating that there was a more humane and person-centred way of caring for people at the end of life and encouraged the spread of the hospice approach through over 300 published papers.[548] However, *The Telegraph* also observes that part of Saunders' success came through her "being tough and authoritative, and often downright difficult".[517]

One respondent says hospices need to be selective, "You've got to pick your campaigns" [8], and speaks about some hospices that "campaign for lots of things [but] do you get them?" These can be campaigns for hospice income, like "We had the massive campaign a few years ago for fairer funding" [8]. However, like others, this CEO says: "We've got a role to campaign as hospices for people that aren't accessing … the right end-of-life care that they need … we could lead like the field around the frailty agenda [but] I think we are not as hospices … good at shouting" [8]. Hence this respondent sees it as one of the roles of HUK to "drive those campaigns" [8]. In terms of hospice leaders not being natural disrupters or "good at shouting" [8], in their interview, one CEO has the candour to ask: "Am I not controversial enough?" [10]. In contrast, another says: "I always really enjoy surrounding myself with leadership teams who constantly challenge me … push me and drive me" [7].

CEOs describe a reduced emphasis on protest and disruption in the twenty-first century. Thus, whilst Saunders built relationships with establishment figures her work was also a protest[120] against the way that things were and a disruption to the status quo. This drew "outright hostility from the medical profession"[517] including the BMJ.[217] Participants in the study recognise the 'disruptive role' of the pioneers as being critical to their success but say that HUK places little emphasis on this today. However, in the literature, whilst HUK's Future Vision Programme focuses on collaboration and influence[37] their 2017-2022 strategy for the hospice movement states: "We must continue to push boundaries, to challenge and provoke".[549]

Whilst recognising the importance of functions, such as disruption, that challenge inadequacies and unfairness in the system, one CEO says that, for them, the function of their hospice is to be the ‘go-to’ organisation that can do more than point to problems, agitate and disrupt but actually be the one to solve them. In other words, they see their primary role as being the solution:

> “What I want to do is become the go-to. You must have heard this so many times. We’re [hospices] seen as the thorn in the side of the public sector commissioning and we need to become the solution. I think we’re the go-to [people]” [7].

This aligns with the views of another participant who says: “We have a finger in every single pie and that has enabled us to partner everywhere and to create a much more joined-up approach so it is less evident that people fall between the cracks” [1]; and: “We will have failed if we end up with a mind-set that this is as much as we can do … we should be constantly challenging ourselves” [1]. Similarly, another says: “My ambition has always been that XXXX hospice is always on the front foot, that it is proactive not reactive” [11]. In relation to disruption and finding solutions, another interviewee says: “We have huge successes disrupting it which has been better care for patients and families … cottage hospice would be one in a big way” [29]. Thus disruption, pointing to issues and offering solutions are brought together.

5.3.8 Being independent and distinct

Finally, in terms of hospice roles, some CEOs say that whilst it is important for hospices to work in a collaborative or integrated way, they should also function independently. For example, one interviewee talks of not melting into the system:

> “We’re not part of the system and I think if we tried to become part of the system we would disappear to be honest. So I think we’ve got to stand out as a place that does death properly and is available to people and accessible” [16].

Another participant speaks about working with the NHS, developing proof-of-concept initiatives but at the same time saying, “We want to support what patients need. We want to continue to be independent so we wouldn’t want more than 50% of NHS funding … we want to be in charge of our own destiny”

[20]. Similarly, another respondent says: “It worries me that this, there’s this drive at the moment from hospices for the NHS to cover the cost of end-of-life because I think you lose that love affair with the local community at your peril” [17]. Here, independence is seen as important because it creates an intimate relationship with local people and a sensitive awareness of their pain and suffering. Furthermore, as one participant puts it: “The people that give us money, give us money because we are *not* the system” [16].

One CEO feels that many hospices do not behave independently, saying: “‘Being an independent charity’ - that phrase means something doesn’t it? ‘Hey, we’re independent’. Do we act like we’re independent? Do we buggery” [29]. So whilst independence is seen as important, this CEO questions the extent to which hospices actually use the strength and benefit of independence in practice.
For another participant, independence means pushing boundaries:

> “I know various … senior clinicians … who you know are constantly pushing the boundaries … saying we should be doing this, can we do this? … We can do that in hospice care which we couldn’t do in the NHS” [19].

This CEO feels that this comes back to “let’s not get completely absorbed into the NHS; you know, let’s lead the ability to innovate and push those boundaries that we can do as independent hospices” [19]. However, this respondent believes, like the above [29] does, that those who do hold this attitude are “few and far between” [19]. Naturally this issue links with Saunders’ “we moved out so that attitudes and knowledge could move back in”.[1] In other words, the pioneers needed freedom to act and to meet necessity as they saw it.

The same participant also talks of maintaining a balance, “You know, to us it's crucial that actually we are integrated and we work really hard to remain independent” [19]. Another speaks about: “The future of the hospice being distinct on the edge, connected to but not part of” [16]. Making a parallel and related point, another interviewee says that the function of independence should be ambidextrous in its application, through stability and agility.

> “We need to really understand what our timeless guiding principles are, what we mustn't let go of in this organisation … what's our soul really. And,

> but equally I think we need to be agile as well. So we need stability and we need agility and that is the ambidextrous bit of it" [5].

Thinking about the effect of independence being under pressure, this participant speaks of "coercive isomorphism [referred to in the literature, see Section 2.4.2][263,550] that is shrinking us down, [so we are …] not paying enough attention to that stuff that I think is so important, those timeless guiding principles that are our stability" [5]. Thus, for these CEOs, independence does not mean isolation and it does not mean absorption into the mainstream either. It means working together but, crucially, with the agility and ability to look and act beyond the coercive conformity and narrative of the mainstream in order to push boundaries, innovate and keep focused on those things that hospices believe are important.

However, from another perspective, thinking nationally, one respondent talks about the challenge and difficulty of maintaining cohesion amongst 200 hospices in the UK, each with an "independent sense of direction and a sense of glorious isolation" [7]. Here again, a distinction is drawn between independence and isolation. Significantly, the same interviewee issues a salutary warning:

> "The fierce independence of the hospice sector is what got it to its peak, is what is potentially driving its demise, in my opinion, [and] that parochialism … that institutionalised independence … there's nothing going on, [apart from] lovely posters at a conference" [7].

From the transcripts, CEOs appear to see risk cutting both ways, with hospices becoming isolated at one end of a continuum or potentially absorbed into the system at the other, with an ambidextrous notion of stability and agility sitting somewhere in the middle.

5.4 The focus of hospices

In this section, having considered CEOs' perspectives on the conceptual basis of hospices, followed by their views on the roles that they believe hospices can fulfil, I now look briefly at the 'focus' of hospices.

For example, one interviewee relayed their board's imperative to stay focused on core purpose, saying: "I think that's what our trustees were saying to us, remember core purpose and don't get drawn into doing more than we should be doing" [27]. A second respondent believes that focus was a key strength of the pioneers saying: "Cicely … was completely committed … to this idea, this focus, this sort of laser-sharp focus about what she was trying to achieve" [2]. Another CEO speaks in terms of the quantity of their work saying: "We've become much more focused about where we think that's appropriate" [30]. Similarly, but from the other side of the same coin, another participant says: "I hear about some hospices … blurring those boundaries and then, therefore, diluting the quality of what we do" [20]. This raises questions about what core purpose is, why hospices are here, how "should be doing" [27] is determined and, of course, what hospices are blurring or focusing on.

Taking this further, one CEO feels that hospices' renowned reputation for high standards could be broken if focus becomes unclear and is not carefully thought through:

> "I think you need to be really careful if you said, you're providing a gold standards service at the moment and I'd like you to go and hunt for somebody who may or may not be there and give them a slightly less good service. I think that would be really traumatic for people actually. I think there is a danger of breaking it" [22].

So here there are views that hospices need to be focused, know what they are focused on and not become blurred and risks the potential of breaking what they have achieved. However, in terms of hospices 'breaking' or 'closing', one CEO says bluntly: "Does it really matter … because arguably you could have extremely good palliative and end-of-life care *without* them [hospices]?" [30], thus reflecting the views of hospice critics cited in the literature.[12,205,217]

5.4.1 Care, education, research

In the literature, I explained that a hallmark of Saunders' St Christopher's Hospice was its focus on the 'practice, education and research' triangle.[29] Respondents in the study agree. For example, interviewees say: "Education has always been a strong thread running through the [St Christopher's] organisation" [19]. They point out that: "[Saunders and Twycross focused on] aspects of science that were … absolutely transformational" [9] and that Cicely saw "[St Christopher's as] an alternative to hospital" [9]. Thus, whilst direct care of patients was vital, so were education and research.

5.4.2 Direct care, network care, community development

In this configuration, the participant in the study [3] referred to *direct* care for patients and their loved ones, and *network* care provided in conjunction with others such as, for example, district nurses and care homes. The third element is described as community development and involves working with communities to inform, enable and empower and thereby connect with local people in ways that are the most relevant and helpful.

Some CEOs particularly espouse community development approaches as seen in the comment: "So we have a big community development team including a youth development role" [10]. Another speaks of "eleven community support groups" [20]. However, some are less enthusiastic, for example, referring to Compassionate Communities,[313] one respondent says: "I'm less convinced than some. It doesn't really switch me on as much as it does others … I would describe myself as an interested observer rather than an activist" [18]. Another feels that the reticence of some to become involved in community engagement is because it is about "sharing power … and genuinely giving up … all professional privileges" [9].

5.4.3 Direct care, public support and education, societal change

Another CEO describes their focus as providing direct clinical care, empowering the public through community support and education (including research) and enabling societal change [9]. The different component here is the third one. Enabling 'societal change' has support from a number of participants, for example one says: "As a society we don't seem to feel angry … that it's a bit hit and miss when you get … good care … there doesn't seem to be a really burning fire underneath people's seats for the governments to want to make it better" [1]. Others say: "I would really like us to be … thinking about the big challenges facing society and then what it means for end of life" [22]; and "I think wider society are not engaged in it, don't understand it and we're still quietly beavering away in the corner rather than in the centre, in the bright light of day" [16].

5.4.4 Specialist care, bereavement support, support for everyone

This configuration is summarised as: “Provide specialist clinical care wherever it is needed and wanted, bereavement support for any type of death, support everyone who has anxiety or curiosity about death” [17]. Again, most respondents in the study would agree with the focus of the first element. However, in terms of the second two, I observe that hospices have traditionally cared for patients and families associated with terminal illnesses but this CEO speaks of bereavement support for “*any type of death* [and to] support everyone who has anxiety or curiosity about death” [17]. Hence, this links with current debates about new definitions of palliative care[24,258] that have a broadening outlook and, of course, it relates back to Lamerton who wrote about the *whole* of medicine benefiting from the hospice approach.[30]

In describing the focus of hospices, the word “everybody” is used repeatedly by a number of CEOs. For example, one respondent says: “It is about ‘you matter because you matter to the end of your life’.[551] I think those words [of Saunders] are just incredible and I think we should remember those about everybody. So that's one of the reasons that we look outwards more [and] I think we’re really aligned in terms of that vision” [4]. Similarly, other interviewees say: “Our vision statement is for everybody to matter in life and death” [31]; and “It really is important to us that this is a hospice for everybody” [6]. Other participants say: “We are not going to ignore anyone that needs us” [17]; “[It is important that] everyone has access to good palliative care” [1]; and “The ambition for us is that anyone that dies in our area … have available to them the services … we offer” [16].

Adding more detail, one participant says: “[That they want to make sure that] there are no barriers [and that] everybody understands what we do, everybody can see what we do, everybody understands how to access it and they can make whatever choice they want to” [16]. On the same line of thought, others speak about unmet need:

> “My mission is to overcome our biggest failing which is unmet need. That’s very much a two-pronged attack on that mission. One is to work out how to meet effectively the known unmet need, but the other one is … go and uncover the unknown unmet need” [7].

This is seen as intentional mission-drift. The CEO says: “I’ve just almost completed the process of convincing the trustees to embrace and encourage mission-drift, on the basis that done properly that can be a good symptom of being patient-led” [7]. Expressing a similar emphasis, another CEO describes standing still as failure, saying: “We will have failed if we end up with a mind-set that this is as much as we can do, we can do no more … [so we must be] constantly challenging ourselves to … find ways of continuing to respond to this growth and demand” [1].

That growth in demand includes: “The sheer volume that is coming exponentially with the baby boom generation” [1]; “[unmet need for those who are homeless] with a piece of newspaper over them” [9]; “[the] lonely and isolated” [13]; “[those who are] in prisons” [5]; “[those experiencing] dementia” [28], “[the] “elderly frail” [29]; “the LGBT community” [22]; “those who are lost” [11]; “[those whose suffering is] unknown” [7]; and “[those who are situated in] communities that are the least empowered” [30]. Here, CEOs describe a broad focus that wants to help ‘everyone’ and be available to ‘everybody’. However, amongst other responses in the study, there is a concern for balance. For example, one participant says:

> “I have heard some hospice leaders talking very passionately about … unmet need and … chasing it. Well that’s great but that’s not balanced … I think the future is a balance of: patient need; with resource; with ability; with quality; and [with] wider connectivity with the system” [16].

Another CEO says bluntly: “I think it's *not* about being everything to everybody … … it’s the impact that’s the important thing … [and] distributing that expertise across the community because we can’t do it all” [24]. Another respondent speaks of an expectation from NHS commissioners that hospices should fill all the gaps in service provision around dying and death, saying: “That expectation was and I think continues … that we can do everything which, in fact, obviously we can’t” [23]. Recognising the immensity and problems of the challenge but still wishing to have an outlook that includes ‘everybody’, one CEO says: “Sometimes I feel like I try to boil the ocean … and I think ‘why am I trying to solve all of these problems?' this is just me and this is just one little hospice but we do keep on trying" [4].

5.4.5 Equip, provide, strive

As with the foci described in the previous section, this interviewee also suggests a broad reach but in a different way. First thoughts about 'equip, provide, strive' were planted during the presentation from Demos at the HtH conference.[15] The CEO says: "[It was] the beginning of me thinking this isn't working [because] if we [hospices] were doing a good job, everybody would be informed, equipped [and] enabled over dying, death and grief" [31]. Their change in focus involved maintaining the provision of specialist clinical care but applying greater emphasis to equipping people to manage their personal circumstances more knowledgeably and effectively.

Again, all respondents in the study agree that hospices should focus on providing direct care and that they should strive to improve. The debate arises over the nature and extent of the 'equip' element. The argument is that hospices can help more people if they rebalance by 'providing less' and 'equipping more'. This notion emanates from a recognition that simply providing more and more can never be enough and is unsustainable. So, to make this hospice [31] capable of delivering their aspirational purpose, i.e. *why* the hospice is here, they chose to re-focus *what* the hospice is. As David Owen commented, hospices are not the NHS unless, of course, they choose to merge into it,[241] and hence there are calls for 'reinvention' in the literature.[11]

5.5 The outlooks of hospices

In describing what hospices are I have looked at respondents' views of their conceptual foundations, their roles and foci. Finally, I consider their varied outlooks. By outlook I mean their attitude towards their mission and work. As Collins makes clear in the literature, what an organisation is, is determined by 'who is on the bus', so to speak, and their positive or negative outlook (or attitude) will determine the organisation's success or otherwise.[487]

5.5.1 Entrench, enquire, go for it

One CEO suggests that, in terms of outlook, there are three groups of hospices in England: "The first category is one of entrenchment … the second category is, 'I wonder what's going on around me, everything is changing?' and the third one is, okay I'm open for anything, let's go for it" [7]. They explain that entrenchment means: "We meet everything we need to meet". So this group, in response to those who are concerned about unmet need would say: "[It] is your unmet need not my unmet need" [7]. The respondent describes these hospices as "more disconnected than ever" and says that they are "crying out to [Government via] Hospice UK to pile more money into the model" [7]. The CEO goes on to describe the middle category as "running out of time, they need to jump one way or another". They are using HUK, they say, to "help me to explore this, help me to do this … that's genuinely searching and probing" [7]. Finally, the CEO describes the third category as basically saying, "I can't afford to wait for HUK to drive me, I'm driving my own type thing" [7].

5.5.2 Monuments and movement

One CEO [17] speaks about outlook in terms of monuments and movement. Here they express frustration that the momentum of the pioneering years is no longer here and that together hospices could be doing so much more:

> "And there's that wonderful quote that Robert [Twycross] made at Cicely's memorial service about movements tending to become monuments and you do hear that.[552] So we just need to keep moving. And again I'm just disappointed, so I go to the HUK conference and I go with the best will and I end up leaving dissatisfied" [17].

This interviewee and some other participants point to the danger of venerating the pioneers to the extent that their work "gets put in aspic … and no one dares do anything different with it" [17] so it becomes a solidified monument. Another CEO says: "That rich period where hospices were being open and mobilised was so successful it almost pushed the sector into a sort of an early status quo" [30] because "the vision from something quite driven and angry [has become] a bit more sort of safe and packaged" [30]. One interviewee sharply criticises the Commission for similar reasons, saying: "When the Commission finished nobody dare question anything around it then because no one was looking at it critically" [29]. In the literature, the Review of the Commission showed that whilst the majority of hospice leaders were supportive, some expressed dissatisfaction with the Commission's approach and findings.[18]

5.6 Summary

In considering what hospices are, a critic of the Commission's work said that: "one size does not fit all".[19] Similarly, in the interviews, many participants express an expectation that I would receive a wide variety of views in this study and that the understanding of 'hospice' has never been so unclear. In the literature, Schneiberg and Lounsbury point to the importance of recognising heterogeneity, inherent tensions and ambivalences when social action develops.[268] Similarly, from the perspective of social construction, Gergen says: "[When an intelligibility is established] so are multiple possibilities for its negation".[425] The results in this chapter include descriptions from respondents of: seven different concepts; numerous strategic roles for hospices; and a range of foci and outlooks across the sector. They show many contrasting views from CEOs about '*what* a hospice is'.

Chapter Six: Theme Three – How hospices are developing

6.1 Introduction

In Theme One, I began in the past describing respondents’ views about the function of hospices and *why* they were established in the second half of the twentieth century. In the second part of that chapter, I went on to explain *why* CEOs believe hospices are here today and finally, how the *where-when* context is a significant factor in determining their ‘function’. In Theme Two, I presented respondents’ perspectives on the ‘form’ of hospices i.e. *what* and *who* hospices are today. Now, in Theme Three, I look at *how* hospices are developing and looking forward.

In the literature, discussions about the development of hospices as proliferation got under way are seen, for example, in the 1981 conference written up as *Hospice: the living idea*,[26] in provocations from James and Field about routinisation[34] and in Clark’s *Whither the Hospices*.[35] In the twenty-first century, the Commission into the Future of Hospice Care[16] considered the development of hospice care in great detail and the keynote speech by O’Leary and Richardson in 2018 offered a detailed example of hospice reinvention in action.[11] Finally, in 2023, an interesting project by St Christopher’s portrays the development of their hospice through six decades in the lives of those who have been a part of it, often in a number of different roles.[192] This is interesting because, as Collins infers, companies, such as hospices, are ultimately about communities of people, their shared commitment, belief and experience,[157] and in terms of their social construction, Gergen would agree.[411]

Whilst there is a broad range of subjects that could be covered in terms of how hospices are developing, the ones discussed in this chapter are primarily those that gained significant and repeated emphasis from respondents. I begin by considering what respondents say about economic development as a charity and then as a business. I move on to discuss obstructions to development and then the relationship between development and purpose. Finally, I consider participants’ feelings about the long-term future of hospices.

6.2 Economic development and sustainability

To continue operating, hospices must remain viable. Consequently, how they seek to develop economically is a key determinant of where they are heading. In the interviews different facets of sustainability are raised. For example, one respondent stresses their contribution to environmental sustainability, saying "I've got XX shops … XX furniture shops. I've stopped so much stuff going into landfill … we've got solar panels … a brand new building is carbon neutral … electric cars" [29], and others speak of workforce sustainability [25] [6]. However, during the interviews, whilst many dimensions of sustainability are mentioned, respondents lent their greatest expression to economic development.

Speaking in general terms, respondents say: "Our biggest difficulties have been around finance … it is risk number one … well sustainability really" [2]; "financially we've had our challenges … just really thinking that we're going to run out of money" [5]; "the main challenges really are income generation and balancing the books … that is the perennial challenge" [6] and "we've got five priorities … so business sustainability … it's got to be like your top priority … the traditional method of raising money isn't going to actually deliver … so how can we go out and look at different ways" [8].

For many participants, sustainability comes up when they are asked about main challenges, for example: "Funding, huge challenge" [14]; "finance obviously" [13]; "oh blimey … absolutely finances and we've run a deficit budget for three years and that's … going to become a million" [19]; "we had an operating deficit of £2.2m"; "so, when I started … we'd run out of money [and I've] spoken to quite a few hospices who had financial crises like us" [28]. When asked about main achievements, respondents say: "[We] balanced the budget for the last three years" [23]; "[it was] surviving … from a financial point of view" [24]; "[it was achieving] financial stability … until my arrival we were spending £2m more than we were getting" [25] and, looking ahead, "sustainability is now obviously, I think, facing its greatest test for the hospice" [18].

It is easy to see in this collection of quotations that for many respondents, nearly running out of money, overspending by four-figure sums, annual deficits and reserves' dependency are challenges that some hospice CEOs have faced and, in many cases, still do as the literature shows.[4,331,394] Economic development has been and is a major concern, if not the main perennial challenge, for many participants in the study. As subsequent sections in this chapter will show, whilst economic development is not necessarily the top priority for all respondents, it is certainly up there in terms of issues that hospice leaders need to have under control. Having established the significance of economic development for CEOs, I now consider how hospices are addressing sustainability as a charity, and then as a business.

6.3 Economic development as a charity

Throughout the study, I have concentrated on high-level strategic issues for hospices rather than day-to-day operational ones. I maintain that focus here as I look at issues relating to the economic development of hospices as charities.

6.3.1 Local identity and reputation

Most hospices in England (and all those where CEOs in the study are working) are not part of a single national charity like, for example, Marie Curie, Macmillan or The National Trust; they are independent local charities.[450] This local identity is seen by respondents as extremely important in terms of income. For example, one CEO says: “People are very explicit when they give to hospices about how local it was and how it made a difference … with them personally” [1]. This respondent compares this to personal experience of working in a national charity where people said: “It’s a great charity but it’s not *my* charity” [1]. They went on to say that the hospice difference is that they make an “emotional connection around death that gives us a fantastic opportunity” [1] which, of course, is deeply personal. Thus, for this participant, whatever strategic developments hospices undertake as charities they must not be seen to be “undermining the localism identity” [1]. So, for sustained economic development, that intimate and local connection is seen here as critically important for hospices.

