“We are all dropping off like flies…it’s a fact”:
A hermeneutic-phenomenological exploration of a bereavement focused Compassionate Communities intervention in extra care housing.

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Abstract

This thesis explores ExtraCare Charitable Trust citizens’ lived experience participating in a Compassionate Communities (CC) (Kellehear, 2005) intervention to address the bereavement support needs of people living and working within their villages and schemes. The CC movement is motivated to redress the medicalisation and sequestration of life limiting illness, dying, and bereavement. Reclaiming death and bereavement as fundamental to the human experience, the CC movement seeks to normalise and neutralise these phenomena and augment clinically focused care with community orientated care and advocacy. This thesis sought to understand the meanings associated with undertaking and participating in an innovative and unique CC intervention. Specifically, by occupying a critical gerontological lens a dialogue was facilitated between multiple, and seemingly disparate, literatures which permitted nuanced, culturally, and historically situated experiential understandings to be constructed.

As there were multiple interconnected actors at play, a multiperspectival approach enabled me to capture not only rich idiographic narratives, but also permitted critical interpersonal and organisational features to flourish. Findings from reflexive thematic analyses are discussed in three empirical chapters. The first explores the nature of bereavement and bereavement support within ExtraCare. It seeks to explicate the needs of bereaved older people and the obstacles that inhibited implementation of the Bereavement Supporter Project. The second occupies a granular position and centres upon the lived experience of volunteerism among older people and the meaning ascribed to this undertaking. The third and final empirical chapter shifts to an abductive logical of inquiry in an effort to connect the generated data from this research to wider gerontological discourses and concerns. All three studies attest to the pervasiveness of so-called positive ageing paradigms and the limits they place on how we *ought* to age and how we *ought* to think about ageing and older people within our societies (Holstein, 2006). I conclude by drawing parallels between ‘successful ageing’ and ‘good grief’ narratives and caution the CC and death positive movements against settling an orthodoxy for what constitutes ‘good grief’.

Key words: Compassionate Communities, bereavement, critical gerontology, peer support, extra care housing.

This thesis is dedicated to all that's been lost along the way.

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It is said it takes a village to raise a child…the same is true of crafting a thesis!

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Chapter 1: Introduction

Research context: The Bereavement Supporter Project

In order to orientate this research, it is important to first introduce the compassionate communities (Kellehear, 2005) project at its centre. The Bereavement Supporter Project was a five-year (2017-2021) partnership between Cruse Bereavement Care and the ExtraCare Charitable Trust (referred to hereafter as Cruse and ExtraCare respectively), funded by the National Lottery Community Fund. The project aimed to address the bereavement needs of ExtraCare residents, including people with dementia. Figure 1 depicts the three-tiered approach employed within the Bereavement Supporter Project. First, the project aimed to increase awareness of bereavement (both pre- and post-death bereavement); the impact that grief can have on physical and mental health; strategies that residents and staff can use to support themselves, and each other; and signposting to wider support services that are available (including, but not limited to, Cruse). Additionally, the project recruited, trained, and deployed ExtraCare residents to be Bereavement Support Volunteers (BSVs) who acted as first-contact listening support to bereaved people within their communities. Finally, the project provided clearer signposting so residents and staff who require more specialist support could access appropriate services easier, and faster.

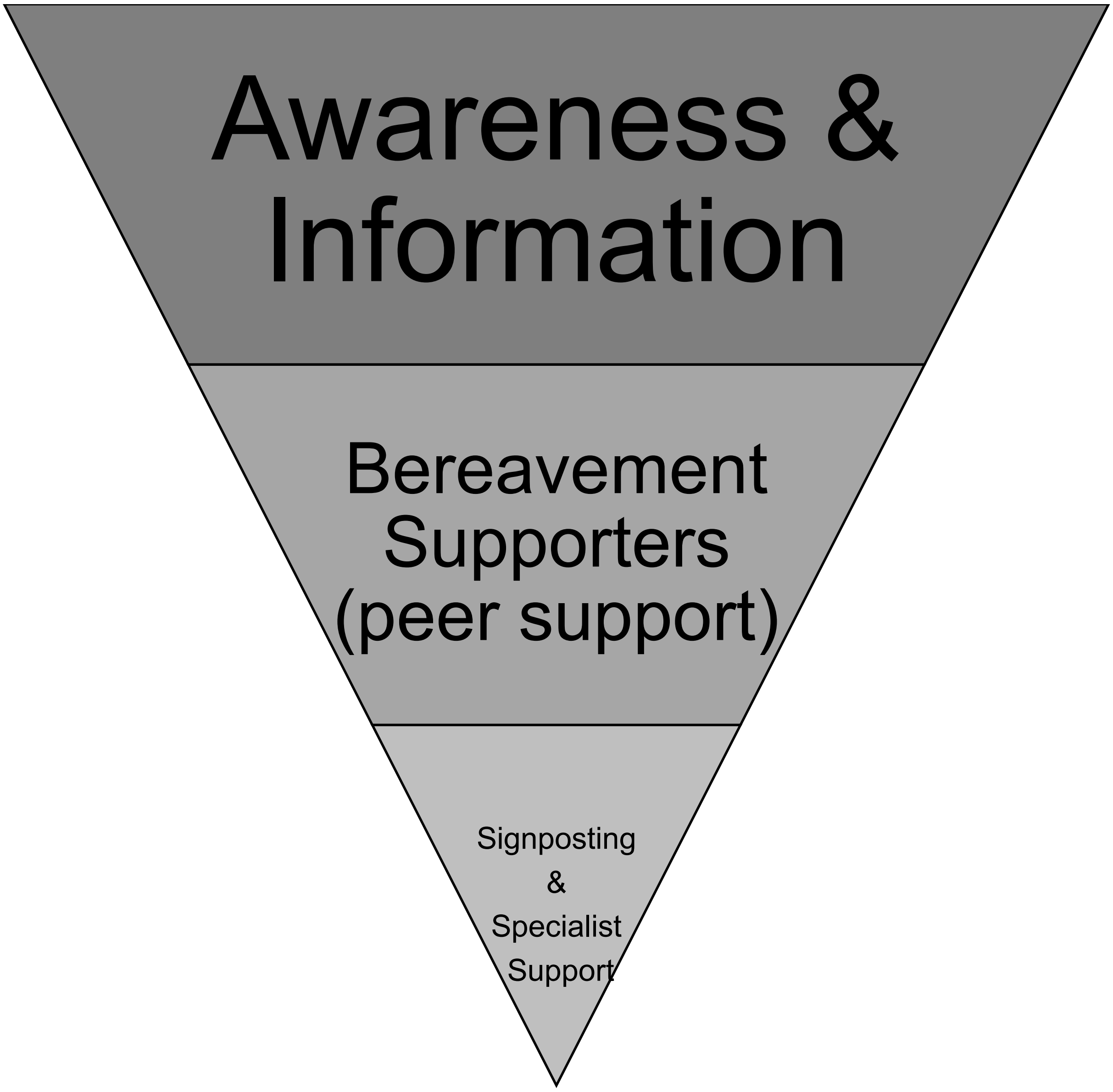

Figure 1. Depicts the three-tiered approach to improvement bereavement support within ExtraCare villages and schemes.

A Public health approach to bereavement support

In its national framework for local action, the National Palliative and End of Life Care Partnership (2021) noted that any end-of-life care strategy should include support in preparing for, and during, bereavement. Drawing on earlier NICE guidelines on supportive and palliative care for adults with cancer (NICE, 2004), the national local action framework identified the need to accelerate public health approaches to bereavement support (Rumbold & Aoun, 2014; Kellehear, 2005), in which raising public awareness of bereavement needs and building compassionate and resilient communities were key elements. This growing recognition of the need to develop the capacities of communities to support friends, neighbours and family members through ‘normal’ processes of grief has led to the development of a three-component model of bereavement care (see Figure 2), in which most support can be accessed and delivered in supportive communities, thereby reducing the need for more professionalised grief counselling to only those cases where grief becomes more entrenched, complicated and may give rise to mental health problems.

It is argued that this community approach is more in line with the kind of support that people say they would like, but often cannot access (Penny & Relf, 2017; Independent Age, 2018), and meets the requirements of the Gold Standards Framework (GSF) in which meeting the needs of those experiencing or anticipating bereavement is a key component of end-of-life care planning (Gold Standards Framework, 2019). As such, it was intended that the Bereavement Supporter Project would eventually be rolled out to all retirement villages and housing schemes run by ExtraCare within the framework of its universal health and wellbeing programme and GSF-accredited end-of-life care planning.

The Bereavement Supporter Project (as depicted in Figure 2) is most obviously located within component 1 of the public health model as the provision of educational talks and activities was the primary intervention function. However, the project also contained elements of component 2 in so far as support was provided by trained volunteers.