Identifying locally connects with comments made earlier, such as: “[Hospices being] for the community, by the community, of the community … mess with that at your peril” [6] and others about the importance of a community that “really understands a lot more of who we are and what we do and why we do it” because we must not “lose that love affair with the local community” [17]. Similarly, another CEO speaks about a local multi-agency group, saying, “the hospice is the most loved charity in the town. Everybody loves the hospice” [13]. Here the community relationship is much more than one of identity, association or interest: the hospice is *loved*. However, for some, this was not always the case with one respondent saying: “It took quite a lot of turning that reputation round, but yes, the hospice is well-known and well thought of now” [13]. In other words, this local reputation needs to be earned with the important corollary being that reputation can also be lost. Protecting their reputation is seen as critical because hospices must not work in a way that “tarnishes the reputation we have” [18] and “reputation is the most important thing” [15].

Thus, for these CEOs, nurturing and maintaining both an informed local identity through intimate relationships and a highly respected reputation are cornerstones of economic development. This emphasis on meaningful relationships with local people and communities is described by another respondent as “*social* sustainability … we need to look, in our neck of the woods, what are they going to die of and think about whether or not we’ve got the right services for the needs of the changing population and the demographics of the population” [22]. Put another way, identifying locally draws social value and economic development together. However, it also brings accountability and responsibility because the deep affinity that many hospices enjoy with local communities is not only a carotid artery; it can also become an Achilles heel.

6.3.2 Accountability and impact

The vulnerability of local accountability is described by one CEO as “the biggest problem that I think we face” [4]. The respondent explains this with regard to people who have given their money for 20 or so years but when a loved one is dying, the hospice does not help:

> “When it comes to them dying, it’s [the hospice] not for you. You’ve not got the right kind of poorly. You’ve not got the right kind of pain. You’ve not got the right kind of death. So, there’s something about our credibility as hospices that we’ve promised you for all these years we’re going to do this and now we’re not” [4].

Similarly, another participant says that “an increasing number of volunteers are saying, ‘I volunteered all my life; why is my husband not allowed in here? I’ve virtually bought a bed?’” [7]. So in terms of economic development, for hospices that are long established, there’s a question of credibility in terms of supporter and volunteer expectation if donations are to be sustained going forward.

Respondents say that a solution to this issue is to broaden impact. This can be directly from the hospice and by “empowering others to change as well” [6]. In this way more people get some elements of hospice care. Following a discussion on this issue in Interview [7], I summarised as follows: “One of the things you seem to be saying … is about getting away from this idea that I only receive hospice care because I go into the in-patient unit”, to which the interviewee replied “yes, definitely” [7], going on to say, as an example, “Mabel was dying and she had ten distinct needs and we met eight of them” [7]. This could have been, for example, by providing information, advice or equipment, companionship or clinical support. So a way of sustaining long-term donor commitment is to offer a broader range of help to a larger number of people at home, in care homes, in hospitals and their communities through information, education and support, in addition to providing hospice in-patient beds.

As I have already mentioned in the study, one way in which hospices are broadening their impact is through community engagement. For example, a respondent says: “Our community engagement work … has enabled people who would never have been able to have any conversation with our hospice whatsoever to have a connection” [13]. Similarly, another participant aligns with this saying, “My mission is to be here for every member of our community … very few people at any one time will need our very specialist expertise but everyone will need something at some point” [17]. One participant puts this conversely saying, “Our bereavement service makes us part of the community that actually generates support and keeps that support going for a longer time as well … the more people that we see, the more people that are there to support us” [8]. I note here that this hospice is seeking to be “part of the community” [8] by seeking to look *outwards* from their perspective, to see situations as local people see them. As a consequence, there has been more relevant long-term support which has, in turn, resulted in a higher financial return to the charity.

A further example of broadening impact is a project with local schools. The respondent who mentions this says, “One of the most incredible contracts to come our way was to take over the emotional well-being and mental health support at the pupil referral unit" which includes "25 to 35 safeguarding alerts every week" [7]. They continue: "We're being called in because there's a child locking themselves in the loo attempting suicide … it's a real departure" [7]. This project opens up a whole new range of opportunities to relieve suffering. It offers a new dimension to hospice care that is proactive and preventative as well as being reactive and responsive i.e. suicide prevention and suicide bereavement. I say 'new' because when I asked the respondent, "Do you know of any other hospice that's working in this way?", the reply was "No". In terms of sustainability this project brings the hospice into contact with a whole new phalanx of potential donors and funders as well as giving it the opportunity to relieve more suffering and reduce the number of tragedies.

Yet another way of broadening impact is by insisting on being at important tables. Whilst I introduced participants' perspectives on partnership working in Theme Two and I will come onto collaborative development shortly, here the focus is on the drive and boldness of respondents to work more widely. Thus, one speaks of insisting upon having "a seat at the table" [4], the tables being where key players, like the CEOs of Councils, the NHS Trusts, Public Health, Adult and Children's Services etc. meet. This respondent argued successfully about unfairness "in the way that the third sector is treated and the way the statutory sector is treated [and the] massive difference in the way we provide care which you need to hear about" [4]. These arguments got them through the door and a seat at the table. Likewise, another participant in the study speaks of the importance of getting alongside "local universities … councils … housing associations … local care providers etc." and says: "We've raised the profile beyond the sector. We've pierced through it; we're telling the story and not only that, we're creating new stories about ourselves" [11]. A further respondent talks of having "a finger in every single pie and that has enabled us to partner everywhere" [1] and "with the sheer volume [of deaths] that is coming exponentially with the baby-boom generation … there has got to be a lot more sharing going on" [1].

An interesting perspective from one CEO on this issue of broadening impact is to question catchment areas. As I explained earlier in the thesis, in most geographical areas, hospices do not overtly compete with each other in terms of meeting patient needs or income generation. I say 'most' because some respondents in the study speak about growing competition from other hospices, for example: “It’s a challenge to work with … other hospices who … as they introduce new CEOs are very much more commercially disinclined to want to collaborate” [15]. This is in an area where traditionally local clinicians have always wanted to work together closely. Another respondent talks of not wanting local hospices to keep “fighting the same commissioners for the same pot of money” [23]. Another speaks of “competition with hospices … in our patch which is difficult” [3] and a third says, “We’re particularly interested in moving beyond income generation in our own patch” [30].

In this regard, an intriguing perspective from one CEO is the suggestion that boundaries and catchment areas are removed so that hospices offer services to whoever wants them. This CEO says: “I do not think it’s for people to gate-keep where people can go. It’s not for GPs to tell people which hospice they go to and it’s not for me to tell them - it’s for them to decide” [29]. This approach of natural selection would mean that hospices could reach out far and wide. However, broadening reach can have consequences as happened with a project in the respondent’s area: “Where I had lots of people very angry with me” [29]. In this regard, I should also point out that all hospices function without boundaries when generating income through the world wide web, there is no restriction to entry for hospice events, such as walks, runs and rides and, of course, many hospices function beyond their local care footprint when sharing education and research. As one respondent says, “[We’re] serving locally but provoking nationally and kind of supporting internationally” [9] and another, “We’re interested in education and research because they impact much more widely” [4]. There are also those who sell ideas to others, for example: “We run lotteries for XX other charities now [and] half of those aren’t hospices” [30]. However, accepting patients from other areas on a consistent basis would be a significant step further in terms of broadening impact.

Whilst broadening a hospice’s impact is seen as important with regard to enhancing reputation and donor support as a charity, the question of maintaining highly expensive hospice beds as part of that offer is another. As I discussed previously, CEOs differ in their opinions about whether in-patient units are a vital benefit to their mission or an unwieldy diversion. Here I consider comments on whether beds within hospice buildings are an unnecessary drain on budgets, putting economic development at risk, or whether they are a mainstay that local people identify with and donate to.

I summarise the important divergences here through the words of one respondent in particular. This respondent says there is a view that beds are fundamental to funding and comments that, while some people will say, “Well, let’s go out in the community and *not* do beds, people still need a good place to die and they still fund us because of beds” [3]. This participant weighs the value of going all out to help people at home against the social value of in-patient hospice beds, saying: “You go all community development, you are at risk of losing your voluntary income because will the community really pay the same amount of money … to go all into community development … you close your beds at your peril” [3]. However, on the other side of the coin, they say, “your community development is definitely creating, I believe, some income [and creating] intimacy at scale” [3]. Another respondent summarises the issue of beds and sustainability saying that, in their hospice, XX beds is an expensive piece of real estate but for many of their donors, that is what they see:

> “They see the ward; they see people coming in here; they see this lovely modern building and that's what they support. The fact that there are four times as many patients in the community being looked after than they do in the ward escapes many of our donors. So I want to make sure that just by cutting the number of beds I didn't make a commensurate reduction in my donations. They generously give me their donations of £X million a year and they allow me to spend it where it needs to be spent” [18].

Here a pragmatic choice is being made: the building and beds are the magnet that generates income that can then be used in a variety of ways to reduce suffering. The argument is that people see the building, despite the fact that far fewer people are cared for within it than at home, because it stands out as a symbol of all that the hospice achieves.

Addressing the critics of those who advocate the end of hospice in-patient units, one respondent says, considering the fact that “the most expensive care is in-patient care” [28] and given the breadth of needs that people have, “people would say, well, some people get a Rolls Royce service and others only get something else. I think that's nonsense because it's all about … that *triangle of need*. There are people that need that top level" [28]. However, combining what has been said here with respondents' perspectives on hospice as a building and safe haven in Theme Two, there is clearly ambivalence over the effect of operating in-patient beds on the economic development of hospices as charitable institutions.

In considering solutions to the in-patient bed issue, the 'Lidl' [1] case study is proffered by one participant. The key point here is that just as there are different ways of operating supermarkets there are alternate ways of running in-patient units that can be explored. This approach is supported by another participant who says: "We've actually cut our staffing and cut expenditure by over half of when I started but doubled the number of people we see" [28]. Another speaks of the possibility of "hospices being driven into different ways of working not necessarily out of choice" [21] and providing "a bronze service to much more people" [21]. Others speak of supporting beds in hospitals virtually and physically as a parallel or alternate option [1] [31]. However, this approach potentially clashes with that of those who feel that maintaining exemplary quality standards is critical. For example, comments from the latter include: "I think we've got to stand out as a place that does death properly" [16]; "We're an important part of the history of hospices so those standards have to be maintained" [25] and "We've got to hold a line to government and others about what is acceptable in the way people die … we are going to have to cap the number of people that we look after because our quality is at risk of completely falling off" [9].

Interestingly, one CEO says that Covid-19 had taught them something about finding the right level of quality saying:

> "No one should aim for mediocrity … we should always strive for excellence but … we were all prepared just months ago to put tents in our car park and run a military field hospital … so we need to match what we are striving for with the set of circumstances we are delivering in" [26].

Here, the context of Covid-19 showed them new possibilities. Similarly, the proponent of 'Lidl thinking' feels that "when they [customers] see it they think that's not bad and I'm quite happy with that" [1]. In other words, whilst hospice staff might think that a particular standard would be unacceptable, patients and families make think otherwise.

Another option to providing hospice beds at reduced costs is described as "cottage hospice" [29]. The respondent who describes it says it was triggered in part by the fact that there is a "demographic time-bomb coming [and] we've got to try these things" [29]. In planning their approach, the senior team from this hospice went to look at other examples that had emerged from a concept in *Dying for Change* that talks about the benefit of creating new super-local "home hospices".[324] The interviewee says: "[Cottage hospice] encapsulates our philosophy of care but it's actually where the family carer gives the care … it's like home from home stuff … back to the future" [29]. This complements their in-patient unit because, "You don't need doctors and nurses to care for people in their dying stage" [29]. The CEO says that it was really hard to introduce this project because of the "push-back" from people in the "profession of palliative care [who] don't want to be disempowered" [29] but feedback from families that use their cottage hospice shows that they do not want to be disempowered either. Considering a similar approach, another participant asks, "Could we have nurse-led beds? [because] that would make our beds more cost-effective" [8]. Here again a CEO asks the question, "Is the medical model sustainable going forward?" [8].

Cottage hospice and models of nurse-led care also connect to workforce as well as economic sustainability because, for hospices as charities, access to consultants is an issue for some. One respondent says that "New and aspiring consultants are more inclined to stay in the confines of the hospital where they've got a big infrastructure to support them" [25] and that there's an issue in parts of the country where the cost of housing is so high or where the population is sparse [14]. Consequently, they say, "We can either sit with vacancies or … let's look at a new model" [25]. Similarly, others talk of shortages of doctors and nurses. Their comments include, for example: "We had a shortage of nurse practitioners" [15]; "I haven't started crying in my soup but I can't get nurses" [29] and "the nursing crisis" [12]. So, whilst the original driver for cottage hospice is a response to "over-medicalised death" [29], this model also offers benefits in terms of economic (and workforce) development and sustainability. As the respondent puts it, “It’s not *why* I did it but it matters” [29].

6.3.3 Capacity

An issue for respondents about hospices developing economically as a local charity is remembering that, although they have grown large, they still, in the main, depend on the goodwill and ability of local communities to support them which in turn affects the capacity of hospices to serve them.

CEOs speak about reaching a financial saturation level beyond which communities cannot go. Thus, one interviewee talks of a “saturation rate” for endurance events, and “what potential saturation is per household … and there is an upper limit to what people are prepared to give” [15]. Another participant speaks of the “world of charities becoming more sophisticated … smaller charities having more opportunities to become larger … new charities being formed all the time” [10] which increases competition and dilutes funding for all of them and, as such, “the pressure on funding is very significant … going up but it seems to be only keeping pace with … costs that others are pushing down upon you” [10]. Similarly, another interviewee says: “This saturation comes also because of the other charities that exist and why would people choose us rather than them … have we reached the maximum amount we can from this area?” [4]. This CEO goes on to talk about reaching saturation in some districts, knowing that they will eventually reach the capacity of communities to support them with people becoming “a bit jaded by any event regardless of whether it’s a new or an old one” [4].

A further participant also considers that “hospices are getting to that point” [8] beyond which they cannot grow, and another says, “We’re mindful of, that’s my population size … of the size of the pocket … there is a limit … I don’t think we can just keep growing and growing and growing” [6]. Whilst this was said in terms of economic development, the last respondent is also concerned that, as a charity, “We can’t overstretch because you’ll lose the essence and the core of what you’re about” [6] which in this case means the intimacy and personal nature of hospice care. For this CEO, development and size are determined by purpose and concept as well as the local economy.

However, another participant says simply, “Rather than worrying about saturation, just go and look for something new”, and “[We need to] be a little bit more agile with our thinking” [5]. In seeking to do that, one interviewee talks of hospices needing to take risks:

> “All of the relatively easy ways of making money we’ve done, we’ve exhausted. Any new ways of making money are going to be high-risk … but we have to do it. We’ve got to push the boundaries otherwise we’re going backwards” [6].

It is worth noting in these quotations that there is reference to costs that ‘push down’ on hospices. Being “overly regulated” [10] is an example of one of them, hence: “if we could change regulation, I think we could make some significant savings” [5]; “regulation is far too much and stifling” [16] and “I’m worried about the CQC inspection regime because I think that could further reduce the desire to be innovative” [1]. Although, exceptionally, one participant feels that the regulation in a previous field was “fifty times more than I have to do here” [18]. However, from the perspective of sustainability the cost burden of satisfying regulators is clearly an issue for participants in this study and “it’s a massively different world … in the last five years” [21], which in turn means that it is a growing budgetary demand.

However, whilst hospices may have a natural capacity if they develop as traditional local charities, respondents speak of their particular strengths that others, including mainstream services, may not have, such as “agility” [5] “independence” [29], “ethos” [3] “reputation” [18], “local identity” [1] and the fact that they are “loved” [13], all of which they can use to best effect. Since hospices are independent, they can be “[flexible in order to] meet more people’s needs” [8] and develop new approaches in terms of their operation and methods of generating income.

In terms of capacity and continued growth, one respondent says that this should be considered within a broader economic view: “We can’t expect every year for GDP to rise and so we’ve got to find a better way of *expressing what’s good about the world*” [5], citing Raworth[160] who writes of economics based on humanity’s long-term goals rather than “the world being ruled by GDP” [5].[553] Speaking similarly, another respondent cites the same work [10]. This of, course, brings together capacity, context and where hospices see themselves in the bigger picture, not just of health and care but also of human need and social value. In the literature this relates to where Gergen is not just concerned with tensions, implicit negations, actions and reactions in social construction but also with what they signify and *mean* to society as a whole both now and in the long-term.[436] Relating this to the significance of Saunders' life, Brown speaks, "[Of how] her long courageous struggle brought about a sea-change in the care of the dying [and how] … courageous people can push back a tide of darkness that can sometimes seem to overwhelm an era".[554]

6.3.4 Collaboration

A further option for development as a charity is to find new ways of working with other organisations. I have already discussed collaboration generally as a hospice role in Theme Two, so the results here in terms of development and sustainability should be seen in conjunction with those.

A number of participants feel that a lack of willingness to collaborate meaningfully "makes the collective voice of hospices significantly weaker" [22]. This was emphasised when a representative from public services spoke to local hospices saying: "If you want to influence a change in commissioning … and how services are delivered in your world you have to speak to us as one" [11]. So here there is a financial incentive to work together.

However, in terms of improving economy of scale through collaborations, one CEO speaks of hospices being held back by the fear of take-over:

> "People talk about sharing backroom services; we share our IT services. I'm sure there's more that we can do. I think until people get really hungry for money they won't. But then some people say … 'we read the articles in the academic papers about mergers and they become take-overs and that's not the right reason for merging'" [15].

So here there is reticence, caused in part by an assumption that collaboration may lead to take-over and absorption. The corollary of this is that some hospices may only be prepared to merge if they are desperate.

In the study, many different views are expressed about how hospices should collaborate. A broad range of words are used, such as “cooperation” [22], “collaboration” [22], “agency” [1], “partnership” [16] “alliances” [5] “brokering” [9], “integrating” [11] “merging” [15] and “take-over” [15]. For example, one CEO says that hospices are ideally placed “between the community and the systems of health and social care … to broker … around agency and power” [9]; another speaks about hospices being well placed to “bring the system together” [30]; one talks of “doing things in alliances, I’m not talking about mergers … taking over you or you’re taking over us” [5], with a further respondent saying “the vision … is that we are far more integrated within the communities” [11]. The last respondent goes on to picture a line between the charity sector and the public sector that “needs to be drawn in charcoal so that you can smudge it”, which can also mean collaborating whilst “retaining the status of charity” [11]. In other words, collaboration can be subtle with soft walls, less definition and more flexibility. However, there needs to be discernment, with one interviewee issuing a warning that hospices should not get caught up in “that governmental narrative … that you realise is only a narrative … geared to make you work in that way” [31], and similarly another says: “We don’t want to sing to somebody else’s tune but define necessity [independently]” [7].

As one might expect, for some, a balance is sought: “I think the future has got to be balanced and sustainable … a balance of patient need with resource, with ability, with quality and wider connectivity with the system … but somehow we’ve got to remain distinct” [16]. That balance can be achieved, the respondent says, by being on the edge:

> “I don’t see the future being part of the system. I think there is a future for the hospice being distinct on the edge, connected to but not part of … if you chase the integration *without* retaining the distinctiveness then you’ll get drawn too far into it” [16].

Similarly, another respondent points out that from an economic perspective, if hospices get too intertwined with the NHS, people will not know “where the NHS and hospice end [and consequently] our ability to raise money from the local population diminishes” [2]. This idea of “being distinct on the edge” [16] relates to the concept of hospice as “grey” [14] (see Section 5.2.7) and a place where things are done and sustained differently. Thus, hospice is seen as neither on the sea nor inland; it is more akin to a coastal region or barrier island that must sustain itself from multiple financial ecosystems. Hence, one CEO says, “[If] we’re trying to beg our way into being a sub-sector of the NHS, I think we would miss the point” [29]. However, to continue the metaphor, it would also be dangerous for an island to become isolated if it wishes to remain viable. One CEO summarises this as follows:

> “I think the attitude, you know back in the day, was no one can touch us … [but] no organisation, whatever they do should work in isolation without knowing what their competitors … stakeholders, partners, whatever you want to call it, are doing” [20].

So here, in terms of economic development as a charity, some respondents see being distinct and on the edge as critical and that this involves a careful assessment of what are the best positions for hospices to adopt in the interests of those whom they serve and, indeed, for the future of their own organisations.

Finally, in terms of collaboration as a charity, there is recognition that size matters. As one participant puts it, you have the benefits of “scale economies”; [1] and another, “I also think from a sustainability point of view … there is that economy of scale, then you know that hospices that only deliver one service are really going to struggle. You’ve got to have multiple services to become cost-effective” [14]. This is because it is cheaper and more sustainable to run a number of services with the administration that requires. Also, in hard times, if hospices have to make savings a service could be cut back or closed whilst the hospice carries on helping to relieve suffering in other ways [14]. Hence, a CEO suggests going “‘big’ … at whatever level, regional, two hospices together and so on” [1].

Summing up, I put it to one interviewee, “So, size matters?” The reply was, “Yeah it does” [10] and, “The charities that don’t have the infrastructure to create new things will be the ones that fall by the wayside” [10]. Looking ahead in this regard, another CEO says:

> “So the only way forward for us is thinking, well, who would like to merge with us? … It’ll be fascinating to see what the impact is on hospices coming out of the virus [Covid-19] because of the issues associated with shares and portfolios diminishing and what’s going to happen” [15].

As these and other quotations mentioned in Theme Two show, there are many differences amongst CEOs about how collaborative development is understood and envisaged, how hospices position themselves and operate in relation to their local communities, other charities, the private sector and mainstream services, and how these different positions affect economic sustainability. Thus, one respondent appears to see hospices placing themselves in the heart of the health and social care system in order to influence or coordinate it as much as possible. Others see themselves in a position of brokerage as a facilitating go-between with communities whilst others warn against hospices becoming ensnared in government narratives in the belief that a hospice should be distinct, on the edge, and therefore capable of addressing suffering freely and independently. This, in turn, enables local people to see them as the independent charity that they love and support.

An example cited in the literature of developing collaboration was presented by O’Leary and Richardson at the 2018 HUK conference where they said:

> “Hospices are uniquely positioned to shape the future of care in ways that balance two questions: What is important to the system? and What is important to people and communities? If they reinvent they will hold the tensions inherent in these questions and the space for radical transformation around end of life, strengthening the voice and contribution of people and communities in it.”[11]

Here they demonstrated how the nature of their collaboration is shifting to a greater emphasis on being *change agents* that balance the tension between what is important to the health and care system and what is important to people and communities in order to relieve more suffering.

6.3.5 Empowerment and reliable income

For hospices in England, collaboration with the NHS and the funding that it awards makes a sizeable contribution to their economic development.[4] However, whilst respondents recognise its importance, some also feel that this funding is often unfairly distributed and unpredictable, creating a sense of disempowerment.

Hospices serving adults in England receive funding from local NHS commissioners which was, on average, approximately 30% of running costs when interviews were undertaken.[450] Whilst hospices are grateful for the funding that they receive from the public purse it is sometimes perceived to be distributed unfairly. One CEO says, for example, "the way in which commissioners historically have funded services hasn't been equitable. We're all getting different sums for delivering the same ask which doesn't necessarily reflect the needs of the community" [23]. Similarly, another participant says, "There's a hospice nearby where they have twice the population, so they get twice the funding yet they don't have half as many beds … they can't possibly care for as many patients as us and yet they get twice the funding" [13]. That perceived unfairness is also seen in the way that funding is administered by NHS commissioners, with one interviewee speaking of "bits in the community contract that we couldn't agree to as a charity [because] the control you're handing over [does not reflect the fact that] they're only funding a quarter of the service" [31].

Another CEO talks bluntly about poor levels of income from the NHS across the country for hospices saying that in terms of funding "the NHS are really taking the mickey … at the moment we are being spanked" [12]. This poor level of income for end-of-life care is compared to the much larger investment for the beginning of life and maternity care [11] [13]. Finally, on this point, another interviewee explains that the level of funding for hospices should be comparable to the rate for NHS hospitals:

> "It was quite a robust discussion … all I want is my fair share, so pay me what you pay for the same type of bed in that District General Hospital down the road … they've [NHS Commissioners] got the benchmark because there's 20 NHS hospices, so run the metrics and apply that metric to all of the hospices" [25].

Here, funding from the NHS is seen to fall short because it is not comparable to rates provided *within* the NHS including for NHS hospices (See Section 3.3.3 regarding different types of hospices) and, as such, is perceived to be unfair and disempowering. Respondents also mention those who seek a “national debate … to make sure we get the right bang for our buck as hospices [from the government]” [25]. This is understandable because neither Tebbit’s Palliative Care Needs Assessment in 2009,[315] nor Hughes-Hallett’s Palliative Care Funding Review in 2011,[555] resulted in any tangible improvements to the public funding of hospices serving adults in England. The only significant change came during Covid-19 when hospices were awarded additional resources from the government to support the NHS and to help tackle Covid.[556,557]

Some CEOs also speak about the unpredictable nature of being a partner with the NHS. One respondent talks of the local health economy having a large deficit that “we can’t ignore … they may well look to reduce our funding [again] which they did last year” [20]. In other words, this hospice cannot predict if or when they are going to have their funding cut next which makes financial planning difficult. On a parallel point, another participant says, “It only needs some numpty in the department … to not understand the hospice business model and given the pressures … they could end up not giving you money for a couple of years” [1]. An example of funding for hospices being redirected by NHS commissioners can be seen in the following interaction.

> Interviewee [13]: “So, with Boris’s money for hospices”.
> Interviewer: “You got some did you?’
> Interviewee [13]: “We did. Did you not?”
> Interviewer: “No.”

This award was trumpeted from the steps of Downing Street by the Prime Minister[558] but not all hospices received it due to *local* NHS decision making. In terms of politicisation, one respondent speaks of the “shifting sands of the politicised commissioning process and whether it will get more politicised or not … you are kind of at the whim of the changing winds” [11]. So, here there is an understanding that where hospices are partners and part-funded by the NHS, whilst that partnership brings much needed funds, it also brings uncertainty due to the way that governments and local NHS commissioners choose to make funds available through political emphasis and bureaucratic processes.

Bypassing all this, one participant looks beyond NHS funding and all the issues of unfairness, unpredictability and disempowerment, saying that their hospice founders,

> "did not pull together the momentum to create the hospice on the basis that we would get NHS funding … we need to prepare ourselves for life *without* NHS funding … we could still do a lot of good as the charity it was formed to be" [10].

Here there is a boldness that has got tired of "when people constantly harp on about NHS funding and we need more funding from the NHS" [10] and looks beyond it. Another CEO shares the same view: "I want to be less and less with my peers … wanting all the money to come from the NHS … [because] they miss what is unique and precious about the hospice movement" [29].

Reflecting on hospices' relationship with the NHS, one CEO speaks about the nature of partnerships. Here a collaboration is envisaged on a strategic level with the private sector, one that is strategically much more significant than a national company making hospices their charity of the year. The respondent talks about the possibility of a "charity-private sector partnership" [29]. This would be akin to public-private sector partnerships[559] with a different relationship and power balance to that of hospices with the NHS because it would be, in the CEO's words, "an empowering partnership, not a subsuming one" [29]. This idea of seeking empowering rather than disempowering partnerships resonates with the comment of another CEO who says, "If you're a goldfish swimming next to a shark and the shark starts talking to you, you're going to get a bit anxious" [11]. A consequence of a subordinate relationship with the NHS is seen as a potential drop in quality, "I also don't think we should become the NHS. I think that's so the wrong path to go down … we've got a local NHS hospice near us and it's very different … It's been run down. It's not nice" [28], and similarly, "In my experience the quality in NHS hospices is poor, very poor" [29].

Looking ahead, one respondent says, “The future of good end of life sits in much stronger partnerships, much more equal partnerships”, in this instance between communities and mainstream provision. They add, “We don’t give enough attention to … things like power and agency” [9]. Here a role for hospices is seen as one of “sharing power and about genuinely giving up professional … privileges that come with owning death, dying and loss” [9]. The corollary of this is that hospices need to be operating in empowering relationships if they are ever going to facilitate better end-of-life living, dying and death which, of course, links back to the earlier discussion about who owns death. The key point here is that rather than being “obsessed with accountability to the NHS and CQC [when] the majority of our funds comes from the community” [9], more empowering relationships need to be sought all the way along the line amongst professional organisations and critically with everyday people in local communities.

The issue of empowerment also relates to volunteering. As I explained at the beginning of this thesis, hospices were formed by people coming together voluntarily and today hospices are still supported by very large numbers of volunteers. For example, one respondent says, “We’ve got 700 volunteers” [19], another “800” [17] and another “900” [22]. As such, in terms of economic sustainability, volunteers are an important, indeed vital, human and economic resource (and inspiration) for hospices. CEOs are “incredibly proud of the volunteers and all that they do day-in day-out” [2] and say things like: “Where would we be without our volunteers?” [27]; “We definitely see them as an important strategic resource; they’re also our champions and they are, on the whole, delightful” [22]; and “The volunteers in the main are wonderful people” [30]. Similarly, a participant interviewed during Covid-19 restrictions, says: “We really miss our volunteers” [27]. As one participant puts it, volunteers are highly motivated and committed because “it’s about memories … hospice is about giving back” [23].

However, despite these high numbers, respondents also say that there is much more that hospices can achieve with volunteers if they were more empowering. One speaks of wanting to be “a bit more adventurous in what we allow them to do” [20] and how Covid-19 has made them think about that “with the right framework from the governance point of view” [20]. In terms of enabling volunteers to do more, I asked a CEO how hospices compared to other charities, such as for example, the Royal National Lifeboat Institution (RNLI),[560] the response was, “We are rubbish in comparison to that … we need to modernise, digitise, be more diverse [and we need to get] a shadow board going of young people that inform the board” [12]. Another CEO also supports the idea of a “shadow board of trustees who are junior doctors, newly qualified nurses … young entrepreneurs” [10], referencing Matthew Syed’s book, *Rebel Ideas* and the huge impact of a shadow board of young designers at Gucci and Prada.[561]

Another participant in the study speaks of how hospices limit the roles of carers and volunteers saying, “We’re frightened of volunteers feeding somebody, even if they’ve had the experience of feeding their husband for a couple of years” and that actually “They’ll be more expert than most nurses” [9]. Here there are issues of “legitimising that opportunity [which arises] because of the whole issue about sharing power and … professional privileges that come with owning death” [9]. The same CEO speaks of a project encouraging families to give injections (within a sound governance framework) and how doctors and nurses are “most unhappy about it” [9], with the ramification being “unless we share opportunity, power and the rest, with the community, I can’t see how people are ever going to die at home with any comfort at all” [9].

Likewise, another CEO also says “I don’t think we … use volunteers enough” [19], offering an example of an airline pilot working as a compassionate neighbour who could be given more responsibility. This respondent wants hospices to open up volunteering by empowering volunteers in a new way. As another participant puts it, “They’ve [hospices] got stale … I want to see a little bit more energy and vibrancy” [26] in the way hospices approach volunteering. One CEO says, “I don’t think volunteering in hospices is particularly dynamic or innovative” and is candid about their own position. The proposal going forward is to have “a shared local volunteer group [amongst charities in the area] that are able to be trained together and work across organisations” [17]. In the literature, many of these concerns about disempowerment and volunteering in hospices were shared by Gale in her study[360] as I explained in Section 2.4.6.

In summary, CEOs recognise the need for hospices as charities to seek empowering relationships. However, hospices must be empowering too, both internally and externally. In the literature the authors of the Lancet Commission

Report on the Value of Death emphasise the importance of the issue of power in relation to death, saying: “Power resides within systems and the systems often maintain the interests of those holding power”;[374] this includes the systems that hospices operate and partake in.

In terms of economic development as a charity, one respondent speaks about the need for “a fundamental shift in reliance on unpredictable income sources” [7]. This includes putting greater reliance on public funding, contracts with schools, charitable grants, major donors and philanthropists and reducing pressure on conventional charitable income such as general donations and events. Here it is understood that there is a degree of saturation in traditional sources of income for charitable hospices on what is described as “the unpredictable side” [7] but there is more to be gained on the “predictable side” [7]. In this regard, examples of other hospices seeking predictable income sources include accessing NHS CHC (NHS continuing healthcare)[562] funds: “We care for people in our in-patient units who we are not entitled to receive CHC funding [for] but actually, if they were to be cared for in a nursing home, they would get that” [14]; and “if we get a referral from out of area we then contact the person’s CCG and ask for payment” [11].

In summary, respondents’ approach to developing economically is to recognise the importance of looking for income that is as regular and reliable as it can be. This is difficult because its proponents also recognise that “predictability always has a time limit” [7] and as I mentioned earlier, some CEOs’ experience of public funding is that it is not reliable and can change unexpectedly. In view of this difficulty, CEOs also recognise the importance of hospices having multiple diverse sources of income because when one revenue stream fails there are more to fall back on, which is recognised by Duncan in the literature.[331,394] I now move on to consider economic development for hospices as a business.

6.4 Economic development as a business

6.4.1 A hybrid approach

Despite hospices’ long standing registration as companies, some CEOs speak about the need to develop a business approach alongside a charitable one. For example, one CEO speaks of a battle to be recognised as a business, “moving from not just being a charity but to be a business as well as a charity is, we still battle with that on a day-to-day basis" [8]. Explaining further, the respondent says: "We've always been a business but probably not business thinking", more like "being a nurse organisation and being charitable … it's moving to being a business so we can do what we do as a charity" [8].

One respondent sees this externally as well as internally, speaking of "a snobbery" that sometimes emanates from the NHS, that "charities don't know how to run a business, they aren't commercial" [15] because they still see them operating from "somebody's garden shed" [15]. However, this CEO is clear that "from a business and commercial perspective we've got to be sustainable" [15]. Naturally, this includes normal business development, for example, to "streamline" and "utilise technology to work differently" [21], apply "performance data" [22], recognise the importance of "a good communications team" [20] and so on. One respondent puts it like this, "It's not good enough just to deliver excellent care. You've got to be a smart business as well if you are going to be sustainable going forward" [20]. Another participant says hospice boards have to stop thinking they are in a comfortable place: "This is a business that has to be run with a sound ethos, aims and that's got to be carried right through and you've got to be fit to survive these days" [24].

This desired culture-shift in development through a hybrid charity-business sector approach is identified by another interviewee who says that, on appointing them, the board knew what they were looking for: "I wasn't a nurse and I had a much more management, business-like approach and so the first few years were a challenge … trustees … needed that business – more of a business mind" [6] to bring a new dimension to the existing NHS culture. Another participant speaks of "change resistance [and a] pomposity that doesn't do us any favours" [18], going on to say that there are lessons that hospices can learn "from what's going on in other sectors" [18].

This respondent also speaks about the benefits of a "public sector mentality … wanting to go the extra yard" [18], rather than simply working to pay shareholders, coupled with a private sector mentality of "really striving, really reaching for stuff, not accepting the old ways" [18] and, in a hospice context, "making sure that you don't just tell everybody how brilliant the painting looks without actually saying to them ‘so do you want to buy this painting?’” [18]. The participant describes this approach as “a hybrid” [18] of the public, private and charitable. Whilst it is not exactly the same, this resonates with the suggestion of another CEO who speaks of the importance of an ambidextrous approach that balances hospices’ timeless guiding principles with stability and agility [5].

6.4.2 Agility and innovation

More specifically, when considering hospice development, two respondents offer comparisons from successful innovative businesses. The CEO who describes the case of Netflix and Blockbuster Video[41] says, “We as an institution or as a sector have to adapt … we’ve got to be more fleet of foot as a business” [11]. The point is that, “We can’t sit here and think because we are a hospice everything will come to us in the way we want it” [11]. The principle of it is, they say, we have to:

> “pierce through into the sector … in a commercial sense … to make the experience better for the customers, that will in turn help our business … to develop … Well, this is a bit disingenuous to say but I think some hospices are still Blockbusters and some are on the Netflix journey” [11].

The comparison with Netflix is that it sustained its growth whilst Blockbuster Video did not and went downhill into bankruptcy.[41]

So here this CEO speaks of the need for a positive business mentality that is prepared to be bold and to proactively take on challenges that hospices face. This is more than just getting alongside others; it is ‘piercing’ through a ceiling or barrier and being creative to make life better for customers. This, in turn, will help the business to be sustainable as in the case of Netflix. Another CEO talks on similar lines saying, “This is a *relationship* business not a commoditised business”. They add that, as a provider of health care, that “relationship dimension doesn’t alter no matter how many more patients we want to see” [18]. Here again there is determination to develop and be creative but critically, with the insight of business intelligence, “We don’t want to grow … in a way that penalises the calibre of excellence that we think we deliver” [18]. The reason for balancing these “qualitative and quantitative touchpoints” [18] is because, the respondent believes, if they tip the wrong way they will tarnish the established reputation that hospices have spent decades building.

The participant who describes the Netflix case [11] goes on to talk about how they as a hospice are working to encourage this kind of creativity in all their staff but many hospices are not. This salutary warning for hospices intersects with comments from CEOs about the Sigmoid (or Second) Curve,[40] which also comes from business development thinking. The important point here is that sustainable development is not simply attained by addressing business efficiency; it comes from being creative, bold and intelligent too, which in the Netflix case involved a new business model, a second curve and challenging people who said, “that will never work”.[41]

It is in this vein that one CEO summarises their economic development by saying that they struggle immensely every year to balance the budget but manage to do so through, “very, very tight controls but also by new innovations and constantly looking and exploring where we can bring in different streams of funding by providing different services” [13]. For this respondent, their planned innovations that include a health village and video gaming project are examples of an entrepreneurial determination to benefit patients, families and surrounding communities while, at the same time, protecting the economic development of the hospice.

Another CEO [1] offers another case study of business development from the retail industry. As mentioned in Section 5.3.7, the participant quotes Lidl, a supermarket chain that found an unexpected niche by discovering a new balance of quality and economy that people have become happy with. As with Netflix, this participant looks at growth and sustainability through a business development lens and how hospices can learn from Lidl by being different, disruptive and prepared to discover, rather than assume, what people want. As the results have shown in Theme One, this is what happened in the twentieth century as the pioneers recognised suffering, identified what people wanted and, despite all the critics,[217] became a resounding success.

The interviewee also sees this in terms of competition from the private sector with an awareness that hospices may be “forced to change, forced to embrace greater scale" [1]. This of course chimes with comments made earlier about hospices needing to be "agile" [5], where respondents speak in terms of businesses needing mobility and flexibility to identify gaps and opportunities and to respond to market forces. This comparison displays a recognition that if hospices are to be sustainable and effective, "you can't sit back in this world" [24] and wait for help to arrive; hospices must respond creatively as successful businesses by being prepared to look beyond established assumptions to what people will embrace and appreciate. For example, this respondent espouses commercial enterprise saying, "One hospice up north has … opened a community café [and that another] has bought some properties, flats and rented them"; in fact, "there's no reason why you should not go into manufacturing" [24]. Another is considering "opening a bespoke climbing centre … a solar energy company [and expanding a] property portfolio" [10]. One interviewee talks of their hospice facility being "an art gallery … a concert venue [and] a café", saying that the income "isn't going to change the world" [17] but an important benefit is that as well as 'normalising' hospice, it connects people to the charity who then become interested in supporting its work.

For many hospices, business activity includes shops: "We currently return a million-pound profit from the 29 shops" [10]; another refers to their "25 shops" [9] and one of "a strategy to open 30" [17]. Another participant speaks of a "tie up with high street retailers" [16] encouraging their customers to bring in pre-worn goods that will be passed onto local hospice outlets, which helps address the environmental issue of "throwaway fashion [not as a] green wash" [16] but as a win-win for both sides. As well as joining up with commercial partners in a joint business venture the CEO speaks of wanting to do the same with other hospices saying, "Why don't we, heaven forbid, heresy, actually have a shared shop? Goodness me, I realised what heresy I'd spoken" [16]. Here is evidence of openness to seizing commercial opportunities facing resistance.

So, for hospices as a charity, broadening impact clinically can benefit economic development through new donors and contracts; while from a business perspective, creating more diverse, innovative income sources can also increase revenue and reduce risk because if one fails there are more to fall back on. Business developments are also driven by identification of local need. For example, one CEO talks about how they "opened a funeral business … because many of our patients couldn't afford funerals and we had people sat in mortuaries for a long time and we saw the distress of those that were bereaved" [15]. So this new business activity, that faced huge opposition from local funeral directors, set out to help people in distress whilst at the same time helping sustainability, with the respondent talking about "regularly making £250,000 … and we've now got a second generation" of people using the service. Others have seen the commercial significance of this, with one respondent saying, "[I am wondering] why did we pooh-pooh the idea [of a funeral service originally because now] I'm considering it because of the way the high street's failing" [11]. The same CEO also says, "We are considering changing our trading company … from retail to service industry" [11], showing that a broader commercial canvas is now envisaged. Here there is an admission of earlier reluctance to innovate and a new preparedness to do so.

In speaking about "exploring a funeral business" [9], another participant is aware of internal resistance in a number of hospices to developing commercial funeral services because some hospice staff and trustees are "just concerned only with the well-being of their patients and not with the long-term sustainability of the organisation" [9]. Consequently, the CEO says, "We have announced it privately internally to people so that they can get over the shock" [9]. Similarly, other interviewees see openness to business thinking amongst non-clinical staff but resistance in clinicians [31], most of whom have come from the NHS and have an institutionalised "public services mentality" [18].

So, many respondents recognise the opportunity for business development to generate new income, including those developments that also bring therapeutic benefits. However, some also speak of internal reluctance and tension between "that will never work"[41] and those who believe it will.

6.4.3 Acuity and altruism

In the examples of hospice business activities that I have just described and that align with the caring work of hospices, there is a charge for those who use them. Thus, for example, affordable funerals that continue care after death, and cafés, shops and concerts that bring people together to ease loneliness and enhance social well-being, all operate through paying customers. As a consequence, these commercial activities support the economic development of the hospice.

Amongst other commercial activity that is aligned with the purpose of hospices one further possibility needs to be mentioned because of the weight and variation of responses that it received. This is the commercial option of potentially charging patients for clinical and social care which includes paying for a bed on a hospice in-patient unit. Thus, one respondent says, “We don’t do private beds because that's not what we do. It goes against the ethos and the ethics and how do you do it? And it divides people and that means the haves and the have nots” [11]. Clearly, the concern here is ethical. Another interviewee is just as blunt when describing a lunchtime meeting with the chair of the board whom the CEO describes as a “really intelligent clever guy” [10]. When asked what was the most important thing about this organisation, the chair replied, “We’re excellent in service delivery and it’s free” [10]. In the literature, Saunders emphasises that hospice admission is free[563] and their philosophy is of “openness of all kinds”.[564]

However, another participant, when asked about charging patients says, “We are and we’ll have to do more I suspect. So, for example, our personal care agency is a private service” [9]. At the same time the respondent says, “It’s philosophically challenging and it’s morally difficult … but I honestly, I think it’s again, it’s denying some of the control that people want and it’s a very practical way forward” [9]. The respondent goes on to say that the challenge is not to let people without those resources become “second-rate citizens” [9]. Similarly, another CEO talks of addressing this ethical dimension saying, “It’s one of those sort of Rubicons that you cross, isn’t it, of going from this sort of idea of being a charitable body but many charitable bodies charge, don’t they [such as the] National Trust?” [2]. The same respondent speaks of the various ways in which this can happen where people pay for some of the services, such as therapies and hairdressing, and says “I bet they think, well, why are they *not* charging for that?” [2].

Counterbalancing this, another CEO says, in relation to charging patients, “I feel quite strongly that we shouldn’t … I think we can be commercial in other ways rather than commercial around the care … the only exception I make is when people have private health insurance” [5]. Part of the concern here is about the practical application: “Who would you choose? Who do you means-test?” [5]. The participant goes on to say, “I think it’s hard enough to get our message across right now when we don't charge for anything" [5]. Finally, when asked about the appropriateness of introducing privately paid for services, some CEOs are in the middle ground, for example: "No, I don't [but] I'm open to persuasion and debate and discussion" [7]. Another says:

> "I think … that could go horribly wrong … because people get very confused about what we do anyway [but] we know there's a lot of wealthy people at the end of life who … are not … able to get it [care] from us because we don't let them pay for it … I think it's a tricky one … it goes all the way back to Cicely and the social justice stuff" [17].