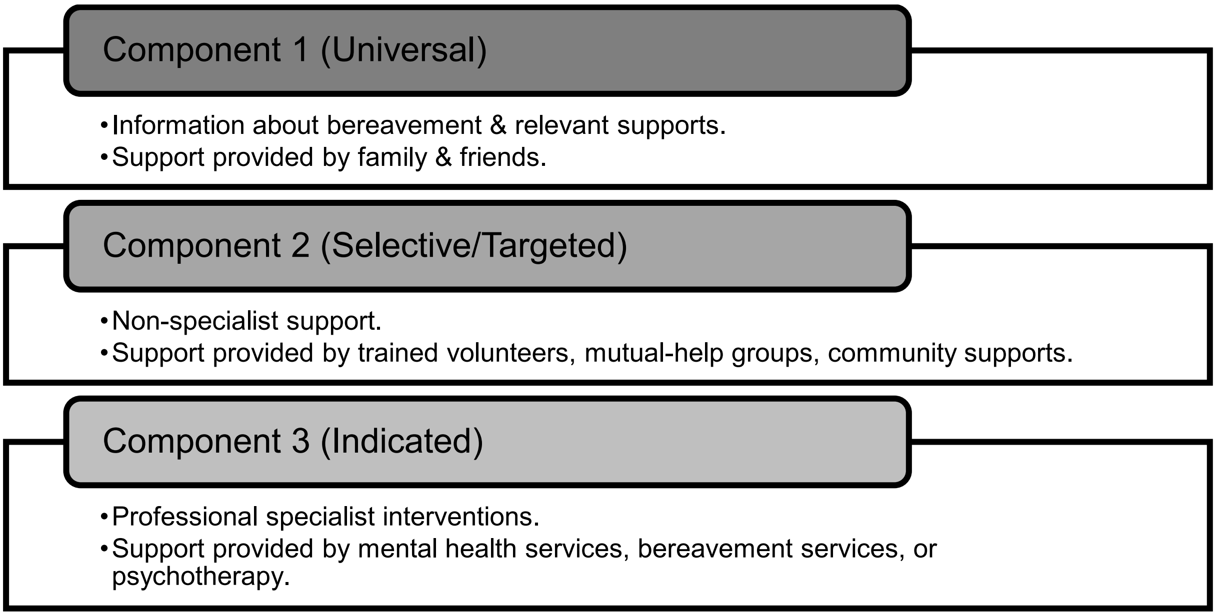

Figure 2. Demonstrates the public health approach and NICE guidelines adapted from National Bereavement Alliance, 2017.

The Compassionate Communities movement

The Compassionate Communities (CC) movement (Kellehear, 2005) is an emergent public health approach to end of life and bereavement care. Kellehear argues that the current landscape of palliative care, orientated within a medico-nursing framework, has positioned death as a medical or personal failure (2005), and has therefore placed a premium on attending to the physical aspects of care, usually in the days and weeks preceding death by a practitioner trained in palliative medicine (1999). Consequently, there has been a mass abdication of responsibility in caring for the dying and bereaved and the emergence of a pervasive attitude that views end of life and bereavement care as the purview of 'professionals' has come to dominate (2005). Influenced by public health movements such as the WHO Healthy Cities programme, Kellehear argues that end of life care is "everyone's responsibility" (2013) and communities would be better served by understanding and acting upon the social determinants of health (Kellehear, 2020). This led to the development of the Compassionate Cities Charter (2005) which seeks a commitment from local government or organising body to "publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences" (p. 80). Specifically, Kellehear advocates for the normalisation of cultural literacy about death, dying, and grief to encourage and empower citizens to help others; greater civic engagement and partnership with clinical palliative care services; and the development, refinement, or expansion of death and bereavement friendly policy and practice.

Peer support and volunteering

A key principle of the public health approach to bereavement support outlined above is that bereavement and grief are a part of everyday life and that the everyday experience of it that inheres in communities can be harnessed in support of others. Volunteers in the Bereavement Supporter Project committed to sharing their own bereavement and grief experiences and capacity for neighbourly support as well as, in some cases, relevant professional experience. As such the project is an example of the kind of asset-based, peer support approach advocated in healthcare by NESTA (Graham & Rutherford, 2016) and National Voices (Nesta and National Voices, 2013). As other research on volunteering among older people has indicated, the provision of support for volunteers and volunteer activities is crucial not only to the success of programmes, but also to the volunteer experience (Hornung, 2018).

Each of the ExtraCare villages had, or later employed a Volunteer Organiser, whose task it was to support the recruitment, training, and retention of BSVs. Many aspects of life within ExtraCare villages are delivered by volunteers (reception, shops, the gymnasium, library etc.) and for many volunteering is a valued aspect of ExtraCare life (West et al, 2017). More challenging functions like befriending and buddying new residents are also delivered by volunteers, but it is probably fair to say that the function of BSVs is the most challenging volunteer role to date. As such it requires a particularly robust framework of support. Part of the Bereavement Supporter Project framework was the wider programme of health, wellbeing, and end of life support across the villages within ExtraCare. In addition to the Volunteer Organiser, it was anticipated that all members of staff, but most notably the Wellbeing Advisors and Dementia and Wellbeing Enabler (senior staff members who support vulnerable individuals, often people living with dementia, to ensure that residents reach their potential for well-being) would be instrumental in identifying and referring bereaved residents to BSVs. Furthermore, BSVs received supervision from the Project Manager and ExtraCare Senior Management during their first few months in the role. Subsequently, village-initiated meetings were encouraged to cultivate support at the community level to supplement the additional training and support sessions (see 'Peer Group' below) that formed part of the project implementation infrastructure.

Cultures of death and dying

The public health approach to bereavement and grief support works from the premise that people can seek support from within supportive communities who are willing to talk about death and dying; to engage in the kind of memorialising "activities that reconnect bereaved people with the ongoing life of their community" (Rumbold and Aoun, 2014, p 133); and which "recognise the solace that sorrow can bring" (ibid). This broader cultural aspect, although hugely important (Kearl, 1996; Kastenbaum & Costa, 1977), is harder to capture in a formal evaluation. In previous research with ExtraCare, which was based on longitudinal engagement with residents, ExtraCare's health and wellbeing programmes have tended towards the physical more than the emotional dimensions of health and wellbeing (see West et al, 2017 and Shaw et al, 2016). The development of the Bereavement Supporter project was viewed by ExtraCare senior management as an opportunity to broaden understandings of wellbeing in ExtraCare beyond physical and cognitive health and to apply the GSF to end-of-life care and support planning. Although previous research within ExtraCare (West et al, 2017; Shaw et al, 2016) does not constitute baseline data as such, it nevertheless acted as a reference point when thinking about the Bereavement Supporter Project as a cultural change programme.

The story of this research

The conditions of my studentship stipulated that in addition to producing a thesis I would form part of a research team that would evaluate the Bereavement Supporter Project, and its sister project the Bereaved by Dementia Project. As such, a schedule of agreed research activities, following a mixed methods design, was established before my studentship had been awarded. Activities included a quantitative survey with support recipients; interviews and focus groups with BSVs; interviews with support recipients; focus groups with staff; and site observations. All research components were to follow a longitudinal design to capture change over time.

The schedule of research activities provided an important shared scaffold that the evaluation team, Cruse and ExtraCare management could refer to, however as it was conceived before the project was launched, adaptation was anticipated. An early example of this pertains to the longitudinal quantitative survey of support recipients. It was originally envisaged that residents who received support from a BSV would complete a survey which would gauge respondents' self-perceived health and improvement; quality of life (Wiggins et al, 2018), social isolation and loneliness (Russell et al, 1984); and attitudes to grief (Sim et al, 2014) over time. The inclusion of this activity was informed by the well-established model of support that Cruse operated within, characterised by a linear progression from (1) referral, through to (2) allocation of support, (3) a structured limited number of support sessions, and finally, (4) ending the therapeutic alliance. There are of course exceptions to this journey, with some clients receiving additional support sessions and/or receiving support on multiple occasions, but this represents 'typical' bereavement support at the national level. However, within the Bereavement Supporter Project bereavement support was more informal, the number of self-referrals was low across all locations; the length, location, and frequency of supportive conversations was variable both between and within individuals; and the identification of what 'counts' and is recorded as bereavement support (as opposed to being neighbourly) has been a challenge for BSVs. These unexpected features of support provision have directly impacted the ways in which BSVs made sense of their role, as well as how the project has been delivered and evaluated. Attention will return to these observations in Chapters 5 and 4 respectively.

The informality of bereavement support rendered the quantitative survey impractical for a number of reasons, (1) without self-referrals it was difficult to identify residents who had received support; (2) the number of self-referrals across locations would not provide sufficient power for the proposed analysis; and (3) support provision was not structured or consistent across individuals (i.e. support was in response to need, so while some residents received ongoing support on an ad hoc basis others received support on a single occasion) so robust relationships between and within subjects would have been difficult to establish. Despite making several adaptations to the administration and content of the quantitative survey it was agreed that this strategy for data generation would be abandoned. Therefore, the evaluation, and this thesis, would utilise a combination of qualitative methods to generate in-depth, rich, and nuanced data.

As part of the ongoing evaluation, I also attended meetings, workshops, and training sessions (discussed in more depth below) that were critical to building relationships both with the senior managers overseeing the delivery of the project, and with ExtraCare BSVs, residents and staff. These sessions also informed how the project was delivered and evaluated, and consequently, in some ways, shaped this thesis.

Management group

The project and evaluation management group met every quarter, typically in March, June, September, and December. The management meeting was attended by the project evaluation team, the Bereaved by Dementia Project Manager, the Bereavement Supporter Project Manager, Cruse Operations manager, ExtraCare Head of Innovation and Wellbeing, and ExtraCare Enriched Opportunities Programme Lead.

The group usually met for 2 hours in-person, usually at one of the ExtraCare villages. When this was not possible efforts were made to 'attend' remotely through Cruse telephone conferencing. These meetings were a priority for all members, however, on occasion, individual members were unavailable to attend either in-person or remotely. Meetings went ahead if there were sufficient representatives for each of the core groups (i.e., research team, Cruse, ExtraCare). The Bereaved by Dementia Project Manager attended management meetings until June 2019 which marked the natural end of their project.

The broad aims of these meetings were:

(1) To maintain communication between stakeholders.
(2) For the project evaluation team to provide updates on the research activities that had been conducted, and how this mapped against the agreed timeline and schedule of activities.
(3) To review relevant documents (e.g., survey, interim evaluation reports etc.).
(4) To discuss any challenges and/or changes to the project delivery (e.g., delay recruiting BSVs) and/or project evaluation (e.g., challenges meeting agreed evaluation targets etc.).
(5) To agree appropriate strategies to mitigate identified challenges and/or to agree on a revised course of action in response to identified challenges.
(6) Plan for future activities and events (e.g., Learn and Share events, evaluation research activities etc.).

The meetings were chaired and minuted by me and followed an agreed agenda of items that all members could contribute to in advance of the meeting. The group was founded in mutual respect for the experience, expertise, and contribution that all group members brought to the discussion, and as such meetings were fruitful and rewarding.

Reference group (stakeholder involvement)

It was important that the BSVs and ExtraCare staff could contribute to the design and delivery of the Bereavement Supporter Project. The reference group acted as a consortium whereby BSVs and ExtraCare staff were consulted to provide their feedback to proposed plans for the project delivery (e.g., forms recording support, feedback cards etc.) and/or the project evaluation (e.g., findings for the interim report).

Reference group meetings were organised and chaired by the project manager. In addition, meetings were usually attended by 3-5 BSVs, 2/3 ExtraCare staff members, and me. While members of the reference group were asked to declare a commitment to attend and engage, attendance naturally fluctuated and changed over time. Nevertheless, there were individual members who attended most if not all sessions providing consistency across the life course of the project. Reference group meetings were organised quarterly and lasted for approximately an hour and a half.

As alluded to above, the reference group was an opportunity to consult with community members about their experience of an identified issue, as well as to share our ideas and documents for them to review and comment on. The sessions, while informal in tone, were structured to ensure the time was used productively. The value of the experiential knowledge of BSVs and staff was emphasised, and members were encouraged to talk openly and honestly.

Critically, the reference group informed the methods of this thesis in a several key ways. For instance, the reference group were consulted: to formulate the information and consent form and study invites to ensure the language used was easy to understand; to gain their feedback on proposed recruitment strategies for support recipient interviews; and to share and discuss the preliminary findings as summarised in the interim evaluation report. In addition, the reference group provided me with an informal mechanism to better understand the project and how it was being delivered and experienced.

Peer group

Peer group was devised as a mechanism to bring together BSVs from across different villages and core members of the project management group (including myself). Peer group had a bigger scope than reference group meetings; BSVs from all Birmingham villages (as the project expanded invitations were likewise extended to BSVs outside of the Birmingham area) were invited and attended. Group size and composition varied, however typically 30-40 BSVs attended.

The overarching aims of these sessions were to:

(1) Provide BSVs the opportunity to meet with and talk to other volunteers both within and beyond their own village.
(2) Share progress on how the project was being delivered and evaluated.
(3) Report back on issues identified during the previous sessions, using the 'You said, we did' formula already utilised within ExtraCare.
(4) Facilitate discussion between BSVs to inform adaptation of the delivery and/or the evaluation of the project.
(5) Provide an opportunity for BSVs to see how the project was working in other villages (e.g., challenges identified and how these have been overcome, share examples of support provided) and how others made sense of their experience.
(6) Ensure BSVs received on-going training and support (each session consisted of a workshop delivered by a Cruse Bereavement Care trainer or an allied professional that was tailored to the needs identified by BSVs).

The peer group sessions were well received and valued by the BSVs as evidenced by the feedback forms distributed, collected, and analysed by the project manager after every session. Considerable effort was made to respond to recommendations identified within the interim evaluation report, as well as to address in-the-moment issues raised by attending BSVs.

Learn and share workshops

The learn and share sessions and events were devised to:

(1) Share learning and resources between the Bereavement Supporter Project and the Bereaved by Dementia Project.
(2) Learn from people with a personal and/or professional experience of loss, bereavement, and dementia.
(3) Use this learning to develop resources and/or to inform project delivery or evaluation strategies.
(4) Share this learning with allied professionals, charities, and organisations.

Learn and share sessions were typically conducted biannually and lasted approximately 3 hours. Attendees consisted of: BSVs; ExtraCare staff; people living with dementia; carers of people living with dementia; Cruse Bereavement Volunteers; representatives from Cruse and Alzheimer's Society Cymru; and the Bereavement Supporter management group (key personnel from Cruse, ExtraCare, and academics evaluating the project). Typically, 15-20 people attended the session. The exception to this was the stakeholder launch event which was held in October 2019 which was a larger event intended to showcase the interim findings of the evaluation.

Selecting ExtraCare locations

To permit idiographic, rich, and contextually situated data collection, a sample of four ExtraCare sites were purposively selected. The decision was informed through ongoing discussion with both ExtraCare and Cruse gatekeepers to maximise variability of resident experiences. The historical and cultural contexts of the ExtraCare sites were therefore of vital importance. While the nuance and complexity within each site is recognised, it was a priority to include sites with resident populations that were ethnically diverse (Sycamore Grove) and newly built (Oaks Bluff), as well as the more established villages which typically house more affluent white residents (Cedar Court and Elmwood Forest). It is noted that the real names of the ExtraCare locations have been replaced with pseudonyms here and throughout this thesis.

The Bereavement Supporter Project was conducted using a staggered delivery approach. This allowed the Project Manager to get to know each village individually; to build relationships with the staff and residents and understand how the village operated. Consequently, the project was launched within the selected villages at different time points, first at Sycamore Grove, followed by Cedar Court, Oaks Bluff, and Elmwood Forest.

Research aims and questions

Aims

Broadly, this research sought to explore a range of stakeholder experiences (ExtraCare staff, residents, and BSVs) of the Bereavement Supporter Project, a peer-to-peer bereavement support initiative aligned with the CC movement. By concentrating on culturally and historically situated lived experience and meaning making, this research aimed to:

- Explore the impact of the Bereavement Supporter Project within the context of ExtraCare.
- Explicate the challenges and successes of the Bereavement Supporter Project with the intention to inform and enhance intervention implementation within the CC movement.
- Explore the lives and experiences of older adult volunteers delivering peer bereavement support to other residents within ExtraCare.
- Identify residents' motivation for engaging in volunteering generally, and within the field of bereavement support specifically.

Main Research Questions

1. What do the lived experiences of ExtraCare communities participating in a CC intervention tell us about the project of de-professionalising bereavement support and cultivating more community-orientated systems of care?
2. What can the findings of a CC intervention contribute to wider gerontological discussions and debates?

Sub-questions

1. What are the motivations for ExtraCare residents to engage in volunteering? And how is this situated within their personal biography?
2. In what ways does the culture, policy, and practices of ExtraCare as a proponent of successful ageing influence the experience and successful implementation of the Bereavement Supporter Project?

Outline of this thesis

The chapters of this thesis seek to tell the stories of ExtraCare BSVs, staff, and residents participating in the Bereavement Supporter Project. This will be achieved within the following chapters.

Chapter 2 maps out the various literatures that have shaped this research. Attention is given to selected literature from the fields of critical gerontology, grief theory and intervention, the Compassionate Communities movement, and volunteerism among older adults.

Chapter 3 outlines the philosophical and methodological underpinnings of the three empirical studies included in this thesis. It situates this research within the interpretivist paradigm, specifically it is orientated within hermeneutic phenomenology. Attention is also given to the methods of data generation and analysis employed.

Chapter 4 is the first of the empirical studies. This chapter utilises a multiperspectival approach to explore the nature of bereavement and bereavement support within ExtraCare. It seeks to explicate the needs of bereaved older people and the obstacles that inhibited implementation of the Bereavement Supporter Project. Specifically, it considers generational expectations, norms, and cultural beliefs about death, dying, and bereavement, and the organisational structures, policies, and practices within ExtraCare that influenced participants' experience of the project.

Chapter 5 has a more granular and idiographic focus. It centres specifically on the experience of being a volunteer in older age and the meaning BSVs ascribed to this undertaking. Particular attention is afforded to the ways in which volunteerism upholds and threatens BSVs' concept of self-identity.

Chapter 6 is the final empirical chapter and considers features of the data set imbued with contradiction. It marks a departure from the data-driven logic of the two preceding chapters and instead pivots to an explanation-driven, or abductive, logic of inquiry. This shift permits a dialogue between the generated data and pertinent theory to enhance our understanding of the phenomenon. As such, it speaks to wider gerontological discourses and concerns.

Chapter 7 concludes this thesis by discussing the key findings from the empirical studies and the implications these have for clinical practice and research. A summary of the strengths and limitations are outlined, followed by a reflective discussion of my personal experience conducting this research.

Chapter 2: Literature Review

Introduction

The preceding chapter outlined the particulars of the Bereavement Supporter Project which served as the foundation from which this thesis has emerged. This chapter will draw upon pertinent pockets of the extant literature to further contextualise the phenomena under investigation and to signpost the key areas to which this PhD is contributing.

The Bereavement Supporter Project was a unique programme that operated at multiple levels meaning there was a complex web of literatures to consider in order to do justice to participants' experience. Identifying and streamlining this unwieldy and sprawling literature was an enduring challenge. In an effort to tame this abundant and at times seemingly fragmented literature it helped to first visualise it as a funnel. One that at its widest point is orientated within a macro framework that seeks to establish the lens through which this research (and the research preceding it) will be viewed (critical gerontology as a challenge to successful ageing), filtering through to essential contextual features (Compassionate Communities broadly, bereavement support specifically) that position the Bereavement Supporter Project within particular traditions and cache of knowledge, and concludes with a more granular examination of volunteerism, a phenomenon deeply entrenched in all of the literature discussed here, and a critical perspective of the empirical chapters presented subsequently.