As part of this debate about the development of hospices as businesses, one participant points to the importance of altruism, saying that one can have shelves full of management books but if "you smile, say thank you and if you are kind, in the broadest sense of the word, that gets you through much of this jungle" [11]. In doing so they cite Henry James's three important things in life, "be kind, be kind, be kind".[565] Here, important though a business perspective is, the respondent believes it cannot be hard-nosed or callous but must be ethically balanced within the altruism of hospice philosophy [11]. That ethical imperative is expressed by another participant as a seeming contradiction when speaking of a number of potential commercial developments in their hospice: "I'm worried that we can do it because our whole raison d'être … is about being charitable and when you suddenly become commercial, you have to be hard-nosed … it's a different kind of discipline" [9]. The interviewee gives an example, "We cannot make our personal care service make money because we are too focused on the experience [and] we want our carers to be highly trained; we want to be very fair employers. Everything about it denies an opportunity for profit" [9]. This in turn has implications for hospice leadership:

> "In the nineties we moved from … a general manager and a nurse and a doctor, you know, is there a time now where we've got to rethink the sort of leadership structure for hospices, [with] somebody who is engaged with hospice care as a business [and] somebody who is concerned with hospice care as a community resource?" [9].

This vision draws together the challenge of balancing the acuity of business with the altruism of charity, hence the earlier suggestions of ‘hybrid’ and ‘ambidextrous’ approaches to the development of hospices.

6.5 Obstructions to development

In this section, I focus on challenge, resistance and opposition faced by respondents as they develop hospices. I do so because of the depth of feeling expressed and the seriousness of the situations described to me. As the next paragraphs show, whilst hospices as intelligibility nuclei are compassionate to patients and families they are not always kind to themselves.

6.5.1 Victimisation and bullying

As one might expect, redesign and changes to service provision including staffing restructures is an area where challenges arise for hospice leaders. For example, one respondent says, “We’ve been through a difficult time internally because I’ve challenged” [20]. They go on to give examples of developing the outreach team and then day care, saying, “You can imagine that change within that team; it wasn’t welcome” [20] and “If you believe in it then you’ve got to be brave enough to see that through” [20]. Other participants speak about the unpleasantness of restructures, “I’ve gone through restructurings and had to make colleagues redundant [but] even when it’s horrible, at least you know the rationale” [27]. Another speaks of “the restructure of the hospice … that came with a lot of pain” [21]. Service development is part of the day-to-day work of a CEO but I noted that one respondent repeated the need to be ‘brave’ six times.

A different challenge faced by another CEO was on appointment. The respondent describes it as “a culture of victimisation, bullying, harassment, negativity, blame [that was] toxic and dangerous” [26]. As a result of this, the CEO says, “The professional reputation of the hospice was non-existent; it was awful” [26]. Here the participant speaks of an internal culture that drove people out of the organisation, “you know a proper witch hunt [that] was evil, nothing short of evil” [26]. This CEO had been working previously for the hospice in a different role away from the main site and was unaware of what was going on before becoming CEO and, as a consequence, feels very “angry that … I was being lied to and things were being hidden from me and I’m still overturning stones now … I felt betrayed” [26]. To make things worse, the issue included collusion from the chair of the board where “red on the clinical dashboard was banned … even if it was red … the chairman was party to that because even when whistles were blown those people disappeared” [26]. In seeking to rectify the situation the CEO faced significant resistance, including from staff:

> “refusing to follow new systems, people refusing to – and people continuing to behave in the way that they had always behaved to test you, to push the boundaries. They try to grind you down and to undermine you, yeah and just continually keep chipping away and waiting for you to fall down or give up” [26].

Reflecting on the situation as a whole the respondent describes it as “eye-opening, challenging, horrific” [26]. As the language in the transcript conveys, the CEO’s experience of this internal culture and indeed that of other staff who fell victim to it, was awful.

Another aspect of internal culture that some respondents talk about is described as ‘neediness’. For example, one speaks of a “softness of culture … there’s a certain person that’s attracted to hospice work and it’s not necessarily a good thing” [24]. Explaining this, the participant speaks of talking with other CEOs about job applicants who come and, “They’re in need of something else; they feel very needy” [24]. There is “a neediness that comes through always wanting a pat on the back” [24] and they know that their hospice “attracts that type of person who has that need and actually it is a little bit concerning because you don’t know how that comes over to patients” [24]. The respondent also says that colleagues know this neediness is perpetuated, in part, by “this huge amount of mail and thank-yous and it’s in the papers ‘our wonderful hospice’ etc.” [24]. However, importantly, there is also recognition that “there is another kind of softness which is actually very reassuring and immensely productive” in an end-of-life setting [24].

So, whilst I have shown in earlier results that warmth, love, compassion and kindness are hallmarks of hospices, this CEO tells us that there can sometimes be a strata of neediness running through it in staff that can become problematic if left unchecked. Addressing this issue and its ramifications is described here as being “enormously bumpy” [24] because, as a consequence, so much had to be done. This included addressing “collusion” and “cosiness” [24] at board level in an “organisation that’s become too comfortable” [24]. An indication of how deeply this affected the CEO came when I asked about main achievements in recent years; the respondent simply replied, “surviving” [24].

Collusion at board level is described by another participant when addressing internal “cultural challenges” [3]. Here the CEO had a fragmented senior team with two members who could not work together, so support from the board was needed but governance was “toxic” [3] because a trustee was “overstepping the boundaries of good governing and basically going completely native … and we were trying to smooth things out and manage the situation that then exploded … it was all very painful” [3]. The respondent says that the trustee was “avidly scripting the fact that I shouldn’t be in charge of the organisation [because] doctors know best; ex-NHS managers should not be in the organisation, especially not a female one” [3]. Despite other good things happening, the participant describes the time when this happened as “a dreadful year” [3]. Thus, challenges to CEOs from internal cultures are exacerbated when they include the highest governance function, the board. This respondent spoke to three other CEOs who had “a board trying to oust them in some way” [3]. Similarly, another participant says, “I struggled with the chair when I came here, really struggled … and I handed my notice in and I was going to go” [5].

However, it is important to add at this point that many respondents seek appropriate or positive challenge to aid hospice development. For example, one says of the board, “I’m happy when they challenge me because I’d want to be challenged” [8]. Another says of their board, “We’re fortunate we’re also getting like-minded disrupters” [29] so that they are regularly challenged and finally, another CEO says, “I always enjoy surrounding myself with leadership teams who constantly challenge me and constantly push me” [7]. Here the difference appears to be between appropriate and inappropriate challenge and good and bad governance.

6.5.2 Parochialism and chronic-niceness

Another CEO talks in starker terms about resistance to change resulting from an isolated way of working that appeared to be in a time warp: “The resistance to change here and the difficulties I’ve had are off the scale … it’s worse than parochial; it's pernicious" [12]. This respondent speaks of a hospice that had been working in isolation, saying it was "almost 1970s when I walked in … it was borderline illegal … nobody had moved; nobody had been challenged; people just did whatever they wanted and there hasn't been any change" [12]. Here the respondent speaks of "disrespect, nastiness, obstruction" [12], of a toxic working environment, of the charity being "torn down by a malicious element" [12] and of staff "coming complaining saying, 'I'm being bullied but don't tell her, I'm frightened of her'" [12]. According to the respondent, these situations could go on for eighteen months because "HR has been horrendous" [12] and "if your Board don't back your Chief Exec, you're done" [12]. Here the effects of an out-of-control internal culture are compounded by the fact that it has penetrated the function of HR and, again, the absolute necessity of having an effective board is highlighted.

As a consequence of dealing with this pernicious culture, the respondent says it has been exhausting and "very, very stressful dealing with staff" [12]. The culture is similar to the neediness described by a respondent previously but, in this case, the causal term "chronic-niceness"[296] is used:

> "The problems are horrendous … it comes down to that chronic-niceness that Peter Speck[296] talks about, where hospice staff actually start to believe they are angels, and they are the only ones who know how this feels, because they are the ones next to the patients and they become very anti-management and resistant" [12].

So, here a picture is painted of an internal self-perpetuating oligarchy that, when left unchecked, develops a cultural belief in its own omniscience and, as such, forcibly resists any attempts to oppose it. This chronic situation is exacerbated by the intimacy of a small hospice, "You are faced with disrespect, nastiness, obstruction … and I think the size of the organisation is really hard, like I don't have a fleet of directors as buffers" [12]. Clearly, size matters as well as the situations left by previous leaders.

When asked about main achievements, this participant used the same word as the previous CEO [24], saying "'survival' … I look back and wonder how I did it because my god it's hard and it's lonely" [12]. This CEO of considerable experience also said that this scenario of a resistant internal culture was by no means unique to their hospice. At the end of the interview I asked the respondent about the skill sets that future CEOs would need, they replied: “They will have to be resilient and if they’re not tough when they come in they sure as hell will be before they leave” [12].

6.5.3 Death threats

Another CEO speaks about opposition that became life-threatening. Before conducting the interviews, I gave a commitment to anonymity to encourage candour in the study. As such, my aim here is to convey the experience of the respondents and not the specific details of the scenarios.

When asked, “What words would you use to describe your recent years as a hospice CEO?” the reply was, “Life-changing; it’s life-changing not only for me, I must admit, actually for my entire team the impact of the last five years has been phenomenal” [15]. The challenges were indeed life-changing, the CEO says,

> “[because] we had a lot of trolling and all those sorts of things [and] I’ve been attacked in my local supermarket. My trustees and I have been abused on social media. People said that they hoped when I was taken into hospital that I had cancer and I was going to die [and] I’ve been screamed and shouted at … we’ve had to send letters from lawyers telling certain third parties to stop what they’re doing” [15].

When asked if the CEO had received *death threats* the answer was “Yeah, yes I have” [15]. Understandably, the experiences of this interviewee are described as “very, very difficult, a very difficult period … pretty awful … continuous harassment … harrowing” [15]. Significantly, the respondent says, “It nearly killed me” [15]. This was not a metaphoric statement. During the interview it became clear that what happened had had a significant effect on the respondent’s well-being resulting in necessary time away from work to recuperate.

In a second case, a CEO speaks about a difficult start to the role. The hospice was in serious deficit with an annual overdraft approaching half a million pounds. The respondent says: “[In] my first month here, I didn’t know how we were going to pay this back … it took an awful lot of taking the business apart [and] we had to cut an awful lot at the start" [13]. The aim was to balance cuts with development so that the hospice "does [continue to] add value to society these days". In other words, the charity stays relevant and valid for local people. The participant describes the experience:

> "It was awful actually because I went through three big rounds of redundancy and I actually got *death threats* here; people were going to the papers … people were trying to get me sacked … Luckily I had a very good board" [13].

At that point I interrupted and checked that I had heard correctly, "You had *death threats*?" The reply was "Yeah. Seriously, it was shocking" [13]. Later on this CEO was asked to assist two other hospices on separate occasions. In one there had been criminal activity and in the other financial incompetence. Having heard all this, it came as little surprise to me that, as with the previous respondents [12] [15], the health of this interviewee had also been affected: "I had a nervous breakdown … because of the situation here" [13]. This was triggered by a further event but came as a consequence of what had come before.

6.5.4 Causal factors

Within the interviews there are some indicators of causal factors for why such aggressive obstruction to development might occur in hospices. For example, one respondent says, "When I came here there was some formal and informal leaders in the organisation … my predecessor here had let a lot of people who really shouldn't have had free rein, have free rein" [5]. The CEO continues, "There were people in this organisation who wore that hierarchy like a weapon [behaving like they are] the keepers with the keys to the castle" [5]. Here the causal factor is previous weak leadership and management that allowed an internal culture to grow in isolation. Similarly, another CEO recognises the risks of poor governance, "I think people who are naughty and nasty, they're attracted to organisations that they think are not robust and don't have good governance" [15]. And as another respondent says, "It was interesting recently, realising and remembering once again that actually not all people who work in hospices are very nice" [17].

Another participant refers to Philip Selznick's work[566] and this "concept of organisations that have social value within their community and therefore how much harder they are to change" [3]. This links with a comment from one of the respondents that I referred to earlier who says, "It's a huge responsibility to make sure the charity survives … we're guardians of something very special" [15]. The suggestion here is that whilst colleagues working in hospices are known for being compassionate and caring towards patients there can sometimes be a parasitical neediness and chronic-niceness that leads to a sense of 'we know best' and, as discussed in the literature, obdurate behaviour (see Section 2.4.2).

6.6 Development and purpose

In the transcripts, a number of participants in the study stress the primary importance of purpose in terms of development and sustainability. In other words, rather than looking for how more income can be found, how a hospice can work more efficiently and how it can reduce unnecessary expenditure, the emphasis here is to start at an earlier point by asking fundamental questions such as: Why are hospices here? What is the hospice idea? and What are hospices seeking to achieve?

Articulating this issue, one CEO describes Saunders as, "one of the last bastions … to be driven by the needs of the people as opposed to other political pressures or financial pressures" [7], going on to say that today, "about 70% of the hospice movement is not motivated by patients; it's motivated by financial pressure and, worse than that, the desire to survive above all costs" [7]. The suggestion is that Saunders began with 'why' (as the literature shows)[1] whilst many hospices today are beginning with 'how': How can they can balance the books? and How can they survive?

For this participant, the absolute priority is "unmet need followed by sustainability" [7], *in that order,* and it is brought about by the hospice "putting itself out there" [7]. So, this CEO says, "You look at it. You start implementing and you start doing it and you end up with something that is completely funded" [7]. Looking nationally, this respondent describes two main challenges for hospices being "reluctance bordering on resistance to change and sustainability of what is essentially an unsustainable model" [7]. Thus, for this CEO, there is a persistent seeking out of unmet need and an openness to change. As a consequence, determination, dynamism and ‘getting out there’ attracts funding and healthy economic development.

This approach resonates with earlier results that emphasise the importance of “agility” [5] [10] and “reinvention” [8] [9]. Similarly, a further participant reinforces this need to keep refocusing the mission, “Flexibility is for me the most important thing, that being fleet-of-foot and keeping an eye on the horizon to see what’s changing, what do we need to do to stay in the best position for our patients” [25]. Emphasising that mutual understanding with local people, a different interviewee speaks of “having a community that really understands a lot more of who we are and what we do and why we do it” [17]. Thus, creating an umbilical link in terms of shared purpose with surrounding communities is seen as vital: “You’re not sustainable if you’re no longer a service that people want and you’re not relevant to the health sector or to the local community” [28].

Another CEO shares a similar view about ‘why’ coming before ‘how’, “If you’re going to ask 30 chief execs what the challenges are for the next ten years, they’re going to say funding and I do not believe that is the challenge” [29]. This respondent expresses deep frustration with colleagues who want all the money to come from the NHS. They believe that it is very important for hospices to meet the needs that they see before them and this includes “[people who are] abandoned by the system” [29].

Likewise, a further respondent, when asked about addressing economic sustainability going forward, says that the “first thing is … to understand what we’re doing now” [16]. On appointment this CEO asked the senior team to summarise why their hospice was here and what part it was playing in the amphitheatre of end-of-life care. A quick answer over a cup of coffee was expected but it took a number of months to extract a response. The interviewee considers this uncertainty highly significant because “what we’re doing … that’s the kind of starting point for sustainability” [16]. In another part of the interview, the CEO affirms that the first priority for a hospice is articulating the challenge, which involves being truly patient, community and population-centred, whilst the “second is money” [16]. So here again, seeking out the need and challenge, being clear about why and what, comes before the how of development and economic sustainability.

A further participant speaks of their “inspirational and vocational team” approach that articulates the challenge, “questioning each other about what we’re doing and why … wanting to make it happen, whatever it is” and adds that “the organisation is still driven by a set of values that’s bigger than itself” [17]. Looking backwards the respondent says, “That’s what I really got from people like Cicely and Robert Twycross … that was actually more important than anything” [17]. Likewise, another CEO speaks about the value of compassion and the hospice purpose, “The future of hospices is still fundamentally at the core about compassion and I think we have to stay on our purpose to be relevant” [28]. In other words, an inspirational and vocational team will be focused on the challenge of suffering and a belief in social values and have the understanding, drive and compassion to work out what part they are going to play.

Using different language, one CEO says, “I’m going to make us indispensable to everybody around me” [27]. In terms of local people, the CEO continues, “They will pay for us to do what we’re doing if they have confidence and believe we’re doing the right thing”, and in terms of community and the NHS, it is about “actively listening all the time, being responsive, providing quality, evidencing that we’re providing quality and that we’re providing value for money” [27]. Again, really understanding need and role coupled with a belief in doing the right thing i.e. why and what, with the added ingredients of transparency and accountability, is this participant’s start point for sustainable development.

Finally, one participant sums up the issue of purpose and development, explaining that when speaking to several hospice CEOs, the questions to ask are fundamental:

> “What are you there for as a charity? What’s your purpose? How do you know? … What’s your belief system behind your purpose? What’s your underpinning methodology of what you’re thinking about? And a lot of them still talk about their services’ outcomes and things like that” [31].

Thus, the respondent says, in terms of economic development, “If you get your model right, then your fund-raisers know what to fund-raise for, because you fund-raise for need: you don’t fund-raise to balance the books” [31]. The clear emphasis here is on the importance of having a “good model that’s right for the community” [31] i.e. on what a hospice is and how it keeps being relevant in order to meet current and emerging local need effectively. This, in turn, makes fund-raising easier because local people understand and can see the benefit more easily. I also note that the respondent says that a lot of CEOs do not address these fundamental questions but focus primarily on service outcomes. This connects with the feeling expressed at the beginning of this section [7] [29] that most hospice leaders are focused on income rather than need, or ‘how’ rather than ‘why and what’. To conclude this chapter, I now summarise CEOs’ perspectives on the long-term future of hospices.

6.7 Looking further ahead

6.7.1 Uncertain, challenging and exciting

Respondents feel that there are tough times ahead, using words such as: doomed [3], perilous [4], not guaranteed [5], vulnerable [6] [30], critical [6], precarious [9], disturbing [7], uncomfortable [7], tricky [10], unsteady [13], doubtful [13], bleak [14], frightening [15], uncertain [18] [26] [30], fragile [18], threats [19], tough times [21], challenging [15] [25] [26] [27] [29] and difficult [19] [21]. These concerns are expressed in relation to “a shake-out in any industry” [2] or industrial life-cycle [1], to “that lingering worry … on sustainability” [20], to being “financially challenged” [5], and to the risk of being forgotten “like the wallpaper … we’re actually victims of our own success” [6]. These responses range from anxiety to deep concern, “I think it’s perilous … I think we’re probably all peering over the precipice and we need to decide are we going to pull ourselves back or fall in” [4]. In other words, for many respondents, this is a compelling moment in the operational life-cycle of hospices; hence they speak of a need for resilience [1], [18], guts [23], being bold [17], brave [26], fearless [26] and confident [30] [23].

Despite this difficult backcloth, CEOs feel optimistic [2] [5] [24] and positive [20] [22], saying that the future holds opportunity [7] [15] [18] [26] [27] [28], looks bright [29] [25] and exciting [4] [14] [15] [19] [21] [23] [27] [28] [31]. One interviewee is “uplifted by the fact that hospices are there” and that they are going to “endure in a really positive way because … people are still going to want to have a good end-of-life experience” [22]. Others say, “It’s not like the business is going to dry up; [in fact there is] a massive surge in the growth of need" [28].

In this regard, participants speak of the importance of innovation [14] [15] [21] [23], evolving [24], being creative [23], in a different form [24] and futuristic [13]. For example, one CEO talks about confidence and vulnerability in the sector saying, "There'll be those hospices which adapt and thrive and there'll be those that fail and fall away" [30]. Again, another says, "If we don't change and adapt, then we won't survive" [8] and that adaptation is seen in terms of meeting "the health needs of people" [8]. Another respondent says, "[For those hospices that have] no desire to change, it will be bleak. I think those who can be innovative and look outside the box that was hospices originally, it could be really exciting" [14]. Likewise, others feel that, "We're in a good place. It's up to us to make the most of that" [27] and, "We will have a massive ongoing impact" [4]. One CEO sees this in terms of hospices needing to adopt "a really futuristic approach [to work] in the right way with the new generation … they want to look after the planet [and] the people on the planet, we have to move with that" [13].

6.7.2 Inspiration and values

Looking to the future, respondents speak about: values and being valuable [17] [20] [23]; being passionate [26]; and about inspiring people and the importance of the hospice heritage [11]. Thus, one CEO speaks of having "the right people in the right places [so that] the verve of hospice will continue, [and that hospices are part of finding] a better way to express what's good about the world" [5], citing Raworth's perspective on human benefit rather than economic growth.[160]

Similarly, other participants speak of wanting people to come into the sector that "have got that integrity" [23] and say that "the future is fundamentally about compassion and we have to stay on our purpose" [28]. While the latter looks within, two respondents look outwards, speaking of hospices being "driven by a set of values that's bigger than itself" [17] and saying, "Death doesn't belong to hospices; death belongs to all of us" [31]. For these CEOs, inner drive, inspiration, values and integrity are critical to future development. They are the 'heart and soul' of hospice echoing, for example, Baron who spoke about the soul of hospice[255] and, of course, Saunders' 'living idea' that combines the heart and mind.[26]

Another interviewee speaks of not “jeopardising the heritage, the connection with the communities” [11]. Community was mentioned many times [9] [18] [23] [26], alongside localism [2] [8] [17] [30], independence [2] and being “distinct on the edge” [16]. Thus for many respondents, going forward, the relationship with local communities is seen as vital; hospices need to be “community endorsed” [18] and a “business and community resource” [9]. They must “listen to what our communities want … be responsive to their needs” [26] and “accountable” [23]. As another interviewee puts it:

> “We've stood the test of time. We're the heartbeat of the community certainly where we are, and I think the community more so than ever will get behind that going forward if they're really clear about why we're doing what we're doing and the value of what we're doing” [23].

Putting it more strongly, one CEO speaking of localism says: “You’ve got to find a way of protecting that at all costs. It’s sacrosanct because without it you will fail” [11]. This includes being distinct from the NHS: “We’re so in bed with what the NHS is and all its regulations and everything … that it slows us down” [5]. Taking this one step further, as I have already stated, one participant says: “We need to prepare ourselves for life without NHS funding. If we didn’t get any NHS funding, as an organisation, we will still do a lot of good as the charity it was formed to be” [10]. In other words, the aims and values of the charity are more important than NHS funding.

6.7.3 Being part of the solution

In their words about the future, respondents speak of the importance of integration [16] [22] [26], collaboration [11] [25] and partnership [27]. This includes being “more trusting of our peers within the hospice movement” [25], “united in national discussions” [28] and therefore pushing an agenda to HUK [23]. As one interviewee puts it, “I don’t think there are too many hospices; we’re just not organised in the right way” [28]. It also includes, as the results show, being “a significant integral part of the integrated care system of this country” [26] but not “acting like the poor relation” [23] because “if you chase integration without retaining … distinctiveness then you’ll get drawn too far into it” [16].

Furthermore, integration is not just with health and social care systems, it is with society as a whole. As one participant says, “I hope they [hospices] will become … more integrated into other parts of society and life … [because] there’s the big long term challenge, what do we want end-of-life care to look like in the UK and how do we be part of the solution and not part of the problem?” [22]. This emphasises the importance of hospices staying relevant to the needs of surrounding communities and not becoming side-lined by matters that are of little significance to local people and society.

6.7.4 Time to reflect

In concluding the interviews, a number of respondents speak about a need to reflect together on the future of hospices. Talking about this study, one participant says, “Hopefully it gives them [hospice leaders] some thinking time - that would be great - and some views … for the future” [24]. Similarly another says, “It’s been an interesting opportunity just to sort of think about some questions that I haven’t thought about for a while and a couple that I haven’t ever thought of” [30].

The study appears to have created an opportunity that is missing. When asked at the end of an interview how the respondent was feeling, the reply was, “quite enthused actually. It’s nice to be asked occasionally about these things because you’re just so embedded in your daily work these things just get forgotten about don’t they, [it’s] nice to make you reflect” [13]. And another CEO says, “I’ve really enjoyed talking to you. Some of the questions I think ‘Why didn’t I know that?’ … It’s good to stop and reflect isn’t it? … I was really happy to do it [the interview] because I think it’s good to. It’s powerful for me to do it” [4].

Speaking more broadly, another CEO says, “I think one of the issues is there’s no … what is a definition of a hospice in the UK?” [17] and, “There is no discussion; there is no leadership forum that is taking these issues and sharing and debating and discussing. It’s sat in your pocket but it’s not happening in a systematic way” [3]. These and other comments in the study demonstrate a desire from CEOs to discuss together these fundamental questions about the purpose, concepts and future of English hospices.

6.8 Summary

Discussing how hospices are developing, CEOs shared their perspectives on the development of hospices as charities and businesses. With regard to hospices as charities respondents recognised the crucial importance of a vibrant relationship with local people to ensure both effectiveness and economic development. However, they explained that this also brings responsibility and that to maintain it, hospices need to broaden the form of their impact individually and in conjunction with others. Maintaining an effective local impact included the question of whether to maintain in-patient beds in hospices given their limited resources as charities. Here some saw beds as a mainstay but others as an expensive distraction. Similarly, participants viewed collaboration in different ways, from working as part of the local hub to being distinct and on the edge. Within this some expressed concern about a perceived reticence of hospices to commit more fully to joint working but also a sense of being pushed in this direction by HUK and a consequent concern for loss of local identity. Again with regard to hospices as charities, respondents considered the issue of empowerment, including hospices' interaction with the NHS but also in relation to how they operate themselves. This raised questions about the use of volunteers and, significantly, how hospices answer the question, "Who owns death?"

With regard to hospices as businesses, CEOs considered the importance of hospices adopting a hybrid culture that learns from the public, private, charity and community sectors. In terms of a private-sector approach, respondents emphasised the vital need for agility, innovation and diversity of income whilst recognising the tension that acuity and altruism can bring and their consequent economic and ethical implications. In terms of a public-sector mind-set, whilst the need to address end-of-life issues at scale was seen as essential, a number of participants expressed concern about some hospices adopting a narrow focus on NHS funding rather than on their purpose and mission.

Instances of resistance to development raised deeply disturbing issues in hospices that were described as 'toxic' and 'dangerous'. Here issues of purpose, belief, morality and professionalism are seen to collide and good governance is seen as pivotal. In a small number of cases these issues reached extreme proportions with CEOs experiencing death threats. This aspect of hospice development sits in stark contrast to the experiences of patients and families. Finally, respondents spoke about the future of hospices, describing ‘uncertainty’ and ‘peril’ but also the inspiration of their work and values that are bigger than themselves. Some also recognised a need to revisit basic principles and to ask questions about what hospice means in society today.

Chapter Seven: Discussion

7.1 Introduction

In the three results' chapters, I have described the views of hospice chief executives in response to the interview questions. In this chapter I begin by summarising conceptual development in the study. I then use Gergen's application of Greimas's semiotic square[438] to his concept of 'intelligibility nuclei',[419] which I described in Chapter Three, as a device to visualise why hospices are here, what hospices are and how they are developing. Through these examples, I open up the social construction that is within and around hospices and discuss it within the landscape of literature that I described in Chapter Two. I conclude the discussion by using Greimas's device to present a framework for the long-term development of hospices.

7.2 Summary of results

Figure 6 is a summary of conceptual development in the study. This begins with the research question that shaped the approach to the literature and the methodology that then led to the semi-structured interview framework of 'yesterday, today and tomorrow' (See also Figure 3). The green 'literature' boxes in Figure 6 summarise concepts described in Chapters Two and Three and the white boxes flowing from the Interviews show the themes, sub-themes and concepts drawn together from analysis of the empirical data in Chapters Four, Five and Six. Together these inform the discussion and semiotics as shown at the bottom of the diagram. As I explained in Section 3.4.3, my application of semiotics is allied to the approach adopted by Gergen in *Realities and Relationships.*[425]

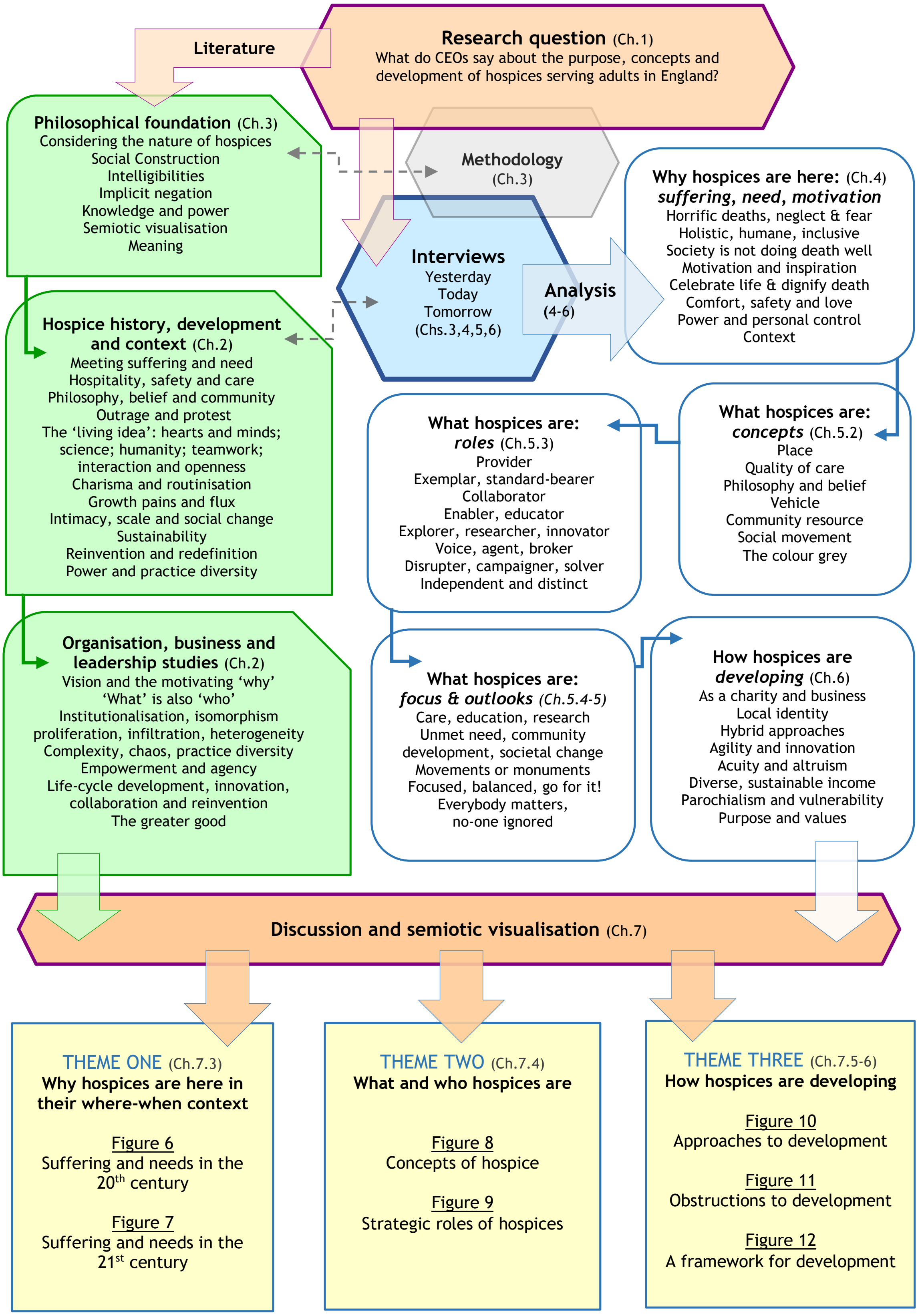

Figure 6 *- Conceptual development in the study*

(Numbers in brackets designate chapters and sections)

7.3 Visualising why hospices are here

The results about why hospices were established in the twentieth century reveal a shared understanding from those respondents with knowledge of that era. Similarly, in terms of why hospices are here today there is a commonality of views about the suffering and needs that people are facing. However, these perspectives still carry tensions that I will now discuss.

From the results, the following two figures visualise suffering and need in the twentieth- (Figure 7) and twenty-first centuries (Figure 8). As I explained in Section 3.4.3, there is a danger of oversimplification if semiotic drawings are not viewed in conjunction with a descriptive commentary. Consequently, the diagrams that follow should be understood in the context of the results described in Chapters Four, Five and Six as well as the reflections offered here in relation to the literature.

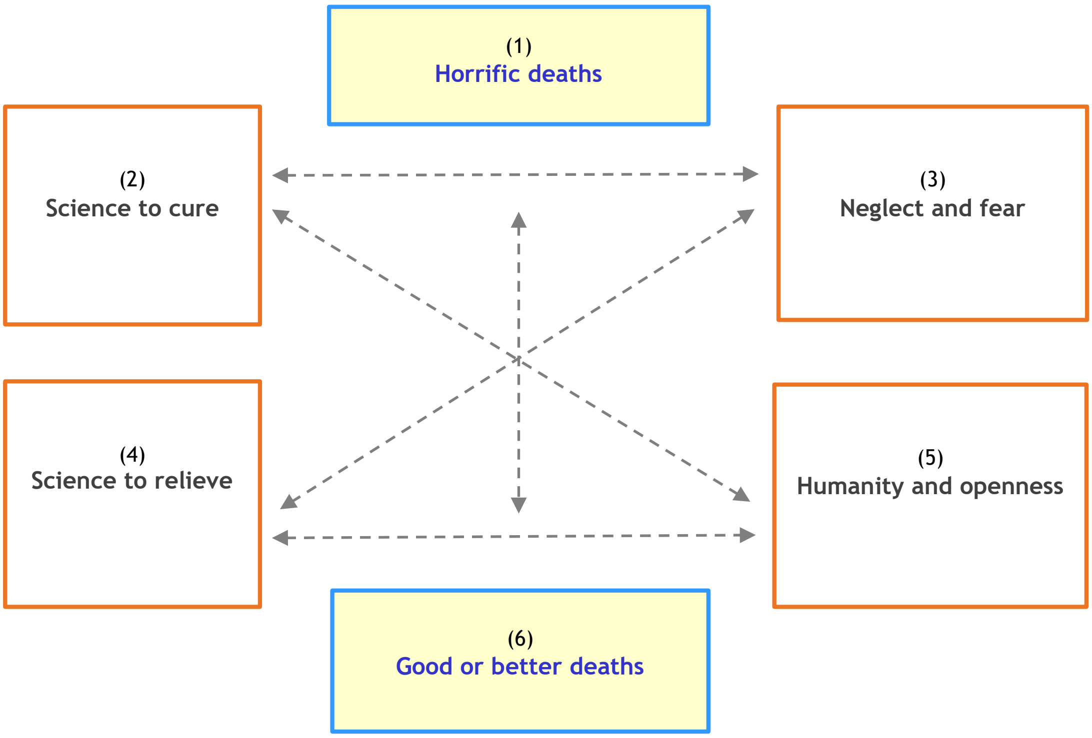

Figure 7: *Suffering and needs in the twentieth century*

In Figure 7, the polar meridian shows the contrast between people suffering horrific deaths, dying in pain and terminal restlessness (Box 1) with the public aspiration for a good death that is intimate, compassionate and meaningful (Box 6).

Tensions in the semiotic such as those between ‘science to cure’ and ‘science to relieve’ and between ‘neglect’ and ‘humanity’ show that, according to Gergen: “As the ontology within the nucleus is established, so are multiple possibilities for its negation”,[425] the nucleus here being those caring for people at the end of life. This creates strain between hospices and organisations that share a different view and amongst the varied perspectives or cultures within hospices themselves. This process of negation may involve formal or informal sanctions of those who do not follow “right thinking”[425] and may include: “Communities sharing in a given system of intelligibility … [trying to isolate themselves] from those who ‘spoil the party’”.[425] Herein lies Gergen’s recognition of the connection between knowledge and power described by Foucault. Thus, the perspectives held by groups that are shown in each Box push, jostle and spar with each other, reducing and strengthening accordingly. For example, ‘openness’ may reduce ‘fear’, and ‘humanity’ may help ‘science to cure’ to be more focused on well-being.

Looking at Figure 7 as a whole, compared to *pre*-twentieth-century hospice literature (Section 2.2.1), there is a greater emphasis on ‘dying and death’ than the broader ‘hospitality’ offered to weary travellers, the sick and impoverished.[62] Some respondents are aware of this, sharing their perspectives of, for example, the ‘hospitile’.[54,63] Similarly, there is a narrower emphasis shown in the semiotic than Mary Aikenhead’s love for the poor and her nuns’ courageous work amongst Dublin’s destitute communities.[54,58] Whilst it could be argued that there is an implicit understanding from hospice history about ‘humanity and openness’ in the semiotic, the twentieth-century shift in focus to the suffering of the ‘dying’, especially in relation to ‘cancer’, is clear.[62,71] Thus, in Gergen’s terms, the broader hospitality of earlier centuries has been ‘negated’ by those concerned about the neglected plight of the dying.

The emphasis on humanity, holism and intimacy is often seen as a major contribution of twentieth-century hospices but whilst seemingly forgotten in the emerging NHS, it had already been espoused by the eminent physician William Osler who expressed concern for the ‘art’ as well as the ‘science’ of medicine and whom Saunders cited.[82] Similarly, twentieth-century nursing manuals reveal an assumption that nurses would know their patients intimately.[96] However, despite discussions in the NHS about multi-disciplinary teams, that hospice pioneers subsequently embrace, power remains firmly in the hands of physicians who determine whether or not a patient should be told they are dying.[97] Thus, death is ‘owned’ by physicians.

In terms of why so many hospices formed in the twentieth century, a semiotic square cannot show every detail described by participants about the Saunders’ era but multiple semiotics could do. For example, another semiotic showing why hospices formed in the twentieth-century might include hospices disassociating themselves from mainstream health’s approach to dying and the rugged will-power of the pioneers to develop something better. According to respondents, the founders’ motivation from painful bedside experiences, inspiration from values greater than their professions, their teamwork and vocation gave them a resilience to withstand criticism that often came from respected sources. These views about motivation, inspiration and criticism, echo with the literature as seen, for example, in Saunders’ letters,[214] James and Field’s paper on the role of charisma,[34] and British Medical Journal articles.[205,217] The dedication of the twentieth-century leaders is similar to the courage of earlier hospice communities, such as the Knights Hospitallers[63] and Sisters of Charity,[71] who risked their lives for the sake of others. However, whilst leadership is important, as Johnson points out, his research shows that the cause is more significant than any individual.[148] Saunders holds a similar view and, as previously stated, cites Victor Frankl, quoting Nietzsche: “He who has a *why* to live can bear with almost any *how*”.[110] This shows the value of constructing layers of semiotics, as both Gergen and Greimas espouse, to produce a richer portrayal of the response to suffering at the end of life in the twentieth century.[428]

Looking to the twenty-first century, Figure 8 visualises respondents’ descriptions of the suffering that people experience today. In the polar meridian, there is an understanding from CEOs that society is still not doing death very well (Box 1) and this lies in tension with the desire of people to celebrate life, dignify death and create good memories to hold onto (Box 6).

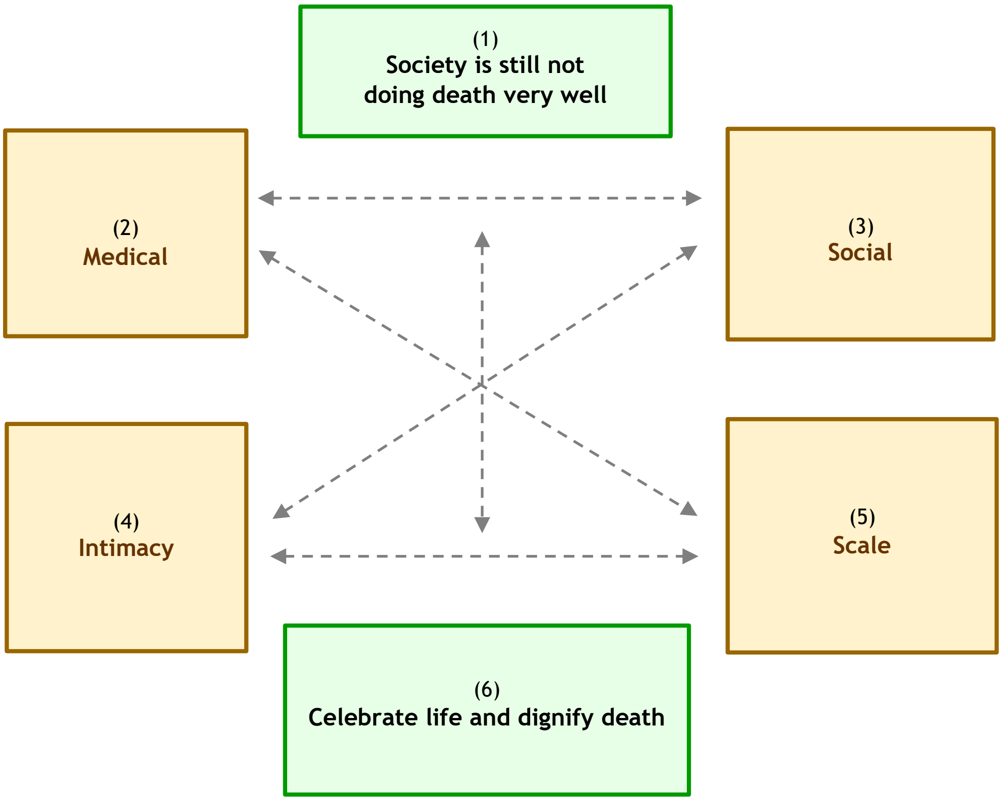

Figure 8 *– Suffering and needs in the twenty-first century*

In Figure 8, tensions such as hospices seeking to fulfil medical as well as social needs are self-evident. Putting Figures 7 and 8 alongside each other, respondents' understanding about the development of suffering and need from yesterday to today can be seen. For example, rather than the language of barbaric treatment and neglect in Figure 7, suffering of all and a concern for known and unknown unmet need are encapsulated within Figure 8.

The descriptions in the interviews of the mission of hospices appear to show a widening aperture beyond the focus on cancer in the twentieth century. However, looking further back in history (Section 2.2.1), the mission has narrowed as hospices moved from their open hospitality for weary travellers and care of the destitute[54] to a specialisation in care at the end of life.[54] Interestingly, the emphasis on the frail elderly which is made by a number of respondents in relation to current need might appear to be new but, as the literature shows, it is raised by Klagsbrun at the *Bar Mitzvah Conference* in 1980, alongside comments from Saunders and others.[21]

There is also a greater emphasis from respondents on personal control, equipping and empowering people, than there was previously. This builds on Clark's 'caring about'[103,228] in the twentieth-century NHS, to Saunders' 'caring for'[119] and a further shift in the twenty-first century to the 'caring with' of HUK's strategic plan[332] and public health approaches.[104,313] However, intimacy in care continues to be squeezed as it was through the march of science in the newborn NHS and the approach of Menzies-Lyth to protect nurses in the 1980s.[306] This became evident when Covid-19 arrived in 2020. During Covid-19, whilst it was seen fit to continue feeding patients and to provide pain relief, for some institutions it was deemed acceptable to deny the oxygen of social contact. For hospices, some enabled visiting throughout the pandemic whilst, according to respondents, others regretted their early restrictions on visiting that, whilst considered against the risk of loss of life,[457] could have been more thought-out in relation to their philosophy, values and infection-prevention options. Naturally, this raises questions about the hospice philosophy of the whole person and the issue of social death.[567,568]

Focusing on why hospices are here today, Figure 8 reflects the challenge and paradoxical tension put forward by Demos for hospices to develop "intimacy at scale"[329] in order to enable more people to have better ways to die. A different semiotic could display their recommendation for a pre-modern emphasis on the need for family and community contact combined with the best that professions and technology can offer.[15] Similarly, the concern to challenge ongoing medicalisation (that is also seen in the literature),[86] including *within* hospices,[89] could be displayed in a semiotic with a different focus. Layered semiotics displaying why hospices are here today would include: the motivation and inspiration of respondents to leave their careers and lead hospices. Like hospice founders, CEOs today express motivation from personal experiences of poor deaths. However, at least one participant laments the loss of the self-sacrificing vocation of the pioneers.[58] Multiple semiotics would also show the issue of today's NHS and social care system facing overwhelming pressures that, according to a Marie Curie report referred to in the literature,[398] leaves people at the end of life more vulnerable than ever. This was at its most obvious during the pandemic[398,399] but continues today,[400,401] making the need for good quality care and support all the more imperative. These pressures are also evident in the ongoing political debates about the NHS being under pressure, strikes of NHS staff and the scale of the NHS Long Term Workforce Plan, 2023.[569] Within this discussion, Sir Keir Starmer, Leader of the Labour Party, draws a distinction between those who see the NHS as a ‘cost’ and those who see it as a ‘cause’.[570] This recognition of the importance of philosophy and belief in relation to why good national healthcare is needed, chimes with Saunders’ emphasis on not just “*how* we do things but also *why* we do them”, and her oft-quoted “truth of the mind and truth of the heart”.[1] The importance of ‘why’ is also seen in organisation studies with Bass and Riggio arguing that successful leaders build emotional commitment through values and beliefs[139] and, similarly, Sinek states that people invest in organisations that excite the human spirit and inspire people to become involved in a cause.[138] According to many respondents in this study, hospices are here not just because they provide good quality care but also because people believe in their purpose.