Successful Ageing

In an attempt to counter the ageist stereotypes and prejudices tied up in 'decline and loss' paradigms of ageing, social gerontologists have provided counter conceptualisations of ageing. These more 'optimistic' models include but are not limited to; active ageing (Havighurst, 1948, as cited in Schroots, 1996), successful ageing (Rowe & Kahn, 1997), and productive ageing (Caro et al, 1993). There is not the scope to offer a comprehensive consideration into the commonalities, deviations, and nuance of each of these models in turn. Instead, a close examination of successful ageing will be presented as this theory has been frequently isolated as being the Goliath of gerontology (Binstock & Hendricks, 1998; Holstein & Minkler, 2003); reflected in its continued notoriety and influence within academia and research, the media and policy making, and consequently, within cultural consciousness (Holstein & Minkler, 2003).

While the notion of successful ageing can be traced back to antiquity (Timonen, 2016), it was Rowe and Kahn (1997) that crystalised its popularity and influence within gerontology. Dissatisfied that the dichotomisation of the elderly into pathological versus normal states did not encapsulate the heterogeneity of the ageing experience, Rowe and Kahn (1987) championed a further dichotomisation of the 'normal' state. Thereby differentiating between 'usual ageing', characterised by non-pathological, age-related changes that predict high-risk for disease and/or disability, and 'successful ageing', characterised by the absence and low risk of disease, and high functionality.

It is acknowledged that defining successful ageing has been contentious and inconsistent (Depp & Jeste, 2006; Timonen, 2016), a critique that I will return to in more detail subsequently. However, first I will summarise successful ageing as defined by Rowe and Kahn (1987; 1997). Within their conceptualisation there are three tenets to ensure successful ageing; absence of disease and disability, preserved cognitive and behavioural functionality, and continued civic engagement (Rowe & Kahn, 1997). While the relationship between these components is dynamic, Rowe and Kahn (1997) stress a hierarchical structure; where 'avoiding disease and disability' sits firmly at the top and exerts a dominant influence over 'high cognitive and physical function' and 'engagement with life'. Furthermore, a central facet to the authors' model of successful ageing stems from their challenge to overturn genetic determinism; the tendency to view disease and disability as an intrinsic and inevitable product of the ageing process, which, in their view, had been overemphasised (Rowe & Kahn, 1997). Rather, they assert that the impact of lifestyle factors (e.g., exercise, diet) upon the increased risk of disease and disability with advancing age had been hitherto understated and underestimated. Rowe and Kahn (1987; 1997) provoked a shift in thinking; rather than disease and disability being a genetically determined 'luck of the draw', agency, responsibility, and culpability is transferred to individual (in)action.

> We can have a dramatic impact on our own success or failure in aging (…) successful aging is in our own hand (...) to succeed means to have desired it, planned it, worked for it (…) we regard [successful aging] as largely under the control of the individual (…) successful aging is dependent upon individual choices and behaviors [and] can be attained through individual choice and effort. (Rowe and Kahn, 1998, pp. 18, 37)

The idea that (un)successful ageing is dependent upon individual choices and behaviours gave rise to the proliferation of research across disciplines to identify a comprehensive and objective inventory of 'modifiable targets' (such as diet, exercise, smoking etc.) from which interventions may be initiated to increase the proportion of successful agers within the population. The sheer profusion of literature in this field prohibits extensive examination and discussion here, but studies identified from the literature review encompass a range of targeted, health-related interventions, from physical activity (Bauman et al, 2016; Daskalopoulou et al, 2017; Hsu et al, 2018; Mañas et al, 2017), diet (Milte & McNaughton, 2016), and broadly defined 'population health' (Tkatch et al, 2016), to musculoskeletal disorders (Luskin et al, 2000), frailty (Chang & Lin, 2015), and resilience (Whitson et al, 2016). However, research suggests that intervention efficacy has been modest at best (Bauman et al, 2016; Daskalopoulou et al, 2017; Mañas et al, 2017) to insignificant at worst (Hsu et al, 2018). There is therefore a dissonance emerging between the unequivocal promotion of interventions targeting modifiable extrinsic factors to transform unsuccessful agers, or those at risk of becoming unsuccessful agers, and the modest improvements such interventions yield.

Critique from Critical Gerontology

While the successful ageing model can, and should, be critiqued on the basis of the limited empirical evidence supporting its claims, it is not the only position from which challenges have been directed. Indeed, a wave of critical gerontologists (Bülow & Söderqvist, 2014; Dillaway & Byrnes, 2009; Holstein & Minkler, 2003; Martinson & Berridge, 2015) have, for many decades, expressed opposition to the successful ageing model(s) from epistemic, ethical, and methodological loci. First, Holstein (1998) challenges the assertion that science broadly, and social gerontology specifically, are value neutral and exposes the ethical implications of not articulating these normative values. She argues that the obfuscation of intersectional inequalities undermines our capacity to cultivate just societies and limits the resources and possibilities available to those less privileged, further compounding inequity. Holstein implores us to be alert to unasked questions because phenomena and/or experiences of which questions are not asked remain unexplored "and therefore cannot be imagined, recognised, and if need be, redressed" (1993, p. 3).

Second, while 'successful ageing' discourse presents the construct as being settled and self-evident, review studies have demonstrated there is considerable heterogeneity and multidimensionality in how successful ageing is operationalised in practice (Depp & Jeste, 2006; Cosco et al, 2014). While for some this lack of consensus presents little obstacle to producing good research (Glass, 2003), others evidence the significant implications such definitional disparities have upon the reported prevalence rates of successful agers within a population (Bowling & Iliffe, 2006; Cosco et al, 2014; McLaughlin et al, 2012). Here I argue that the ambiguity of the construct does matter. Given that successful ageing is bound in our current cultural consciousness, who is identified as ageing (un)successfully has profound implications to policy, healthcare provision, and the perception of self and others (Holstein & Minkler, 2003).

Third, as Holstein and Minkler (2003) succinctly express, the reductionist, dichotomy of "'successful' and 'unsuccessful' [ageing] then become rubrics to interpret, organize, and give meaning to experience" (p. 788). The unreflective normative assumptions inherent within successful ageing position older people within a hierarchy; a hierarchy that is skewed in favour of privilege. Within this binary, those with chronic conditions or disabilities are automatically relegated to the ‘unsuccessful’ pile (Minkler, 1990; Holstein & Minkler, 2003; Martinson & Berridge, 2015). The automaticity of pairing disease and/or disability to the absence of even the possibility of a ‘successful’ age, exposes the ableist foundation of the successful ageing model. Further to this, Morell (2003) asserts more broadly, successful ageing perpetuates ageism through its “implied hostility toward bodily aging” (p. 83).

Fourth, Rowe and Kahn’s (1997) emphasis on individual action has also been demonstrably controversial as it places responsibility for successful, but more likely unsuccessful ageing, onto the shoulders of individuals (Dillaway & Byrnes, 2009; Holstein & Minkler, 2003; Martinson & Berridge, 2015; Timonen, 2016). This is problematic not only because it contributes to the moralisation of health - where health behaviours and status are bound in moral precepts (‘good’, ‘bad’; ‘right’, ‘wrong’) - but because it erases demographics (ethnicity, gender, social status, etc.) and structural inequalities from the conversation. This erasure of contextual features - critical to our experience, possibilities, and values - censures the lives of those already marginalised and serves only to privilege the already privileged. Moreover, it is argued that Rowe and Kahn’s (1997) considerable emphasis of individual action and responsibility is consonant with neoliberalism, a social theory that gives “a vision of ‘society’ as the cumulative product of free individuals, loose of all but the necessary constraint by the state” (Greenhouse, 2010, p. 1). Through this lens, there is a suspicion that siphoning responsibility to individual (in)action absolves the state and policy makers of responsibility and justifies the withdrawal and/or reduction in welfare provision, and subsequently propagates poverty, vulnerability, and marginalisation of those most in need (Dillaway & Byrnes, 2009; Martinson & Berridge, 2015; Rubinstein & de Madeiros, 2015).

This thesis is aligned with philosophical and axiological sensibilities of critical gerontology. It is argued that the traditions of hermeneutic phenomenology and the principles of ethics and justice which underpin critical gerontology operated synergistically within this research. Such that they operated as beacon, a means of imposing organisational structure but more importantly, a ‘homing signal’ that called me back and nurtured reflection and growth when I found myself lost. By this I mean I was primed by Holstein’s (1998) call to question and reflect deeply not only on the ways in which the various stakeholders framed their experiences but to interrogate my own assumptions, positionalities, and research practices actively and iteratively throughout the research process. And in so doing, the epistemic contribution of this research was deepened.

As outlined in the preceding chapter, ExtraCare Charitable Trust retirement villages served as the setting for this research. Unpacking the extant literature concerned with retirement village living and extra care housing more broadly provided a critical grounding into the organisational structure and underlying culture at the heart of this research. The subsequent section will therefore summarise key research in the field and make explicit the parallels between the successful ageing discourse and the ethos, practices, and culture of ExtraCare Charitable Trust.

Extra care housing

The ExtraCare Charitable Trust (ExtraCare henceforth) is an example of extra care housing and can be characterised as accommodation for older people (usually 55 years and above) which offers flexible care delivered on-site, 24 hours a day; domestic care; communal facilities and services; social and leisure activities; and security of tenure (Bäumker et al, 2012).

> The ExtraCare Charitable Trust is committed to developing inspirational villages for the over 55s, as an alternative to the traditional care home. We enable older people to enjoy healthy, active, and independent lifestyles in their later years. (www.extracare.org.uk)

As West et al (2017) summarise, while residents are encouraged to live independently, ExtraCare employs key personnel to facilitate the maintenance of residents' physical and mental health, as well their social well-being. Each village for example has a Wellbeing Advisor (a nurse) who manages general health (e.g. blood pressure monitoring, diet and physical activity, cognitive functioning advice etc.) and signposts to external health services; a dedicated member of staff ('Dementia and Wellbeing Enabler' formerly 'Locksmith') whose primary function is to unlock the potential for well-being in residents with dementia (Brooker et al, 2011); an Activities Coordinator who organises entertainment and activities; and a Volunteer Coordinator who oversees the recruitment, training, and retention of resident (and external) volunteers within the village. Residents are encouraged to engage with these services to promote their health and well-being and maintain an active, agentic, and engaged older age.

For most residents, moving into ExtraCare is a considered, autonomous decision rather than the consequences of an acute crisis (Bäumker et al, 2012). A relatively large-scale (n = 949) survey conducted with ExtraCare residents across three sites has explored the multivariate push and pull factors which influenced residents' decision-making process to move. Findings revealed that health concerns (push factor), both current and anticipated, and the provision of flexible, on-site care (pull factor) were the residents' primary motivation for moving into ExtraCare. Such a move therefore could be considered a pragmatic solution to guarantee access to care services in the future. Additionally, on-site social facilities were identified as a significant pull factor, particularly for residents without care needs. Taken together, these findings suggest that the decision the move into ExtraCare is motivated by the provision of social activities and facilities which serve to maintain an active and independent lifestyle whilst simultaneously anticipating future health-related decline and need.

In recognition of the paucity of in-depth qualitative research investigating the lived experience of moving to, and living within, ExtraCare, West et al (2017) and Shaw et al (2016) conducted focus groups and longitudinal interviews as part of a larger longitudinal mixed-methods study. While neither of these studies directly examined older adults' volunteerism or bereavement (the main interests of the current research) these themes were nevertheless embedded within resident discussions and interviews. Both studies for example stressed the critical role of resident volunteers in maintaining the various activities synonymous with ExtraCare. Indeed, West et al (2017) point out that participation in the focus group was also considered to be part of their democratic duty and civic responsibility of being an ExtraCare citizen. Thus, demonstrating that as well as offering an opportunity to maintain social activity, there is also individual responsibility to engage with such initiatives and activities to ensure sustainability. A responsibility which, for some, was becoming a burden. Furthermore, both studies demonstrate that residents experience significant losses (e.g., death of a spouse, loss of friendships, loss of physical functioning, and independence) both prior to moving to, and whilst living within ExtraCare, which elicited ontological insecurity. For instance, residents explained that they were unable to engage in organised, task-orientated activities which had consequently reduced their opportunities for social interaction and well-being. Moreover, residents displayed an ambivalence towards agedness and their own ageing. Some demonstrated a genuine acceptance and readiness for death, whereas for others there was a palpable reticence in seeking care as it was feared that this signalled a future of dependency and decrepitude. Both West et al (2017) and Shaw et al (2016) emphasise that moving to ExtraCare had provided residents with a wealth of opportunities which are manifestly enjoyed and valued. Complementing, and extending the findings from quantitative studies (Bäumker et al, 2012; Darton et al, 2008), West et al's (2017) and Shaw et al's (2016) qualitative investigations have demonstrated that motivations for moving into, and living within ExtraCare, are complex and multifaceted. As observed in quantitative studies, they report that residents are motivated by both current and prospective health needs, and the desire to maintain and extend social relationships. However, using in-depth, longitudinal analyses of both individual and group data revealed a richer, but also more complex understanding of the lived experience of moving into an ExtraCare village. Residents simultaneously valued but were reluctant to seek support; sought social activities but then shouldered responsibility for their continued provision; maintained active involvement in volunteer work in the face of external apathy; and enjoyed physical, cognitive, and social independence whilst witnessing and anticipating loss.

Similar findings have been reported in relation to moving into a continuing care retirement community (CCRC) (Ayalon, 2015; 2018; Ayalon & Green, 2012). CCRCs are broadly equivalent to extra care housing models in that they too represent an alternative accommodation for older people that likewise offer healthcare, domestic care, and an array of social activities (Ayalon & Green, 2012). However, unlike in ExtraCare, living within CCRCs is contingent upon being functionally independent at the point of moving in with the level of care provision to be renegotiated to permit ‘ageing in place’. Nevertheless, Ayalon’s series of qualitative studies display striking similarities to findings reported by West et al (2017) and Shaw et al (2016). For instance, Ayalon (2015) captured a dissonance between (not) feeling and/or looking old and the inherent inevitability of impending losses. However, Ayalon and Green (2012) also more explicitly examine residents’ experiences of bereavement and grief during their move into a CCRC, revealing that the transition surfaced historical, contemporary, and anticipatory losses. Residents experienced their move into a CCRC as both a literal and metaphorical transition, both of which house inherent losses. The move into a CCRC automatically assumes a move away from their previous accommodation, this literal spatial change is tied to the loss of a previous home as well as the life that was lived there. Furthermore, these losses are compounded by the confrontation of future losses associated with decline – residents were faced with their own mortality, with their move into a CCRC representing a step closer to their inevitable death. This fear is intensified within CCRCs as housing units are segregated based on the functional capacity of its inhabitants, with separate independent and assisted housing units contributing to the perception that CCRCs are ‘a place of death’.

The ExtraCare ethos then is saturated in successful ageing discourse. These are facilities for older people purpose-built to provide ‘supportive independence’ and a ‘positive retirement-community lifestyle’ and simultaneously promise the continuity and care to ‘age in place’ (Bernard et al, 2007). There is relentless appeal to ‘activity’ within ExtraCare so deeply entrenched that residents police each other’s participation in public life (West et al, 2017). The emergence of the ‘ideal of activity’ was problematised by Katz (2000) who cautions, “the aged subject becomes encased in a social matrix where moral, disciplinary conventions around activity, health, and independence appear to represent an idealized age” (p. 140). Further to this, Katz argues that the perpetual motion endorsed through the ideal of activity “reinforces the point that bodies, to be functional, must be busy bodies” such that quieter contemplative pursuits are side-lined or even scorned as being “a bland approach to life" and activity becomes an organisational tool for "behaviour management" (pp. 140-142).

Bernard et al (2007) likewise cautioned that by channelling the precepts of agentic ageing – avoiding disease and disability, maintaining cognitive and physical functioning, and civic engagement – ExtraCare were upholding normative prescriptions that pressured residents to conform and limited the possibilities for successful ageing trajectories. Furthermore, Bernard et al (2007) underscore the paradox operating within ExtraCare wherein they have enthusiastically embraced housing models informed by successful ageing that had been developed in North America whilst simultaneously promising to accommodate the 'frail' and 'ageing in place'. Given the propensity to dichotomise older people as either 'fit' or 'frail', 'successful or 'unsuccessful', ExtraCare risks obscuring the variety of experiences inherent within the spectrum of ageing and privileging and elevating some at the expense of others. The Bereavement Supporter Project was conceived precisely to respond to and redress this tension; seeking to move away from interventions centred on the concerns of successful ageing and instead attend to the psychosocial needs of residents more directly.

Bereavement: Theories, experiences, and support interventions

A brief history of grief theory

While grief theory per se is not a central feature of the present research, in that I do not seek to test the predictive capacity of either of the theories described, it is argued that these theories possess cultural currency in how bereavement is discussed, understood, and experienced that is relevant here. Not least because these models were a central feature of Cruse Bereavement Care's training materials which will undoubtedly have influenced participants' experiences and conceptualisations of bereavement and coping with loss. I have therefore concentrated on the two grief theories that the Bereavement Supporter Project training rebutted (Stage Models of Grief) and championed (the Dual Process Model).

Stages of grief

The necessity of 'grief work', to work through, and move on from, one's experience of loss is pervasive in popular as well as academic literature and owes its origins to Sigmund Freud's (1917; cf. Stroebe & Schut, 1999) concept of *'trauerarbeit'* (grief work). Kübler-Ross' (1970) five-stage theory of grief remains a potent stage-based model that is actively taught, practiced, and accepted unconsciously into the discourse of bereavement. While it was recognised that some individuals might experience oscillation between stages, the expected, or normal, expression of grief was proposed to be demonstrated through the progression of the stages of denial and isolation, anger, bargaining, depression, and acceptance. The linearity and prescriptive nature of this model has a practical appeal; deviation from the model signifies 'abnormal' or 'melancholic' grief whereas conformity to the model is reassuringly ‘normal’. Delineation between the two is (deceptively) simple and offers counsellors and healthcare professionals a tool to make quick assessments to establish what, or if, resources are required and will be provided.

Perhaps due to its intuitive appeal, the validity of stage model(s) of grief remained unexplored empirically until the late 2000s when the model was finally tested and ultimately did not support the progression of grief through linear stages (Holland & Neimeyer, 2010; Maciejewski et al, 2007). Despite the flagrant lack of empirical support for stage theory model of grief, Maciejewski et al (2007) conclude their paper by asserting that their findings can be used to educate professionals and bereaved persons about the ‘natural progression’ of bereavement. These conclusions, and the paper more generally, sparked a furore within the scientific community (Bonanno & Boerner, 2007; Silver & Wortman, 2007; Weiner, 2007). With Silver and Wortman (2007) arguing that the endurance of stage-based model of grief, despite contrary evidence, is foolhardy and potentially dangerous as it can lead not only to bereaved people internalising failure of not ‘grieving right’ but to ineffective and potentially harmful support provision from social networks and health care professionals.