Thus, for hospices, as well as the contextual shifts from the twentieth to the twenty-first century, there are inherent tensions to work with as they seek to meet the array of suffering and need that shows why they are here today. Figures 7 and 8 demonstrate that these productive tensions are, in Gergen’s terms, ‘more than binary’ and point to a bigger picture. These drawings are examples that others can build on using this device to develop a more magnified picture of responses to suffering and needs at the end of life. This in turn can help hospices to understand in more detail why they are here. Put together, multiple semiotics have the potential to show the multidimensional structures in which hospices operate: the implicit negation and broader horizon that Gergen points to[44] and the opportunity of heterogeneity that Schneiberg espouses.[268] In short, multiple semiotics build multidimensional pictures.

7.4 Visualising what and who hospices are

In this section I discuss results in relation to Theme Two. I begin with the foundations upon which all else stands, the hospice concept, or, in terms of Gergen’s intelligibilities, the ideas from which all else flows. Hence, I have given the most attention to this semiotic.

The results show seven concepts of hospice: a place; a quality of care; a philosophy and belief; a vehicle; a community resource; a social movement; and the colour grey. These are shown in Figure 9.

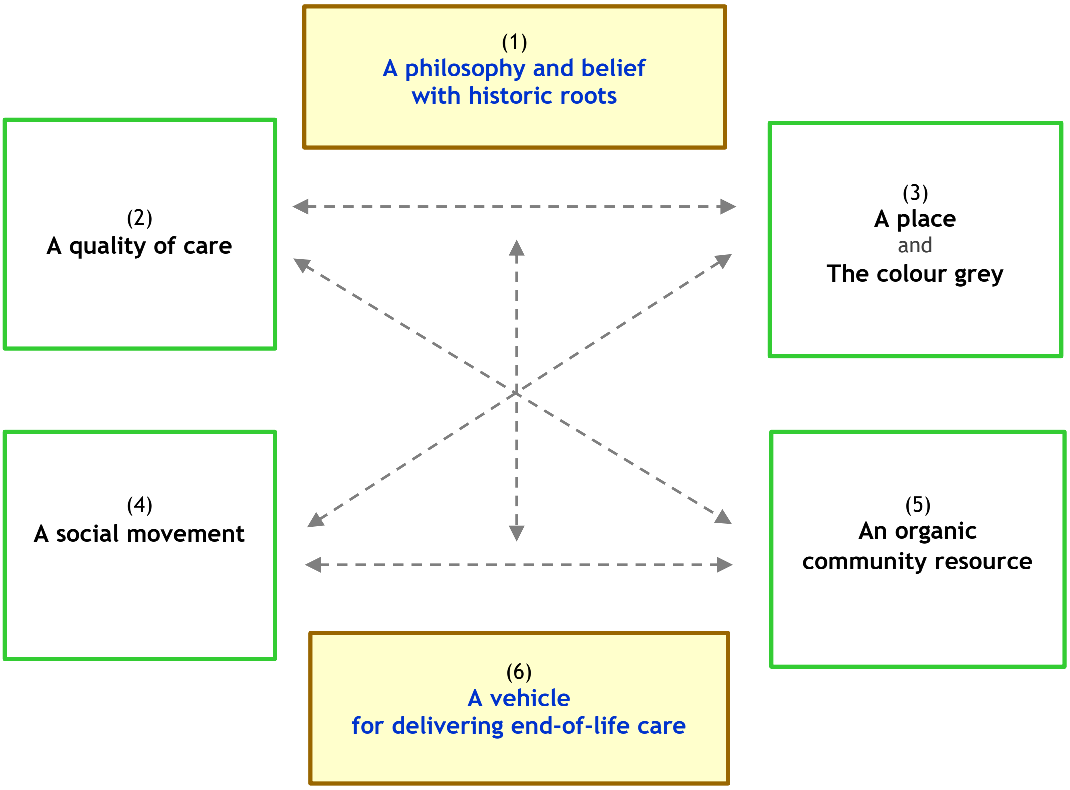

***Figure 9** - Concepts of hospice*

In this square, I have selected philosophy and belief (Box 1) and a vehicle (Box 6) as a significant tension between intelligibility nuclei in the polar meridian. In fact, one respondent who says that ‘hospice’ is a vehicle adds weight to the differentiation by saying explicitly that ‘hospice’ is *not* a philosophy. This echoes with Gergen’s multiple possibilities for negation that activate the binaries[425] which is the case here, where there are contrasts between all the boxes in the semiotic.

I begin this discussion with hospice as a ‘quality of care’. It is described by respondents as being holistic, personalised and intimate with love at its heart, standing against the more objective view of twentieth-century medicine in the NHS. These views align with the literature; for example, Twycross speaks of rebalancing cure, relief and comfort[120] and Young of hospices caring for the person before the disease and the importance of humanisation (rather than depersonalisation) in all aspects of medicine.[216] Hence Saunders said: “Dying people need … a doctor who will see them as another person”.[204] Similarly, like Clark[214] and Barnard,[20,23] respondents recognise the holism of ‘total pain’ within the hospice idea although discussion about lack of definition and the potential for 'reduction', considered by Klagsbrun[21] and more recently Wood,[23] are not raised by respondents except perhaps in terms of medicalisation and conflicts with physicians.

Another concern about reduction in the concept of hospice as a 'quality of care', is raised by Demos which says hospices are "in danger of becoming niche providers of specialist services within the system they set out to change",[325] a warning which is repeated by The Commission.[343] This perhaps comes through a shift in focus from 'hospice' to 'hospice care' and a drift away from the aspirations of a social movement:[239] hence Moore's question about whether hospices are focused on care or the greater good.[144] In addition, a further concern expressed by some respondents, that is not obvious in the literature, is that hospices cannot assume that their care is high quality, with examples of poor quality cited from personal experience. This links to Lewis's warning that hospices should not fall into the conceit of élitism.[237]

This change in terminology can be seen when Help the Hospices (HtH) established the Commission into the Future of Hospice Care, 2011-13. Its work was well received by many hospices but was criticised for giving limited attention to the role of social professions[571] and for not recognising that the sector is "a loose and baggy monster in which there are more differences than commonalities", a view supported by Ashcroft.[359] The transition from the 'living idea' of hospice at the 1981 conference[1,26] to the more neatly packaged 'hospice care' in the Commission reports, could be seen as a step away from the broader heritage of 'hospice'. This becomes more apparent in the HUK Future Vision Programme, 2020[391] that, whilst recognising that "a one size solution simply won't work",[572] changes its emphasis in terminology from 'hospice care' to 'palliative care' and offers no significant place for conceptual thinking about the philosophical foundations upon which all else stands.

According to respondents, hospice as a 'philosophy and belief' points to something that incorporates hospice care but is also about culture, ethos, human value and a belief that, as the literature shows, has its roots in the history and heritage of the Hospice Movement.[54,56] In this concept, hospice is a way of life that is all about people, an openness to speak about dying and death and a belief system about living well to the end. As such, one respondent talks about hospice being something you have to experience and feel. Hospice as a philosophy and belief brings a feeling of transcendent quality and meaningfulness that one CEO describes as an atmosphere of “hospiceness”, saying that we work in hospices because “something sings to us” [5].

Contextualising this contrast between hospice as a quality of care and hospice as a philosophy, Saunders speaks of people believing in their shared purpose and values.[170] She sees hospice as a living idea[26] with historic meaning, a founding philosophy which, like all philosophies, holds inherent tensions to be utilised positively through their coexistence.[1] In this respect, Klagsbrun expresses concern that the hospice idea does not become reduced to pain management because it is about people, feelings, interaction, openness[573] and a dimension greater than the individual and the self.[21] Hence, Lamerton talks of a ‘bigger idea’ that looks beyond the body as a reservoir for stowing medicines[574] and recognises the philosophy of the love of giving and caring, and that embodies a rare combination of spirituality and medicine.[30] Similarly, Moore speaks of hospices having ancient roots and being so much more than providers of healthcare.[144] This contrast between hospice as a philosophy and a quality of care is echoed by respondents, as I have said, who say that hospice is driven by a set of values that are greater than itself.

In organisation studies, Collins emphasises the importance of great companies getting the right highly motivated people ‘on the bus’ because ‘who’ determines what an organisation is. He argues that the purpose, philosophy and values of a company are foundation-stones that determine how well a business functions.[157] Hence, in Saunders’ *The Scheme* for St Christopher’s Hospice she says that she sought people with the appropriate clinical skills who *also* loved and believed in their shared endeavours.[163,573] More recently, hospice as a philosophy is espoused by Hartley,[209] O’Leary and Richardson,[11] the former asking if hospices are moving from: “[the philosophy of] you matter because you are you [to the] … cosy ambiance of routinization”,[209] and the latter posing the questions: “Is hospice dead? [and] How do we ensure it lives on with real impact?”[575] Considering this in Gergen’s language of social construction and semiotics, ‘hospice as a philosophy’ appears to be being ‘negated’ and squeezed by other ideas as the workforce changes over time and the presentations of Hartley, O'Leary and Richardson are examples of reactions that push back.

In the concept of 'hospice as a place', respondents talk about a place of welcome, hospitality and safety for all. The work of the first hospices involved medical care but its hospitality was broader, based on the philosophy of: "I was a stranger and you invited me in … I was sick and you looked after me".[53-55] This was Dr Barrett's "person in need".[564,576] For proto-hospices[71] this included a place or building where, for example, Davidson offered warm, homely surroundings full of kindness.[74] Similarly, Saunders wants St Christopher's Hospice to feel welcoming, comfortable and secure in order that the body can find a restful place to be.[36] This emphasis on a 'safe haven' is reflected in the study; it may, of course, be in a variety of places, including a person's home. As I have shown, it is a fallacy to think that early hospices were all about buildings as the Sisters of Charity aptly demonstrated working amongst Dublin's cramped population.[55,71] Similarly, in 1973, Lamerton wrote: "The simple caring embodied in the hospice movement will be needed *wherever* and *whenever* there is a human race".[59]

However, participants in the study also say that sometimes hospice as a place is identified with buildings. They say that buildings are something that communities associate with and can act as a magnet for generating income. Buildings can accommodate complex care that cannot be replicated at home and, for some interviewees, they are fundamental. In contrast, other participants argue that buildings can become status symbols (quoting Clark's 'citadels')[71] and that moving into buildings was a mistake because they drain funding and consequently reduce the number of people that can be cared for. With regard to buildings becoming a financial burden, following the 'Wilkes Report',[247] Saunders commented: "We want to spread care and too many buildings might stand in the way of doing that".[250] However, if hospice in-patient units are closed, respondents ask whether the NHS would provide suitable alternatives and whether hospices would attract as much income as they do currently to help people at home.

Saunders took great care over her building design, working with the respected architect Peter Smith to create a family atmosphere that was away from NHS influences.[181] A respondent takes this one step further, suggesting an innovative approach to make hospice buildings even more familiar by integrating them with other day-to-day activities such as a café and gallery. Following the work of the Commission, the literature points to other hospices adopting a similar approach.[533] However, as I have shown, the concept of 'place' is not necessarily associated with buildings and, of course, some hospices do not have buildings in which care is provided.[112,537] Ultimately the concept of 'place', in the literature and this study, is about making: "The patient's body a comfortable enough place to live in",[134] *wherever* that place might be.

According to respondents, hospice is also a place to do things creatively and differently, to improve and think beyond government narratives. Education, innovation and research are hallmarks of St Christopher's, ones that Broome argues are keys to hospice proliferation in that era.[74] However, as some respondents in the study show, there is concern today that research and innovation in hospices are perilous, a point which was highlighted by the Commission.[355] An example of this is the 'home hospice' concept suggested by Demos[324,577] facing resistance from clinicians when introduced in practice. This challenge asks the question, "Who owns death?" [12] raised by a respondent, by Taylor in the literature,[300] by Sallnow[313] and by the writers of the Lancet Commission Report on the Value of Death.[191] As with innovations by twentieth-century hospices, it comes as no surprise that twenty-first century innovations face opposition from those who feel their power being eroded. Hence, it is another example of the dynamic shown by Foucault between knowledge and power that Gergen espouses[425,578] and portrays in semiotics.[420]

In relation to this idea of innovation and doing things differently, one respondent in the study describes hospice as the colour "grey" (Section 5.2.7). This is understood as "the bit in the middle", a way of working that is not "healthcare with a red line round it" or one that is caught up in mainstream bureaucracy. It is about having the flexibility to be genuinely person-centred. This connects with the concepts of hospice as a 'place', as a 'community resource' and as a 'social movement' because it is about doing things differently, being different and making a difference. It links with comments by those in the study who stress the importance of hospices being independent and distinct in their endeavours. For one CEO, this is about being ambidextrous: agile on the one hand and anchored to the deep philosophical and social values of 'hospice' on the other. In the literature, this concept resonates with, for example, Young's view that hospices reach into those grey areas neglected by conventional services,[216] Kinnock's that hospices offer a new dimension[239] and Owen's that hospices pioneer, innovate and take a lead.[241]

In contrast again, 'hospice' is described as a 'community resource', depicted by one participant as a repository of everything around dying, death and bereavement. This is an organic living community hub that enables, equips and empowers. For the pioneers, 'hospice' includes the organism of community which is an energy source for all that they do. This is described pejoratively by Ahmedzai as Saunders' religious enclave.[205] However, for Saunders: "Hospice means a team or a community … doing hospice work[184]… [and] … [St Christopher's is a] community of the unlike"[180] that includes people with different religious affiliations and non-affiliations and a shared commitment to the cause of the dying.[180] In the twentieth-century, Saunders preferred the power of community, multi-disciplinary teams, openness and the religious-medical or science-spirituality tension to the prevailing medicalisation, depersonalisation and institutionalisation of the NHS.[56,179]

Here in the semiotic, the concept of a community resource is for *all*, whoever and wherever they are and it is a latent energy to be called upon. Klagsbrun sums up this symbiosis saying: "The care of the dying is the care of all of us … in a way it is the dying who are giving us a much better awareness of the gift of life".[218] In social construction, Gergen says: "To participate in the intelligibility nucleus is to 'make sense' by the standards of a particular community".[411] In organisation studies, Reed observes the importance that is often given to a sense of community and willingness based on shared values.[38] Similarly, Handy emphasises the value that successful entrepreneurs place on creating a work environment that "feels like a family".[579] Interestingly, St Christopher's recent living history project shows how a hospice community is still valued today. Their report offers: "A new ecological map that describes the relationship between the hospice and people's physical, interpersonal, health and wellbeing".[403] Here the hospice is seen as an organic resource that people contribute to and call upon during their different life stages.

The concept of hospice as a 'social movement' is primarily outward looking: a group of people who champion a cause together facing the challenges that come to society.[542] Here, respondents say that 'hospice' reminds society of human value and amplifies the voices of people you cannot hear. As Saunders puts it: "A society which shuns the dying must have an incomplete philosophy".[102] This society-wide perspective identified by Moore's greater good[144] is mirrored by participants in this study who referred to Raworth who urges companies to look beyond the economics of growth and profit to humanity's shared long-term goals.[160] From this perspective, hospices have a broad social responsibility. In this regard, some respondents say that there is no longer a preparedness to be "disruptive"; there is "no call to arms" and "no fires burning under seats" which contrasts sharply with the pioneers who "put death and dying on the big stage". This is perhaps why a number of interviewees say: "There is no Hospice Movement [any more]". Finally, in Figure 9, hospice is described as a 'vehicle' and this is usually (but not always) combined with other concepts.

For respondents, the concepts of hospice shown in the semiotic are philosophical, scientific, situational, social and pragmatic revealing a broad diversity of views. The application of these concepts can be seen in the roles that respondents see hospices undertaking. These are displayed in Figure 10 below:

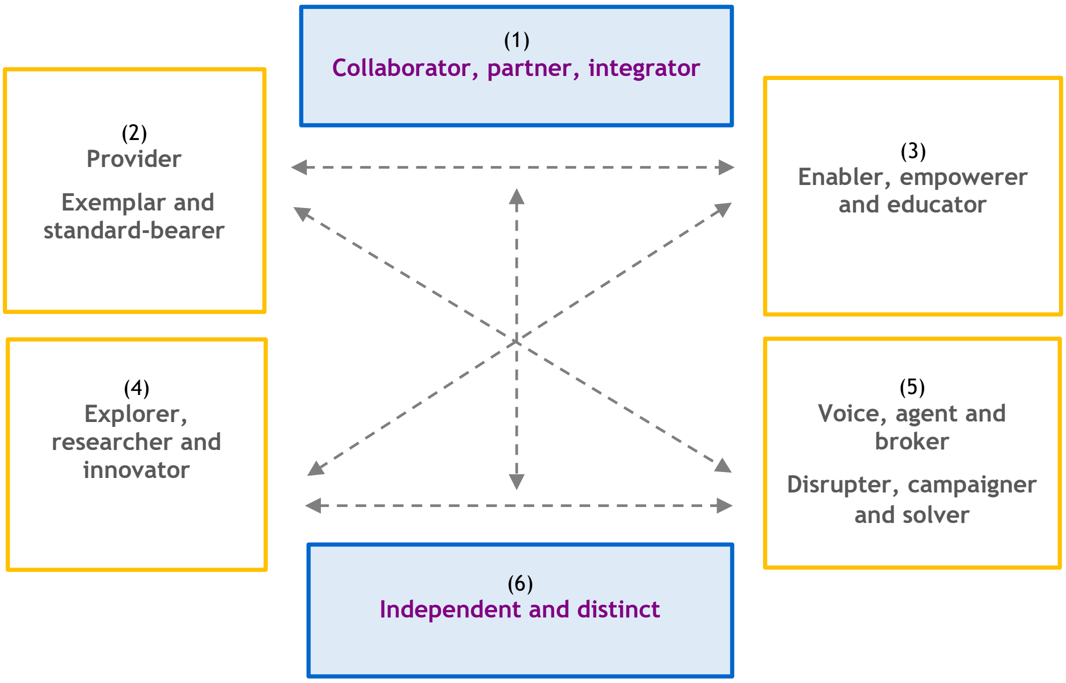

***Figure 10** - Strategic roles of hospices*

The most obvious observation here is that CEOs perceive hospices having many more roles than that of a ‘provider of care’ for people near and at the end of life. Whilst the language is not always the same, all these roles are reflected in the twentieth-century literature. Thus, for example, Wilkes speaks about the benefits of integration,[247] Kinnock about the value of hospice independence and partnerships,[239] Twycross about protest and Saunders develops education and research alongside the care that St Christopher’s provided.[132]

In that era, discussions about hospice roles created energetic debate: hence Saunders calls for openness, a readiness to ask new questions and a preparedness to co-exist.[1] By the time of the Commission, most of these roles continue to be discussed but with less emphasis on hospices as campaigners and disrupters.[343] As with hospice concepts, the roles in Figure 10 raise questions about whom hospices represent and are focused on. Consequently, there is reference to Agency Theory and conflicts of interest by respondents.[140] So, for example, when income is stretched, hospices might be worried about criticising the proverbial hand that feeds a significant percentage of their annual income.[4] Although interestingly, one respondent says that hospices could prepare themselves for life without government income and still do a great job.

In the semiotic, as well as tensions between the roles there are also tensions *within* the roles. For example, respondents present contrasting approaches to collaboration: some aspire to being in a position of coordination at the heart of the system whilst others think that hospices should be distinct and on the edge. These differences can be fundamental and track back to a hospice’s conceptual view of itself. So, whilst all respondents recognise the importance of collaboration and integrated working there is a kaleidoscope of views with regard to how this might happen in practice. Furthermore, whilst the stresses between the boxes in the semiotics are to be expected (as Gergen explains) this does not mean that they are necessarily incompatible. For example, being ‘independent’ does not deny the possibility of ‘collaboration’, and being ‘a partly NHS funded provider’ does not prevent a hospice from being a ‘broker’ between communities and mainstream health and social care.

It is also evident that, depending upon which concept or idea a hospice upholds, its emphasis on respective roles will vary. For example, where ‘hospice’ is seen as a ‘quality of care’ it is less likely to give attention to its role as a disrupter and campaigner than where hospice is understood as a 'social movement'. Similarly, where hospice is depicted as 'grey or a place that does things differently', it is more likely to recognise its role as an 'explorer and innovator' in the pursuit of excellence than where hospice is seen simply as a 'vehicle' to deliver care.

What is critical to many participants is the capability (or incapability) of a hospice to achieve its mission. Put another way, can *what* a hospice 'is' be capable of delivering its response to *why* it is here? Hence, a respondent describes listening to Leadbeater's presentation at the 2010 HtH Conference[328] and suddenly realising that the way their hospice was working could never deliver their aspirations. This led to a reprioritising of roles with a reduced emphasis on 'providing' care and an increased focus on 'equipping' people. It was a shift from a service-focused approach to an empowering one. In terms of the semiotic (Figure 10), this example is a reminder of the importance of commentary because the drawing gives no indication of emphasis.[483]

The variety of roles and different emphases amongst participants reveals, once again, the energy of difference in the sector. From Woodward-Carlton's perspective, a major tension for hospices is between the attraction of 'integration' (that he sees being linked to funding, legitimacy, scale and status enhancement) and that of 'independence' (that seeks to protect the values that hospices set out to introduce and could easily be squeezed in a cost-saving bureaucracy).[172] Hence, this points to the criticism from some respondents about the quality of care in fully-integrated NHS hospices. Reflecting on the importance of independence, Woodward-Carlton quotes McAdam who warns against movements being tamed by the purse strings of external sponsors, losing their idealism and critical force.[266] This resonates with the routinisation that James and Field point to.[34] However, in this regard a number of respondents express the importance of hospices being proactive. They argue that, rather than simply pointing to problems with public services, hospices should seek to be the solution. For this reason, alongside 'campaigner' and 'disrupter', 'solver' is included in the semiotic. This, of course, has been the approach adopted by hospice pioneers since the Middle Ages.[56] They see a problem and their protest or corrective[204] is demonstrating how to fix it, whether it be for distressed travellers,[62] the destitute dying in squalour,[580] or patients lying in misery not being told that they are dying.[96,97,179]

The results in Theme Two show many differences and tensions amongst the various ‘concepts’ and ‘roles’ of hospices that participants in this study present. In their application they subsequently lead to varying emphases in ‘focus’ and ‘outlook’. In this regard, an attraction of semiotic squares is that their visualisation provokes discussion about what goes into each Box, how they relate to each other, where the emphases may lie and what is missing. For Gergen, this leads to a search for meaning but, as he states: “Nowhere in semiotics is the sense of uncertainty more obvious and profound than in relation to meaning”.[420] It is perhaps partly because of this uncertainty and the difficulty of finding meaning that these conceptual discussions have drifted from national debates.

7.5 Visualising how hospices are developing

In this section, I consider approaches to development and then obstructions to development. In the study respondents speak about the value of adopting a hybrid approach to development that involves learning from and engaging with different sectors. In sharp contrast to this CEOs also see some hospice leaders adopting a singular approach. These various approaches are shown in Figure 11.

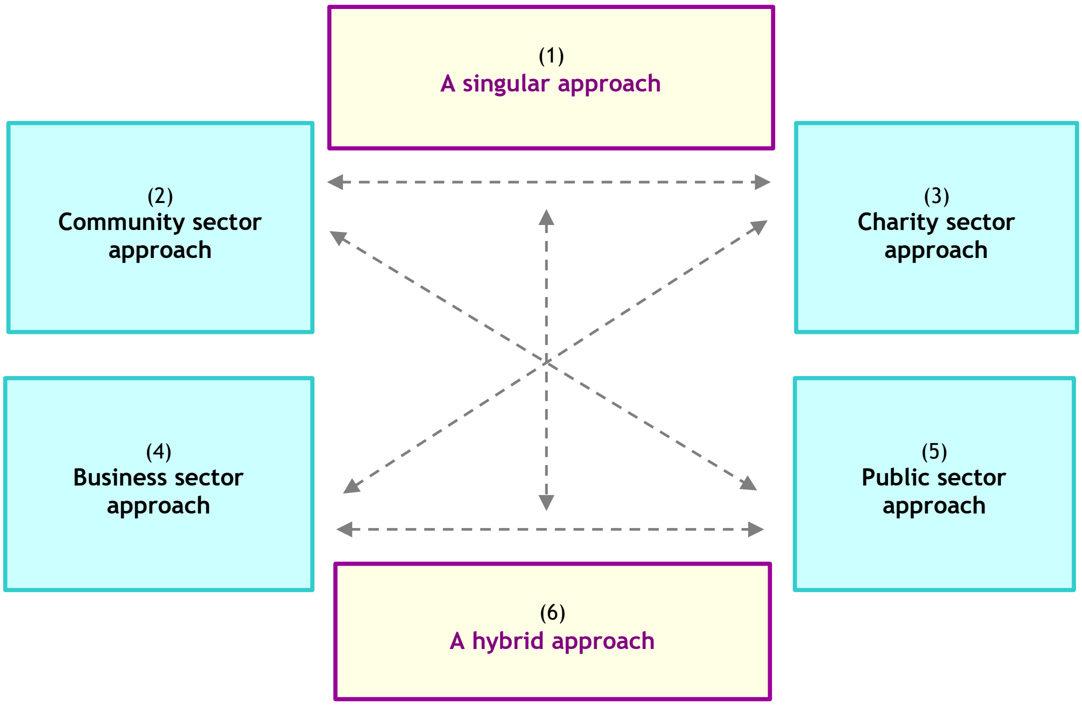

Figure 11 *– Approaches to development*

The polar meridian displays the difference or tension between those who adopt a singular approach (Box 1), for example, by operating primarily as a charity or like the NHS, and those who seek a hybrid approach which combines various models (Box 6). The nature of these approaches is, of course, debateable but they offer a window to view and consider hospice development that I will now discuss.

In Theme Three, respondents describe hospice development as a 'charity' and as a 'business'. As I have shown, according to Clark, the word 'hospice' is associated with faith communities and charitable endeavour that the phrase 'palliative care' sought to detach from.[258] As a consequence, what has perhaps received less attention in recent years, is hospices' recognition of their charity sector strengths, that motivation for a cause driven by inspiration and values greater than itself that has perhaps been their golden ticket to success. This can be seen in Saunders' decision to step away from mainstream services in order to create a better way of caring for people near the end of life.[1,34] In doing so she seeks people with passion and commitment.[107] Through the creation of St Christopher's and its multifaceted approach, Saunders finds inspiration and discovers new insights that can be fed back into the NHS.[56,581]

Thus, it may be the case, that when Mount, for sound linguistic reasons in French Canada,[257] felt that he had to look beyond 'hospice' in his terminology and move to the term 'palliative care' he perhaps unintentionally muffled the heartbeat of what had brought dying and death into the limelight in England. Whether the drift away from the term 'hospice' has been critical or not is another matter. The point here is that in the development of hospices the causal drive, with its underpinning altruistic philosophy, symptomatic of the charitable sector and social movements,[541] sits within a semiotic with all the negations[44] (and attractions) that other elements create. Hence, a number of interviewees express concern that some hospice leaders seem to have moved away from their original purpose and are now singularly focused on drawing more funding from the NHS as their only route to economic sustainability. In other words, the public sector influence is seen to be 'negating' the charitable one.

An example of this can be seen in the University of Warwick's post-Covid-19 interviews with hospice managers who speak of financial sustainability in terms of improved long-term funding for hospices as a core part of the health and care system.[395] This sits in stark contrast to Saunders' belief-driven approach of: "We can relieve suffering if we put our minds and hearts to it. It is just because so few people do, that pathetic cases exist”.[582] Naturally, over time a hospice’s purpose and mission will develop for a variety of reasons. In the context of this discussion, issues for respondents include: ‘What is influencing that development?’, ‘What difference will it make?’ and ‘What might it mean for society in the long-term?’

Another important component of hospices’ charity sector approach, described by interviewees, is their ‘local’ focus. In Figure 11, this sits in tension with the national focus of mainstream health and social care (despite the latter’s attempts to be more geographically relevant in its strategies). In the study, respondents describe the personal association that many supporters make with hospices. They often describe them intimately as “*my* charity”. However, for hospices this also brings local scrutiny. Hospices have to stay relevant locally and meet the needs of their volunteers and donors. Consequently, there is a perceived need for hospices to broaden their impact beyond the provision of beds, including through working with others, so that *more* people receive *some* elements of hospice care which is in tune with their milieu, as Kubiac argues.[88] According to participants, this localism and personalisation must be closely guarded which can be challenging to achieve sometimes, especially when it clashes with national requirements. As the literature shows, debates about local development, independence and integration have continued since the twentieth century.[247,250] Participants also recognise that being a charity has limitations, not least in the capacity of communities to support them. As Owen points out, whilst hospices may work with the public sector, they cannot have the same capacity as the NHS.[241] Thus, in terms of hospice development, the strengths and weaknesses of a charitable approach need to be understood.

Moving on from charity-public sector approaches, respondents recognise the importance of development as a business, in keeping with the call from the Commission for hospices to be more businesslike.[343] This relates to economic sustainability and the need for more diverse sources of income as well as learning from the acuity of business and its cyclical process of reinvention. As a number of CEOs point out, Handy’s second curve[40] needs to be taken heed of, where, like Greiner’s model,[154] organisations are seen to go through cycles of development that if ignored are likely to lead to a downward curve in impact and viability. This may also include a preparedness to ‘de-couple’ and step into entirely new projects that are free from the negative constraints of hospice development and institutionalisation,[271,583] hence the argument for hospices to reimagine their vision and how they approach it. To achieve this, some participants suggest that hospices learn from the business sector, which, whilst it does not have a monopoly on creativity, often demonstrates an ability to break the mould of "that will never work".[41]

Finally, in terms of approaches to development, participants speak of community sector approaches, making reference to public health, Compassionate Communities and Death Doulas. This raises questions about community focus and what that means for hospices but also about issues of scale and how far service orientated delivery in end-of-life care can go compared to delivery focused on community and family empowerment. In fact, more than one respondent in the study considers that significant improvements in end-of-life living, dying and death will not take place in England until tangible shifts in power from professionals to people take place, a view echoed by Gale and Hodges.[271,360] In this regard, a concern raised by a respondent is also made by Sawyer et al., that community sector approaches do not become formulaic because it is their inherent energy and sometimes chaotic nature that gives them vibrancy.[379] This lack of definition, that can sometimes be interpreted as ineffectiveness, is perhaps why the value of approaches emanating from communities sometimes receives lukewarm reception from participants in this study and elsewhere.[379]

However, other respondents applaud such endeavours, recognising practice diversity and the value of de-coupling from traditionally institutionalised mainstream and hospice approaches. Thus, looking backwards, Sawyer et al.'s embracing of tensions and diverse philosophies appears to reflect Saunders' coexistence of opposites.[1] Looking forwards, these endeavours relate to the flux in Baron's river,[61] Schneiberg's heterogeneity,[268] and figuratively to the dynamic map of an end-of-life system in the Lancet Commission report on the Value of Death that, like weather charts, vividly displays the intricacies, tensions and dynamics that hospices respond to and engage with in the field.[382] This outlook explains the importance that is given by some participants in this study for hospice leaders to recognise the complexity and chaos that is around them and to adopt flexible approaches accordingly.

Moving on to consider ‘obstructions’ to hospice development, Figure 12 shows some of the issues raised by participants in the study. The polar meridian displays tensions between hospices that are ‘stagnating’ (Box 1) and those that are ‘developing’ (Box 6). According to respondents, the former is associated with those that become isolated or are in such awe of the pioneers that they do not change anything. Such a position recalls Twycross’s concern that the hospice movement does not become a ‘monument’, a point that Hartley reinforces.[366] In the literature, Baron writes of sub-cultures developing in hospices that become inordinately resistant and almost unchallengeable,[255] as examined by Harmer and Speck. Harmer writes of one group being seen to be “tearing the heart out of a hospice” whilst another is seen as “a group of romantics whose time has passed”.[290] Within these cultures, Speck’s ‘chronic-niceness’ may develop amongst hospice staff with ‘an only we know best attitude’ becoming a defence against the day-to-day emotion of working with dying people.[296]

This negative internal friction can damage the development of a hospice and, according to respondents, may emerge as a result of poor leadership and governance. It may involve an organisation becoming detached from its purpose and values, leadership being helplessly tolerant and board members colluding in poor practice. In the literature, this also relates to clashes between amateurism and professionalism and whether the latter squeezes the life out of a charitable endeavour or the former allows levels of informality that result in the chaos of an organisation pulling in different directions.[74] As McVey[274] and Baron[255] point out, there are many cultures within hospices just as there are competing professional perspectives. Consequently, hospice leaders and boards need to understand them, the flux that they generate and how they can facilitate harmonious and effective development going forward.

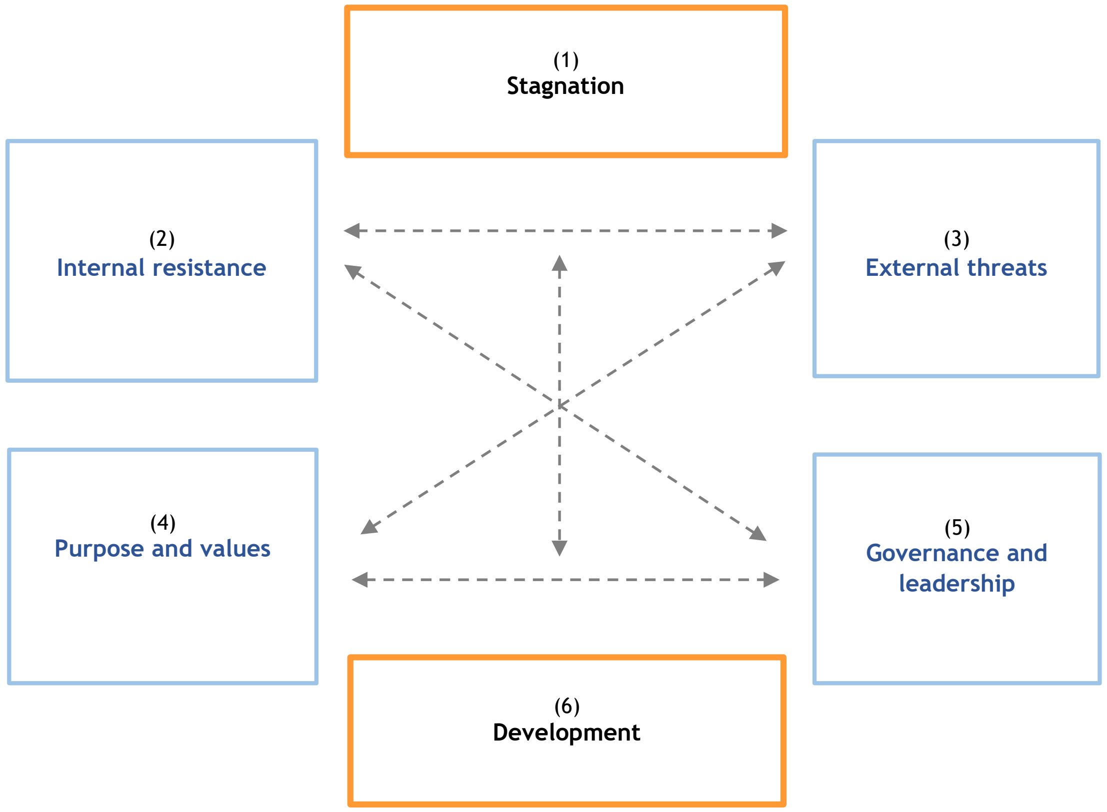

***Figure 12** – Obstructions to development*

Poor leadership and governance can also make hospices vulnerable to external fraudulent activity that not only stops progress but has the potential to seriously damage a hospice's hard-earned reputation.[303,304] In cases described in this study, this can include self-serving individuals identifying a hospice as a weak organisation and then seeking employment in order to make personal gain. According to Duncan, poor leadership can also lead to incompetent business development[331,394] that, as a consequence, threatens the viability of the hospice. This shows the importance of the emphasis that HUK lays on supporting good leadership and governance in hospices.[584] Other external threats include the influences of other organisations as already described in the study. According to participants, these are more likely to be detrimental where an organisation has no clear purpose or direction.

Finally, as the results show, the tensions in this semiotic resulted in some respondents facing 'death threats'. This will come as a shock to many because the experience of most people is that hospices are compassionate and caring environments. As such, this finding acts as a reminder to boards of trustees to follow the rules of good governance[584] and to adhere to the Seven Principles of Public Life (Nolan Principles).[585] The responses in this study make clear that deep feelings are generated around the hospice cause that boards must be aware of and treat with the highest respect, diligence and care.

7.6 Reimagining where hospices are heading

So far as the future is concerned, respondents feel that there are tough and challenging times ahead partly because of national issues such as an uncertain national economy, competition from other charities and ever-increasing regulatory requirements, but also in relation to the natural shake-out of any organisational life-cycle over time. This requires hospices to keep reviewing their purpose and development. Of course, this is nothing new. Over the lifetime of modern hospices in England there have been many calls to rethink, revise and reinvent from Demos,[586] the Commission[16] and the likes of Richardson,[11] Hartley,[209] Gale[360] and Sallnow[313] as well as Lamerton,[30] Klagsbrun,[21] James,[36] Clark,[35] Twycross[366] and Saunders with her “hospice as a Bridge Builder … [and] … the new directions we are looking at”.[587,588]

As hospices seek out their way forward, respondents also say that leaders will need to be resilient, bold and courageous. These qualities have been shown by so many hospice pioneers down the centuries like Fabiola, Aikenhead, Davidson and Saunders.[63,64,71] Thus, participants speak of the fearless hospice spirit and that hospices are driven by philosophy, values and belief. Practically, this involves staying relevant, working in the right way with new generations, being at the heartbeat of communities, more trusting of peers and recognising that being distinct is as important as working together. Respondents also talk of a need to step back and reflect on fundamental issues together and to consider what end of life in this country could and should look like.

Kipling’s six wise friends[2] offer a helpful summation of the empirical findings in the study and Gergen’s semiotic application offers an appropriate framework to visualise and consider them and the future (social) construction of hospices. Since this framework can be applied more widely, Figure 13 is written in the plural first person to indicate the perspective of a ‘hospice’, ‘business’ or ‘organisation’. The six questions sit in natural tension with each other and the polar meridian is between an organisation's 'why' or reason for being here (Box 1) and 'how' it develops effectively (Box 6).

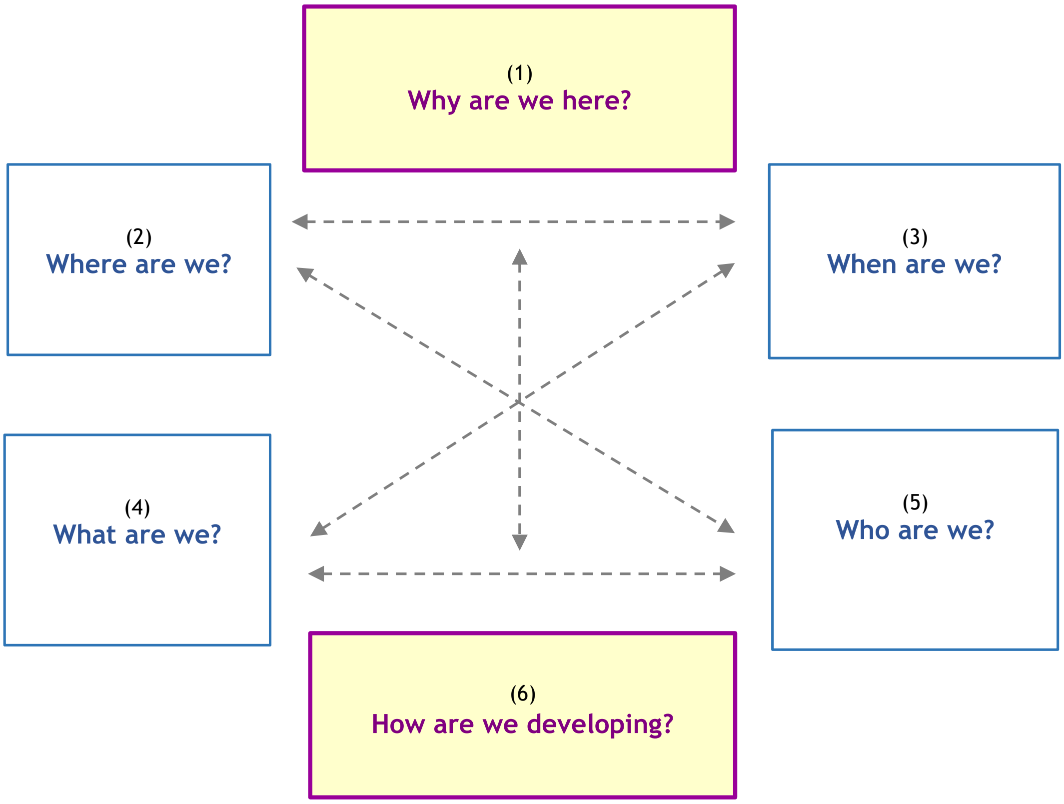

Figure 13 *– A framework for development*

From an organisation and leadership studies' perspective, the tensions of 'why-where-when' and 'what-who-how' are important, as shown in the statement from Dougherty in *The Sage Handbook of Organization Studies*: "People working on successful innovation know what their jobs are, who they work with and how, to whom they report, what the priorities are and how their activities fit with those of the enterprise as a whole".[39] Thus, a company's performance depends on its understood purpose, its idea about how to solve a problem and who is involved in doing so, as well as how they go about it.

The upper horizontal meridian shows the influences of location and time that affect why an organisation is here (Boxes 2 and 3). For example, as Figures 7 and 8 show, the context of suffering and need near the end of life changed over the intervening 50 years. In this regard, respondents in the study express concern that some hospices have become set in aspic, solidified by the aura of the pioneers. Consequently, participants speak of the importance of maintaining hospice values, being relevant to local needs and being open to new ways of working. This is what Saunders did. Learning and listening from those who came before her, she adapted various models from proto-hospices[74,167] and created a new one that combined the inspirational energy of community and team working with new knowledge in medical science.[31] From a leadership and biographical perspective, Clark says: “Her [Saunders’] steely look and assured manner masked years of vulnerability”;[112] and yet Mount describes her as “a hurricane”.[261] That humility at the heart of Saunders’ Christian values was perhaps a stimulus to ardently seek out learning from many directions. This can be seen not only in her social work, nursing and medical training but in the breadth of her reading that included the likes of Carl Rogers,[589] Teilhard de Chardin,[112,590] Paul Tournier[23,589,591] and countless poets, novelists, philosophers and theologians.[180,183,592] Most important of all, that vulnerability and openness extended to patients and their families, where according to du Boulay, Saunders: “Learnt from the dying in order to help the dying”.[100] Saunders kept pushing forward which is why she preferred St Christopher’s to be referred to *not* as: “A centre of excellence but [as] a centre of enquiry”.[593] Speaking metaphorically she said that: “The most constructive thing I could do to improve hospice work would be to conduct a ‘sacred cow’ shoot”.[593] This is because, for Saunders: “[Hospice] has itself to be a traveller”.[594]

Considering the ‘who and what’ tension in the semiotic prompts the question: ‘What kind of hospice do hospices want to be?’ (or ‘What kind of business does a company want to be?’). From descriptions in Theme One an obvious comparison for hospices is with a small hospital that includes teams of nurses going into people’s homes. In Themes Two and Three respondents’ identification of potential roles of hospices prompt comparisons with other charities. For example, the British Red Cross (BRC) provides help with others in time of crisis, lobbies governments to take action, persuades statutory authorities to follow up and conducts research.[595,596] In Theme Three, participants describe learning from the attributes of successful companies such as Lidl and Netflix. Thus, as in semiotics, comparisons such as these offer ways for hospice leaders to reimagine potential futures in new, creative and insightful ways.