Dual Process Model of Coping with Bereavement: An alternative to Stage Models

The aim of the Dual Process Model (DPM) “was to postulate regularities in coping processes that are predictive of (non)adaptive outcomes (Stroebe & Schut, 2010, p. 274). Stroebe and Schut (1999) sought to uncover the ‘hows’ and the ‘whys’ of coping post-bereavement in order to reflect the dynamic and multiplicity of experience; theirs is a taxonomy of coping with loss. Unlike previous models, the DPM posits two categories of stressors associated with bereavement, loss- and restoration-orientated stressors. Loss-orientation mirrors the grief work concept of previous theories, it supposes that one concentrates on, and deals with, some aspect(s) of the loss experience. In particular one might be expected to ruminate on the relationship with the deceased, the life that was shared, and the nature of their death. Restoration-orientation recognises the role of secondary stressors, and potentially further losses, in the process of coping with bereavement, such as adapting to new identities (e.g., from spouse to widow(er)), new responsibilities (e.g., finances or cooking), and reorganisation (e.g., selling the house). As with loss-orientation a plethora of emotions are expected and will be felt with varying intensity differentially at different moments in time. A unique, and critical, component of the DPM is oscillation. Oscillation describes the movement between loss and restoration orientations, it supposes that at times the bereaved will confront their loss, while at other times it will be avoided, and yet at other times still, attending to additional stressors will be unavoidable. In this conception then, avoidance is not indicative of pathology. Rather, it is a necessary function for optimal adjustment over time providing the bereaved the opportunity to attend to other things and have a break from their pain (the DPM diagram has been reproduced in Figure 3).

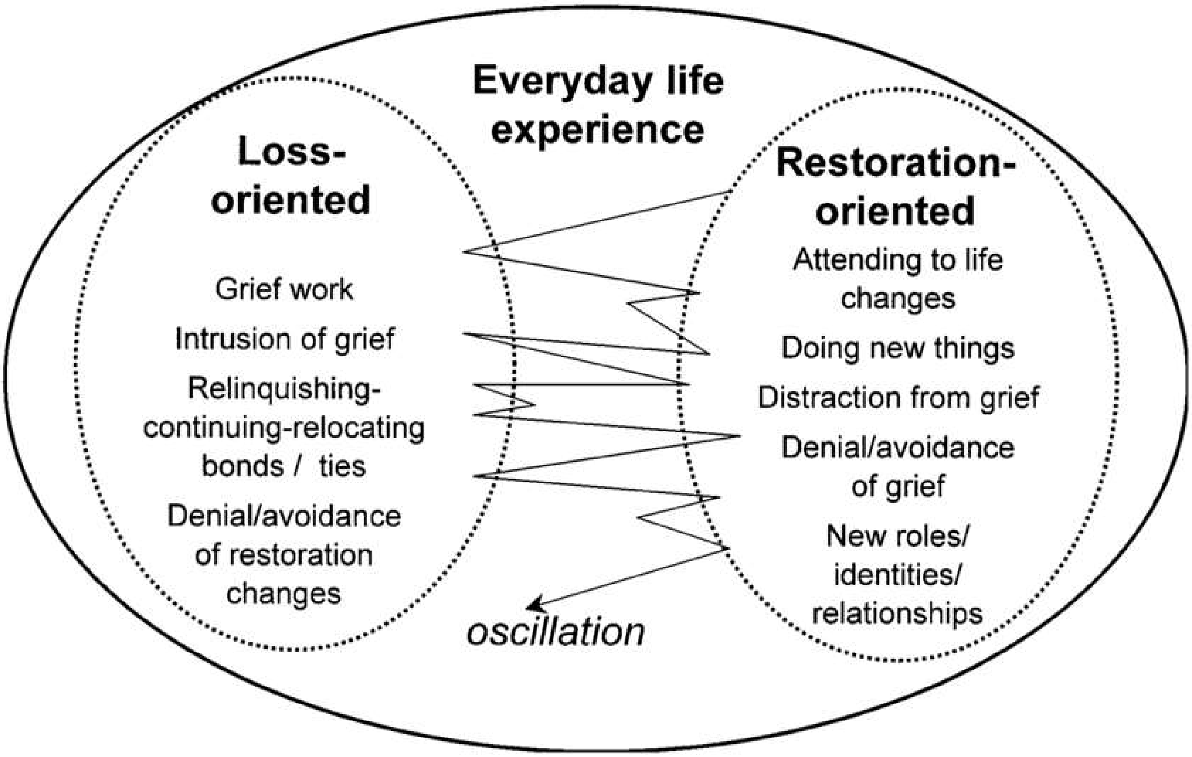

Figure 3. The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999).

As predicted by the DPM, there is evidence that restoration orientated coping is an important aspect of positive adjustment to loss, additionally, avoidance, in small doses, is also demonstrably adaptive (Carr, 2010). Critically, studies emphasise the importance of heterogeneity in the adjustment to loss, “whether, how, and to what end one copes with loss is conditioned by characteristics of the death, the late marriage, and the psychological and social resources of the bereaved spouse” (p. 375). However, Carr (2010) hypothesised that social, economic, and psychological resources may give rise to both stress/coping factors and post-loss distress and argued that more concentrated empirical work is required to unpack the influence of these factors.

Grief and bereavement support among older adults

While bereavement is considered to be a normal, and natural, feature of human experience it can nevertheless be characterised as a period of intense suffering and adjustment (Stroebe et al, 2007). Among the older adult population in particular bereavement has been associated with an increased risk of suicide among widowed men (Li, 1995); poorer perceived health (Thompson et al, 1984); increased risk for weight loss (Shahar et al, 2001); elevated anxiety and sleep disturbance (Byrne, & Raphael, 1997); increased risk of depression (Alexapoulos, 2005); increased risk of complicated grief (Newson et al, 2011);

and increased psychological distress (Thompson et al, 1991). As with the population more broadly, the bereavement experience and coping strategies among older adults is heterogeneous, although this accumulation of findings does implicate older adults as an at-risk group. That being said, Schut and Stroebe (2005) caution against universal bereavement support because routine intervention has been demonstrably inefficacious. Similarly, Raphael et al (1993; cf. Schut & Stroebe, 2005) assert "there can be no justification for routine intervention for bereaved persons in terms of therapeutic modalities - either psychotherapeutic or pharmacological - because grief is not a disease" (p. 146). And yet, there is evidence that some older adults experiencing (non-complicated) grief welcome the opportunity to receive bereavement support (Bui et al, 2018; Lund et al, 1985), and that older adults more generally value more informal support "with the intention to serve, not fix" (Steiner, 2006, p. 46).

Bereavement experiences of older adults

A qualitative study exploring older adults' recent experiences of bereavement and bereavement support (Bellamy et al, 2014) found that the majority of participants were ambivalent about the term 'bereavement support' and what it entails. Participants' scepticism about their need for, and the value in, formalised bereavement support services was perhaps rooted in the belief that accepting support from professional bereavement organisations was indicative of character flaw or weakness. Other research has likewise identified that older adults hold a narrow conceptualisation of bereavement support, reducing it to only professionalised counselling to ameliorate the psychosocial aspects of bereavement (Kirby et al, 2018). While participants recognised counselling could be valuable to 'some people' they emphasised that it offered no benefit to them as they were "strong" and "able to cope", as one participant remarked, "I can sort it out in my own head, I'm not stupid, you know" (p. 400). Nevertheless, Bellamy et al (2014) report that participants did receive, and value, informal support from friends, family, neighbours, and community or religious groups which had positively affected their wellbeing. In particular participants were drawn to peers who had also experienced bereavement and could connect and empathise with them on the basis of shared experience. Similarly, bereaved people (not necessarily older adults) in other studies (Aoun et al, 2018; Breen et al, 2017) have likewise expressed the importance of seeking, and accepting, support that is offered from within personal networks. While there was no evidence within the Bellamy et al (2014) study that participants had unmet bereavement support needs, their narratives perpetuate successful ageing discourse of personal resilience and independence, and "expressed the view that an overreliance on others could be considered a character flaw" (p. 99). It is possible therefore that some older people may avoid help seeking so as not to undermine their sense of self, or how others perceive them.

Bereavement support interventions for older adults

In light of their disproportionate vulnerability to loss and bereavement, and the severity of the potential consequences, it is surprising that the literature review yielded limited research examining bereavement support interventions (and their efficacy) focused on older adult populations. Intervention in the field has largely focused on experiences and efficacy of bereavement support groups. Cumulative evidence indicates that support group attendance produces increases in support satisfaction and positive affect and decreases in support need and negative affect (although the latter was not significant) (Stewart et al, 2001); is a valued opportunity to connect with others with shared experience which mitigated feelings of loneliness and social isolation (Casserta & Lund, 1996; Näppä & Björkman-Randström, 2020); and provided a safe space through which they could reminisce, express their emotions, and express themselves creatively during a period when words alone were insufficient (Young & Pringle, 2018).