Looking at the semiotic in Figure 13 as a whole, I refer again to Gergen who says: “To return to the alternatives laid out in the semiotic squares, we find that effective counters to any given nucleus of intelligibility must optimally rely on suppositions contained within *alternative* nuclei”.[435] So, what also matters in looking ahead is not just how hospices perceive their ‘why-where-when’ and ‘what-who-how’ but critically, how others interact with their activity and what their joint action might *mean* for society.[436] Relating this to the twentieth century, there was a tension between the approaches of the NHS and hospices. However, in addition to those lives that benefited at the time, dying and death gained greater prominence and significance in society[437] or, as one respondent in this study says: “They put death and dying on the big stage” [2].

Fifty-six years on from the opening of St Christopher’s Hospice, respondents in this study, alongside many others, continue to work to improve end-of-life living and dying in this country. This thesis shows that the potentiality of hospices depends to a large extent on how they visualise, question and address the tensions in the ‘why-where-when’ and ‘what-who-how’ conundrum which is offered here as an aid to long-term development. Looking forward, as well as considering the suffering that people are experiencing, the impact of mainstream health and care strategies and the responses of hospices, what perhaps matters most of all is what this ‘joint action’[436] signifies for society as a whole. The search for *meaning* is the ultimate purpose of semiotics and I would suggest of hospices too because as a respondent in this study says, “Hospice exists to remind society of value” [9].

Chapter Eight: Conclusion

8.1 Contribution

This thesis examines the subject of hospices through the lens of a rarely studied cadre of hospice leaders. In considering their perspectives, it offers a historical trajectory of hospices, describes their conceptual foundations and considers their contemporary and future development. Its originality lies in the application of its social construction roots using a visualisation device applied by Gergen. This framework offers new insight for future hospice development and an approach for others to build on within and beyond the hospice sector. In doing so the study opens a window into the variety and intricacy of hospice development, the dynamic context in which hospices operate and the meaning and value of their contribution to society. The thesis sits between the broad panorama of the 2011-13 Commission[16] and Baron et al.'s detailed examination of a hospice in Northern England published in 2018.[597] To my knowledge, this is the first study to open up the social construction of hospices through the application of semiotics and to consider their significance in this way. As such it offers benefits to academic researchers, practitioners in the hospice sector, those working in related fields and potential funders.

In the study, CEOs say that leaders in the NHS, HUK and most hospices do not understand what the hospice idea is or what hospices are. They say that there is no definition of a contemporary hospice in England and that the picture of what a hospice is and should be providing has become blurred, mixed and confused. Furthermore, participants believe that consequently local people are in a similar position. This in itself affirms the need for hospices to reimagine their purpose, concept and development and validates this study.

It is clear from the results that, amongst the views of respondents, the hospice concept includes within it 'hospice care' and 'palliative care' but encompasses much more than that. As the literature shows, a broad conceptual view of 'hospice' is espoused by twentieth-century pioneers who believe that whilst the aim of the care of the dying is to make a patient's body comfortable enough to prepare for death, the idea is much bigger.[134] Furthermore, they say that for 'hospice' to be known only because of pain management and specialised care misses the point.[388] Thus, they argue that a task for the future is defining more clearly those qualities which make up a hospice and this means focusing on the people providing hospice care and their symbiosis with those who are dying,[388] hence Saunders' emphasis on interaction and community that involves vulnerability and exposure to the power, trauma and magnitude of death.[100,598]

In the twenty-first century, the dynamic map of an end-of-life system in the Lancet Commission Report on the Value of Death (Figure 3 in the 2022 report), depicts an example of the intricate settings in which hospices now operate.[382] This not only reinforces the argument that a discussion about hospices' purpose and their place within the field is overdue but it also shows that using devices to visualise 'why hospices are here', 'what and who hospices are' and 'how they are developing' is probably essential in such a crowded market-place.

Following the intensity of the Covid-19 pandemic, the current period of economic struggle is a challenging time for hospice leaders as many watch their financial reserves dwindle.[4,393] So, considering hospice concepts and going back to basics may be nowhere near the top of their overloaded inboxes but perhaps it should be. Hospices have been under pressure from the outset in convincing people of their approach,[163] being told not to proliferate,[247] that their time is over,[217] as well as having to traverse numerous national economic crises. They have faced many provocations through the likes of Mount,[599] Wilkes,[247] James,[36] Clark,[35] Douglas,[217] Kirkham,[12] Demos,[15] the Commission,[16] numerous mainstream health and social care restructures and of course the Covid-19 pandemic. This is no bad thing because these 'prompts' stimulate new thinking and, in Gergen's terms, a higher level search for shared values and meaning.[436] So now may be time for another rethink, especially if those second-curve thinkers referred to in the study are right in terms of the point that hospices have reached in their organisational life-cycle.[40]

8.2 Reflection

I commenced work as the CEO of St Catherine's Hospice, Lancashire, in 2005 and quickly gained a sense that there was more to hospices than their clinical output, important though that was. Whether I was joining a cleaning shift, talking to patients first-hand or running round at a busy fund-raising event there was something inspiring about the work and I wanted to learn more about it. In 2017, when my voluntary role on the board of HUK came to an end, I contacted Professor Clark. I said that I was looking for a project that would help in some small way to inform the work of hospices going forward. I began my research in October of that year.

For me, this study has been a privilege. I have learned so much from colleagues past and present and cannot thank them enough. It has been hard work and at times has felt a bit like an out-of-control leviathan. There have been many surprises along the way, the most obvious being when respondents told me that they had faced death threats which was deeply concerning. Another was the question: “Who owns death?” which I had not considered before. However, the biggest surprise has been the breadth of perspectives. Whilst I knew that there were many views amongst those involved in hospices I did not expect there to be such a variety.

Reflecting on my approach to the study, a central question for me has been whether I adopted the most effective approach to answering the research questions. As I said in Chapter Three, there were, as there are in many social science research projects, a perfectly legitimate number of ways of seeking to answer the questions in hand. However, I do not think that I would have unearthed some of the more sensitive matters if I had not conducted anonymised one-to-one qualitative interviews in the way that I did. There are also many ways in which hospices can be articulated but this approach has been especially helpful because it foregrounds the breadth of perspectives from participants without seeking to reconcile them. Rather than explaining the diversity away through some form of single vision it gives space for all to be seen and considered. My use of semiotics, as it was for Gergen, displays the energy that is there and creates opportunities for their wider significance and meaning to be explored.

A second question is whether I should have conducted so many interviews because the volume of work became so challenging. It was extremely difficult to reach so many respondents during a pandemic and then to analyse nearly 600,000 words. However, the reason why I pressed on, as agreed with supervisors, was in order to reach saturation. Having persevered, I am delighted with the rich material that I found and I am immensely grateful to interviewees for affording me their time. Finally, I comment on the challenge of conducting a six-year project. I have been involved in long-term projects before so I have some experience of the need to keep threads together and that there are times when one feels lost amongst them. However, this project has been an interesting journey and all the more so for the time that it has afforded for reflection. In that regard, I have ended up in a quite different place from where I started that feels well worth the effort.

8.3 Further research

The results of the study and subsequent discussion are at a philosophical and conceptual level. As such they need to be made more easily accessible, especially for busy practitioners and those interested in the field. I am already discussing how this might be undertaken. Examples of some observations for hospice leaders are listed below. For some, these may not be new questions but as this study shows they are timely.

(1) Why (where and when) are hospices here?

- Hospice leaders will benefit from rethinking *why hospices are here* today.

    - This could be articulated locally and nationally as a follow-up to the Commission and by considering the potential breadth of purpose of hospices that has been shown in this study.

(2) What and who are hospices?

- Hospice leaders will benefit from reconsidering *what hospices are*. This includes:
    - Answering the question: ‘What is the hospice idea or concept upon which all else stands?’ or more succinctly: ‘What is hospice?’

    - Considering the power and dimensions of Saunders’ multifaceted ‘living idea’ that led to the development of one of the biggest social movements in British history, gave hospices their special quality and made them distinct from mainstream services. Saunders’ ‘living idea’ includes, amongst other things: maintaining a vibrant symbiosis between colleagues, patients and families; balancing science and humanity; being an empowering and innovative resource for all involved in the work of the hospice and surrounding communities; and being a catalyst for social change.

  - Understanding the many commonalities, contrasts and variation that has developed in the roles, foci and outlooks of hospices as they have proliferated and grown. This study offers an approach to visualising this through Gergen's application of semiotics. Creating a deeper understanding has the potential to lead to more effective 'co-existence' (as Saunders sought)[1] that, in turn, may involve more impactful joint working. This also raises questions about whom hospices represent and their level of preparedness to stand up for those who are not heard.

  - Recognising the potential of varied hospice 'models' and being honest about the capability of different approaches to deliver their mission. This includes going back to the question that Demos posed about whether hospices, that started as disruptive innovators, are in danger of becoming incorporated as niche providers within the system they set out to change.[325]

  - Whilst understanding that recruitment can be very difficult these days, do hospice employers still seek people with the requisite skills *and* a commitment to the hospice ethos and cause?

- Hospice leaders will benefit from asking the question: 'Who owns death?' In seeking answers to that question colleagues can learn, not only from their own history and that of the NHS, but also from approaches such as *Compassionate Communities* and *Death Doulas* that seek to give more 'ownership of death' back to local people. This, in turn, raises the question: 'In what ways and to what extent are hospices community and people centred?'

- Respondents in this study considered questions about what hospices are, they also considered: 'What is HUK?' which is an important question in this discussion.

(3) How are hospices developing?

- Hospice leaders will benefit from reflecting on:
    - The strengths and weaknesses of public, private, community and charity sector approaches as they address the various tensions shown in the semiotics in this study.

    - Potential vulnerabilities that can obstruct and weaken the development and impact of a hospice which should not be lost sight of in the glow of local popularity. CEOs in this study have experienced serious harassment and in two cases, death threats. Issues have included: ‘pernicious’ subcultures being allowed to grow unchecked; individuals spotting weaknesses in governance arrangements that led to fraudulent activity; and unacceptable reactions from groups and individuals when difficult decisions have been made. The inspiration and deep feelings that many have when working in and supporting hospices is a positive strength but it can sometimes become a negative force that should not be underestimated. Respondents say that trustees must have a good understanding of their hospice’s purpose and that they should have mechanisms in place to enable meaningful feedback from staff at *all* levels in the organisation. Since some of these issues have been exacerbated by collusion at board level, arrangements need to be in place to address this possibility. Boards need to consider how they balance sufficiency in oversight with the need to create opportunities for imagination and new ideas.

    - The benefits and responsibilities of hospices being seen as ‘my local charity’. This includes considering how to broaden impact so that people appreciate hospices for *more* than the provision of specialist care at home or through in-patient beds.

    - The understanding that there are no easy answers to economic development although a number of helpful possibilities are considered in the study. From a strategic perspective, respondents point to the potential of articulating hospice roles more clearly, and conveying them within hospices, to local people and potential funders, including the NHS and local councils. As hospices move forward it will require a preparedness to be ambidextrous. This means being agile and flexible on the one hand whilst holding on to hospice values on the other. A key point here is that hospices will continue to develop differently from which all hospices can learn.

- The study offers a framework for future development that is described in Section 7.6. It includes considering and holding in tension Kipling's six wise men in the 'why-where-when' and 'what-who-how' conundrum. In addition, this includes considering not only the responses of hospices to current suffering, the approaches of mainstream and other services to health, care and wellbeing, and the activities of individuals and communities but also what their 'joint-action' (as Gergen puts it)[436] may *mean* for society in the long-term.

Discussions on the above, amongst other issues in the study, will inevitably lead to further avenues of enquiry that can not only test and triangulate aspects of the findings but also broaden the research base to involve other groups working in and around the landscape in which hospices function. In this regard, I would like to see further application of semiotics to shed more light on the complicated phenomenon of hospices, their broader context and potential going forward. Of course, as this thesis has discussed, new approaches to improve quality of life and death throughout society will continue to appear and hospices will have to consider where they see themselves in this expanding field and what kind of hospice they wish to be. Further research will help them to do so in informed and effective ways.

8.4 Significance

This study explores the social construction of hospices. First, it describes seven concepts, eight groups of hospice roles, various foci, outlooks and approaches to development from a rarely interviewed group of hospice leaders. This in itself is significant. Second, this new knowledge can help academic researchers, hospice leaders and many others working in the field to understand 'why hospices are here' in their 'when-where context', 'what and who hospices are' and 'how they are developing' by visualising the commonalities, contrasts and configurations that are in and around them. This understanding comes not just by seeking to see what hospices are but also, through Gergen, by observing what they are not. Third, through Kipling's six wise friends, the study offers a conceptual framework for the reimagination of hospice and hospice development going forward.

In looking at the historical trajectory of hospices in England, the 30-year period of growth at the end of the twentieth century is both remarkable and inspiring.[213] At the heart of it are Saunders and the pioneers of hospices throughout Britain who were dedicated to their cause. Today, the phenomenon of hospice is influenced by the development and impact of 'palliative care' but, as this study has shown, for many participants, 'hospice' can still be about much more than that. Respondents in the study proffer many interpretations of the hospice concept and a variety of approaches to operational delivery. For some, as the likes of Leadbeater intimated,[15] the idea has morphed into a more measured form of specialised care detached from the driving force that brought it into being. In this view, hospice has been routinised[34] and some would say that it is all the better for it. In fact, Kirkham suggests that now is the time for the absorption of hospices into the NHS.[12] However, some interviewees in this study believe that hospices have a rich historical and philosophical heritage; they are far more than a charitable arm of the NHS delivering palliative care and a business with books to be balanced. In that view, there is a feeling of frustration that progress could be so much more than it is.

When I was interviewed as part of the study in 2018 and asked the question: 'What is hospice?' my response was: "Hospice is about helping people to live lives that are worth living". Here, on reflection, having heard all the interviews and delved into the literature, I describe hospice as follows:

> "Hospice is a 'living idea'[26] based on the ancient belief of offering hospitality to the weary traveller; it germinates in the hearts and minds of patients, families and clinicians as they come together. Combining science, humanity, collaborative working and openness, 'hospice' incorporates the concept of 'total pain'[600] that recognises the holistic needs of individuals and that every person matters until the end of their days. The 'hospice' philosophy inspired one of the biggest social movements in British history that not only changed our view of death but of life itself.[437] In the hands of dedicated people it has the potential to keep doing so."

If hospices are to be reimagined, this study shows that in doing so leaders need to reflect on the energy of their inception, the intricacy of their surroundings, the heterogeneity of their development and their capability of fulfilling their mission. This will involve working out and understanding the possibilities that are open to them, drawing new comparisons, understanding what they are *not* and considering what kind of hospice they want to be. For some this may be an ever more intimate relationship with the mainstream. For others, it may involve an ambidextrous approach that is agile and open on the one hand and vibrantly connected to the driving force that made them on the other. For all of them, looking forward will involve addressing the 'why-where-when' and 'what-who-how' conundrum, considering their 'action, reaction and joint action'[436] with those around them and, importantly, finding ways to reflect on the long-term significance, meaning and enormity of it all.

At the beginning of this thesis I quoted Cicely Saunders, who gave measured advice on how the rapidly growing number of hospices could work together with others to make end-of-life living, dying and death better. Recognising the dichotomies that they faced, she said:

> "It is as if one were continually putting up two different poles and letting the sparks fly between. The truth is we must preserve a readiness to ask new questions and seek new truth in all spheres. By establishing what look like opposites and not trying to achieve a false reconciliation, we may end by showing in fact that they can co-exist."[1]

In the light of the findings of this study, this feels as relevant today as it was then. Hospices need to come together in a new spirit of openness and curiosity to 'let the sparks fly' if they are to continue to remind us that life has its greatest meaning when it is going to end and be an inspiration for more meaningful living, dying, death and compassion in society.

Appendix 1: Interview questionnaire

Interview framework

(As semi-structured interviews, this is a framework within which respondents make their own emphasis. Thus, whilst respondents answer questions under each heading, the supplementary questions are used only when needed.)

1. About You

1.1 How long have you been in the role of hospice CEO?

1.2 What brought you into your role?

1.3 What do you describe as your profession?

1.4 Why did you choose to work in a hospice?

2. Yesterday

2.1 What stands out for you in the history of the modern hospice movement?

  2.1.1 What is your understanding of the founders' original mission i.e. What were they trying to achieve?

  2.1.2 What inspired and motivated them?

  2.1.3 What were the big challenges of the day?

  2.1.4 What did hospice mean to them?

2.2 In the twenty-first century landmarks have included Demos - *Dying for Change* and The Commission into the Future of Hospice Care. I am wondering if those works have influenced you and if so, in what way? If not, any other key influences?

2.3 Thinking of the last 50 years, what are the biggest losses and gains along the way?

3. Today

3.1 Moving into the present, what do you see as your vision and mission today?

  3.1.1 What is hospice?

  3.1.2 Do your views about mission coincide with those working with you?

3.2 What are your main achievements in recent years?

  3.2.1 What are you particularly pleased about?

  3.2.2 What has been creative?

3.3 What have been your main challenges?

  3.3.1 Local factors?

  3.3.2 Anything you wished you had done?

3.4 What are the priorities that you are focusing on now?

  3.4.1 What do you spend most of your time doing?

  3.4.2 Are there other priorities you are considering?

3.5 In terms of governance, how do things work for you?

3.6 Your thoughts on regulation?

3.7 What words would you use to describe your recent years as a hospice CEO?

3.8 Thinking nationally for a moment, would you like to comment on HUK?

    3.8.1 What is HUK?

3.9 Do you enjoy what you do?

    3.9.1 What does or does not makes your work enjoyable?

4. Tomorrow

4.1 In thinking about our national approach to death and dying, how do you see that unfolding in the next decade or so?

4.2 How are you looking to address sustainability?

4.3 Please comment on the following: the challenge going forward is balancing Quality, Quantity and Sustainability

4.4 How do you see hospices helping the environment?

4.5 What would good look like in five or ten years' time?

4.6 What skill sets do you think incoming CEOs will need?

4.7 What words would you use to describe the future of hospices?

4.8 We're nearly at the end of the interview and I just want to check how are you feeling?

4.9 Is there anything else that you would like to say?

Thank you for kindly participating in this interview

Appendix 2: Interview consent form

Title of Project: **Change and Development in English Hospices**

Name of Researcher: **Stephen Greenhalgh**

Consent Form

I confirm that I have read and understood the Participant Information Sheet for this research study and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

I consent / do not consent (delete as applicable) to my interview being audio-recorded.

I acknowledge that participants will be anonymised. They will only be referred to by pseudonym in reports, further research and any publications resulting from the study.

I acknowledge that there will be no effect on my employment arising from my participation or non-participation in this research.

I agree to waive my copyright to any data collected as part of this project

Detail

- All names and other material likely to identify individuals and their place of work will be anonymised in the study.
- The research material will be treated as confidential and kept in secure storage at all times.
- The material may be stored at the University of Glasgow securely for 10 years once the project is completed and then destroyed.
- The anonymised material may be used in future publications, both print and online and, by other researchers.

I agree / do not agree (delete as applicable) to take part in the above study.

Name of Participant ……………………………………………… Signature …………………………………………………………..

Date …………………………………….

Name of Researcher ………………………………………………… Signature …………………………………………………………..

Date ………………………………

Appendix 3: Explanatory notes

Hospice

The word 'hospice' has roots in Sanskrit[59] and the Latin word *hospes* meaning 'guest' or 'host'.[54,601] Conceptually, hospice is described by Cicely Saunders as a 'living idea'.[26]

Hospices

The Hospice UK (HUK) website states that hospice care aims to improve the quality of life and well-being of adults, children and young people who have a terminal illness or long-term medical condition that cannot be cured.[602] Hospices supporting adults offer a wide variety of services. HUK states that these may include: pain and symptom control; trained staff that can provide care in your home; psychological support; physiotherapy; occupational therapy; complementary therapies; spiritual care; support for family members; companionship and practical support to help people at home; financial advice; bereavement support and respite care. A hospice may have other services to meet the specific needs of their local community.[603] These services vary across hospices so, for example, some will have an in-patient unit to care for patients and families in a hospice building whilst others may focus on caring for and supporting people in their own home. This study will add to and challenge aspects of this description. The majority of these are independent local charities and businesses registered at Companies House. An explanation of the number of hospices in England is in Chapter Three.

Cicely Saunders

Cicely Saunders (1918-2005) qualified as a social worker, nurse and physician and is recognised as the founder of the modern hospice movement. Saunders' 'living idea'[26] of hospice, based on the ancient belief of offering hospitality to the weary traveller, germinates in the hearts and minds of patients, families and clinicians as they come together. Combining science, humanity, collaborative working and openness, 'hospice' incorporates her concept of 'total pain'[600] that recognises the holistic needs of individuals and is underpinned by the philosophy that every person matters until the end of their days. Inspiring one of the biggest social movements in British history, Saunders' teaching has been applied across the world. Former British Prime Minister, Gordon Brown, describes her as one of the most courageous people of the twentieth century saying: “In changing our view of death, she has changed our view of life itself”.[437]

Help the Hospices (HtH) and Hospice UK (HUK)

Help the Hospices is a charitable organisation formed in 1984 by the Duchess of Norfolk to support and lobby for hospices in the UK. Based in London, it rebranded as HUK becoming a membership organisation in 2014.[604]

Palliative

The word ‘palliative’ has its roots in the Latin word *pallium,* meaning ‘to cloak’ or ‘wrap around’. ‘Palliative care’ was couched by Balfour Mount in 1974 and ‘palliative medicine’ became a sub-speciality in Britain in 1987.[71]

St Christopher’s Hospice

The first hospices were formed in the Middle Ages. Saunders worked in and learnt from hospices and homes for the dying operating in Britain before she opened St Christopher’s Hospice in 1967.[605] St Christopher’s is depicted as the first modern hospice based on practice, education and research that led to an era of proliferation described by Lamerton in 1973[59] and the *Nursing Times* in 1976,[34] as the ‘Hospice Movement’.

Demos and the Commission into the Future of Hospice Care (Commission)

The Commission took place between 2011-2013. It followed a study entitled *Dying for Change* in 2010[15] undertaken by the think-tank Demos[606] that examined how people in Britain die and how it could be better. Both were sponsored by HtH. The Commission produced a body of literature and a final report entitled, *Future ambitions for hospice care – our mission and our opportunity.*[16] It is recognised by many as the most comprehensive study of hospice care in the UK that has been undertaken in the twenty-first century.

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