The majority of bereavement support interventions focused on group-based activities which overall were well received and valued by participants (Casserta & Lund, 1996; Näppä & Björkman-Randström, 2020; Stewart et al, 2001; Young & Pringle, 2018). Findings suggest that older people value having people they can talk to openly about their grief without judgement, and that group members become important social connections for bereaved people. Although it is not claimed that the interventions mentioned here captures all of the empirical studies conducted examining bereavement support for older people, it is noted that surprisingly few studies have been identified. While all of the studies presented have demonstrated, to some extent, that their respective interventions were efficacious in supporting older people through their bereavement it is nevertheless prudent to examine these studies against the wider backdrop of research pertaining to bereavement support. Overall, reviews examining the efficacy of bereavement support interventions have likewise reported that whilst they are well received (Efstathiou et al, 2019) and yield small positive effects at follow-up (Harrop et al, 2020; Hewison et al, 2020; Maass et al, 2020), the cumulative evidence is weak. Hewison et al (2020) conclude, “the impact of bereavement support services is largely unknown and assessing quality of the services offered is challenging” (p. 75).   While it is not claimed that the research presented in this thesis will correct and overcome the limitations of the field, it is argued that an in-depth examination of older people’s experience of bereavement and bereavement support would enrich our understanding of this complex and nuanced experience.

A critical perspective

So far, this chapter has explored pervasive bereavement theories, identified older adults as a group that is vulnerable to complicated grief and lengthy periods of grief which can affect their physical, mental, and social functioning, and explored interventions to support bereaved older people. Findings have revealed ambiguity regarding what bereavement support entails, with participants equating support with professionalised counselling, and frequently eschewing support in an effort to assert their independence. Researchers have interpreted this as being indicative of great resilience and inner strength. However, I argue that participant narratives resonate with Holstein's (2006) problematisation of the successful ageing agenda, in that it produces very troubling, and very powerful "double oughts" (p. 21), which regulate how we *ought* to age and how society *ought* to think about the ageing members within it. Within a paradigm that positions the absence of disease and disability as the benchmark for success it is not difficult to envisage a situation where older people feel inhibited to seek help and support for their problems because they fear it will expose vulnerability and reveal them to be ageing unsuccessfully. It is of course not clear from these studies whether or not the participants needed or would have benefitted from bereavement support services. However, their narratives intimate that irrespective of the potential benefits, help seeking is not considered to be a viable option for some of the participants, particularly in the form of traditional counselling. The consideration of older adults' understanding, beliefs, and attitudes towards bereavement support may therefore be important considerations when designing and implementing bereavement support services for older people.

Moreover, the bereavement literature presented thus far has uncritically accepted an orthodoxy that positions 'bereavement talk' as adaptive, good, and 'successful grief' while not talking about one's bereavement is positioned as 'death denying' or maladaptive. Indeed, as Zimmermann and Rodin (2004) write, "the idea that it is wrong not to discuss dying was taken up by the death and dying movement both in a general sense and particularly with respect to disclosure of a terminal prognosis" (p. 122). In addition, Walter (2019) argues that in modernist bereavement there is an expectation that "the dead must be left behind; life is to proceed without them" (p. 393) and not doing so is considered pathological. Borrowing again Holstein's (2006) "double oughts", I suggest that the death and dying movement has, perhaps inadvertently or with good intentions, established an expectation that we *ought* to face up to the realities of death and bereavement through discourse and disclosure, and society *ought* to view those who do not perform their grief in this way as being in denial. As I have argued with respect to successful ageing discourse more broadly and will come to argue in relation to civic engagement subsequently, such a reductionist and dichotomised framing of bereavement prescribes what is desirable or 'successful grief' and limits or else pathologises alternative ways of grieving as maladaptive, in denial, or 'unsuccessful grief'.

The Compassionate Communities movement: A public health approach to bereavement care

Introduction

The Compassionate Communities (CC) movement, spearheaded by Allan Kellehear (2005), asserts that over the last 150 years we have observed an unparalleled rise in 'caring professions' (nursing, social work, medicine, psychology and so on) which has "meant the mass abdication and referral of community care concerns to these occupations" (p. 5). Kellehear argues that this overidentification with medicine and their health care allies has resulted in the delegation of end-of-life care to truncated medicalised systems and services that frame "death as a failure of public health policies and initiatives" (p. 1). Further to this, the siloing of end-of-life care to medicalised institutions has resulted in the dizzyingly contradictory experience of having a great number of direct experiences of loss, but few, if any, direct experiences of the 'process of dying'. It is against this backdrop that the CC movement advocates for death, dying, and loss to be reclaimed as phenomena fundamental to the human condition (Kellehear, 2005), and seeks to make death and dying everyone's responsibility (Abel & Kellehear, 2016).

Compassionate Cities/Communities Charter

Influenced by the World Health Organisation's Ottawa Charter (1986) which embraced "a holistic definition of health as an empowered lifestyle which is more than the mere absence of illness" (Kellehear, 1999, p.3), Kellehear challenged the idea that "the prospect of death disqualifies one from legitimate health care attention and interest" (p. 4). He has gone on to develop the Compassionate City Charter which serves to invite cultural and social sectors into end-of-life care and was designed to be employed over significant geo-political areas, such as cities (Kellehear, 2005). The charter demands commitment from governments and community organisations to drive changes in policy and programme development across a range of integral institutions (such as schools, workplaces, and prisons), community and religious groups, and hospices and care homes.

It was anticipated that CC programmes would be implemented in two major ways. First, by a palliative care organisation as part of an ongoing community development programme, and second, by social care or cultural organisations advocating for its implementation in their local government, community or religious group, or business. Given that CC programmes are intended to respond to community needs, a one-size-fits-all approach would be inappropriate. Nevertheless, Kellehear (2005) argued that "*ALL* public health involved an educational component, a community effort, and a government role in one capacity or another" (p. 19, emphasis in original).

Compassionate Communities Interventions: A Scoping review

Many communities, cities, and countries have responded to Kellehear's (2005) call for more compassionate communities. To better understand what this looks like in practice I conducted a scoping review which sought to synthesise what is currently known about the nature and efficacy of CC interventions (see Appendix A). The review yielded 62 papers for inclusion which were then mapped against Clark et al's (2016) taxonomy of interventions at the end of life. In summary, the included studies were identified as educational (n = 17); service (n = 20); clinical (n = 3); cultural (n = 4); and multi-dimensional (n = 18). Rather than reproduce the findings of the review, which was motivated to capture and synthesise the breadth of CC interventions, I will instead attend to more selective sub-sets of the literature that are concerned with phenomena central to this research - bereavement and volunteer mobilisation.

Compassion in pre-existing communities

Research examining the experiences of bereaved people provides a critical grounding in what support networks are currently utilised and valued, as well as identifying opportunities to enrich, mobilise, and connect new and existing networks. Samar Aoun has been prolific in the field, and their research has demonstrated that support from within one's inner network of friends and family is most frequently accessed and valued source of bereavement support (Aoun et al, 2018, 2020). Specifically, participants reported that informal support provided a sense of connection with others that provided security and reassurance that there were people in their life on whom they could rely. While professional support, from psychiatrists, bereavement support groups, and case coordinators were least frequently accessed, they had the highest proportion of perceived unhelpfulness.

Qualitative work has emphasised the idiosyncratic nature of bereavement (Aoun et al, 2018). For example, some participants reported the importance in receiving ongoing support or support several months after the initial bereavement whereas for others the immediate support after the death of their loved one was most valued. Other research has emphasised the importance of practical advice such as funeral arrangements and knowing who can help and how to contact them (Breen et al, 2017). While participants also valued emotional support (largely provided by friends and family) they expressed concern about the reaction of others and were apprehensive of the "rules of grief", particularly in relation to time, with many reporting they felt a pressure to be 'over it' or to no longer talk about their grief after a certain amount of time had elapsed.

Extrapolating from these findings, Breen et al (2017) argue that all bereaved people would benefit from appropriate information and compassion, before and after the death of their loved one. A finding supported by the quantitative evidence reported by Aoun et al (2014). Aoun et al (2018) prioritise the development of interventions to improve the goodness of fit between the bereaved person's needs and support provision. Aoun et al (2014; 2018) suggest that mobilising and training community members to identify and enhance existing networks using network mapping and development techniques is a promising strategy to ameliorate the current gulf between what support bereaved people receive and the support they would like. While these papers provide a critical overview of the kinds of support bereaved people receive and value, they do not, despite the authors claims, provide much insight into how to identify bereaved people at moderate risk of developing complicated risk (according to Aoun et al's (2014) bereavement support model), or how an intervention might upskill the wider community to better support bereaved caregivers, or to mobilise more efficacious support networks. Indeed, Logan et al (2018) argue that "the assumption that the general public is universally prepared, capable, and willing to provide such support is not evidenced" (p. 478), and that the mere existence of (potential) support networks is not sufficient to address unmet needs. They advocate for stronger partnerships between formal bereavement services and communities to "upskill the general public and develop more appropriate, targeted grief support from the ground up" (p. 478).

Cultivating more bereavement friendly communities

Prior to the Covid-19 pandemic research focused on bereavement was relatively obscure within the CC movement (Aoun, 2020). The extant literature revealed that caregivers of people accessing palliative care reported that while care for their loved one had been excellent or good, support for themselves pre- and post- death had been insufficient (Aoun et al, 2017); indicative of the obfuscation of caregivers' support needs by palliative care services which may then negatively impact their grief trajectory. Indeed, Aoun et al (2017) argued that the pre-death period was a 'window of opportunity' for palliative care services to tailor support to meet individual needs in an effort to mitigate the risk of complicated grief. Interestingly, the Covid-19 pandemic has seen a surge in interest in the CC movement broadly, and the drive for improved bereavement support specifically (Harrop et al, 2020; Stroebe & Schut, 2021). My scoping review for example identified six interventions that focused explicitly on bereavement support, the majority of which had been published in 2021 (Bruce et al, 2021; Riley et al, 2018; Hagström et al, 2021; Ummel et al, 2021; West et al, 2021; Zuniga-Villanueva et al, 2021).

Two of the programmes combined psychoeducational techniques with peer support (Hagström et al, 2021; Zuniga-Villanueva et al, 2021) and found the sessions well attended.

Zuniga-Villanueva et al's (2021) study is largely descriptive and provides a snapshot of the profile of people who had accessed the service - women who had experienced the death of a loved one, most frequently their partner – and so provides little insight into the experiences of those accessing the service. Hagström et al (2021) on the other hand employed a longitudinal narrative approach which produced a rich understanding of the experiences of children who had attended a grief support camp for families affected by parental suicide. They reported that attendance increased understanding of grief and provided a framework for families to understand their thoughts and emotions and encourage them to identify personalised coping strategies (children) and contributed to more supportive family communication (parents).

Moreover, both Bruce et al (2021) and West et al (2021) described established volunteer-based bereavement support programmes for older people that pivoted to online and telephony technologies to maintain or establish connection with bereaved people during the pandemic. It is noted that the West et al (2021) study sprang from the Bereavement Supporter Project which used diaries as a means of capturing the in-the-moment reflections of pandemic bereavement for posterity. Both studies emphasised the unique challenges endured by bereaved people during the Covid-19 pandemic including being denied the opportunity to be with loved ones at the end of their life, not having the usual recourse for remembrance, and the palpable pain of grieving alone. Nevertheless, both studies also identified affordances nurtured through pandemic grief, such as reflecting more deeply on life, collective mourning practices, and providing a welcome respite from "mandated happiness."

Given the surge in interest in how we might better support bereaved people post-pandemic, the Bereavement Supporter Project is uniquely situated to contribute to our understanding of the experiences and challenges implementing a bereavement-focused CC intervention. Community mobilisation, achieved through volunteers, is a central component to cultivating CC (Kellehear, 2005). However, the CC literature on volunteers has concentrated on volunteerism within the parameters of intervention implementation. By that I mean that publications typically focus on evaluation metrics such as the feasibility of meeting recruitment goals, the acceptability of training materials, and client-focused outcomes that they have observed. Consequently, the field is largely disconnected from the wider corpus of literature pertaining to the phenomena of volunteerism and specifically what this form of civic engagement means to older people. What follows then is a summary of the evidence related to volunteerism among older adults which provides critical context for the empirical studies presented in subsequent chapters.

Volunteerism among older adults

One of the tenets of successful ageing (Rowe & Kahn, 1997) is the maintenance of civic engagement. Given the pervasive popularity of successful ageing discourse (Martinson & Berridge, 2015; Rozanova, 2010) it is perhaps unsurprising that interest in ‘elderly volunteerism’ has amplified. Cnaan and Cwikel (1992) argue the proliferation of the ‘elderly volunteerism’ agenda can be viewed as a response to three transformative social developments. First, as the population ages a large nonworking population is propagated (Kerschner & Pegues, 1998; Randall, 2017). The economic consequences of this are twofold, first there is a shortfall in workforce availability, and second, there is a surge in welfare resources as pensions are claimed. They argue that, within the American context in particular, younger members of the population are becoming increasingly aggrieved at the perceived rewards being cashed in by retirees, leading to an expectation that older adults should ‘earn’ their social standing by ‘giving back to the community’ through volunteerism. Second, they argue that older adults have been pragmatically identified as the largest group available to replace the volunteer work previously shouldered by women who are now frequently required (or choose) to return to paid employment after giving birth. Third, they argue reliance upon volunteers is a direct response to ubiquitous funding cuts that require agencies to develop strategies to deliver cost-effective service provision. Comparative policy discourse can be observed in the UK,

> One of the most important tasks for twenty-first century Britain is to unlock the talents and potential of all its citizens. Everybody has a valuable contribution to make, throughout their lives. Unless we encourage older people to remain actively engaged in socially valued activity, whether paid or unpaid, everybody in Britain will miss out on the benefits of their experience and social commitment. (Policy Innovation Unit webpage, 2000, p. 1; cf. Biggs, 2001)

More recently, it has been suggested that the current practice of providing those of retirement age with pension information is a critical opportunity to promote volunteerism with the aim to “nudge them towards volunteering” (House of Lords, 2018, p. 62). Against this backdrop it is then expedient for governments and organisations to catalogue the character profile of older volunteers to permit strategic recruitment drives to maximise their volunteer ‘workforce’. Considerable research attention has therefore been afforded to building up a character profile of older adults who volunteer.

Volunteer profile of older adults

Researchers have utilised population level data from longitudinal ageing surveys (Amilon & Larsen, 2020; Dávilia, 2018; Dury et al, 2015, 2016; Einolf, 2009; Haski-Leventhal, 2009; McNamara & Gonzales, 2011; Okun & Michel, 2006; Okun et al, 2007), as well as other longitudinal social research surveys (Ariza-Montes et al, 2018; Choi & Chou, 2010; Saz-Gil et al, 2019) to establish a robust volunteer profile. Cumulatively, findings indicate that older people who are younger, have greater self-reported health, and have a higher income and educational attainment are more likely to volunteer than older adults who fall outside of these profiles.

There has also been considerable research interest in establishing relationships between social capital theory and volunteering. Research has demonstrated that attributes, attitudes, and behaviours used to measure social capital, such as strong religious affiliations, altruism, social connectedness, trust in others, and community engagement predict volunteerism in older adults. This trend is observed across a number of countries including, the USA (Bolano & Arpino, 2020; Choi, 2003); Europe (Amilon & Larsen, 2020; Ariza-Montes et al, 2018; Dury et al, 2014); China (Lu et al, 2020); and Korea (Kim et al, 2007). However, there is emerging evidence to indicate the relative importance of these factors in predicting older adult volunteerism differs between countries, perhaps as a result of societal norms and welfare systems within the respective countries (Amilon & Larsen, 2020; Fukuzawa et al, 2020; Haski-Leventhal, 2009).

This cluster of privileged characteristics maps onto Rowe and Kahn's (1997) tenets of someone who is ageing 'successfully'; the absence of disease or disease-related disability, high cognitive and physical functioning capacity, and civic engagement. Unsurprisingly then, older people who are in better health, and possess greater financial and social resources are more likely to volunteer than those with poorer health and fewer available resources. Further to this, Haski-Leventhal (2009) suggests that in countries with weaker welfare systems, particularly where governments have implemented austerity measures, the wellbeing of older adults is negatively affected both directly through insufficient support services and indirectly, through a public discourse that positions older people as a burden. Volunteerism then provides older people with a socially sanctioned avenue to demonstrate their 'worth' which may in turn improve their wellbeing.

Sources of lifetime inequity are rarely acknowledged or discussed within the parameters of successful ageing (Holstein & Minkler, 2003), or volunteerism among older adults. As Tang et al (2012) point out, research examining racial differences in (formal) volunteering is limited. As evidenced in this review whereby none of the studies reported so far include analyses on the basis of race. Tang et al (2012) suggest the trend that volunteering is dominated by white participants may be particularly acute amongst the older population because "older black people have historically experienced more socioeconomic and political marginalisation and have restricted access to certain type of volunteer organisations" (p. 90). Their research suggests that while older black people were less likely to engage in formal volunteering, once engaged, they devoted a greater amount of time to volunteering and reported greater health and psychological benefits than their white peers. Nevertheless, when interventions are purposively designed to recruit and retain non-traditional volunteers (Morrow-Howell, 2012, 2014; Tan et al, 2006), older adults from lower socio-economic and ethnic backgrounds have demonstrably engaged with, and benefit from, such programmes.

Volunteer motivation

As a complex phenomenon there are multiple theories that attempt to catalogue volunteer motivational domains that can be harnessed to predict and modify behaviour over time. While historically there has been contention among researchers regarding the definitive number of motivational categories for volunteerism (Clary & Snyder, 1999; Cnaan & Goldberg-Glen, 1991) there is nevertheless a level of consensus that has led to the Volunteer Functions Inventory (VFI) (Clary & Synder, 1999; Clary et al, 1996; Clary et al, 1998; Omoto & Snyder, 1995) to be championed, "the standard tool to measure volunteer motivation" (Gage & Thapa, 2011; p. 413). The VFI identifies six personal and social functions served by volunteering: *'values'* (such as humanitarianism), *'understanding'* (to learn more about the world, or use one's skills), *'enhancement'* (personal development), *'social'* (to strengthen social relationships), *'career'* (to gain career-related experience); and *'protective'* (to reduce negative feelings). The psychometric properties of the VFI are well established (Chacón et al, 2017; Clary et al, 1996), including the translations into Dutch (Niebuur et al, 2019) and Chinese (Wu et al, 2009).

Furthermore, a considerable number of studies have used the VFI to explore the motivations of older adults specifically. Findings indicate that older people are mostly motivated by the 'values', 'understanding', and 'enhancement' dimensions (Okun et al, 1998) and least motivated by the 'career' dimension (Okun & Schultz, 2003). Indeed, research has demonstrated that the 'values' dimension is the most significant and consistent motivational factor for older volunteers in Germany, Italy, the Netherlands, and Hong Kong (Ho et al, 2012; Principi et al, 2012). Moreover, Brayley et al (2014), informed by the principals of continuity theory, introduced a new factor, *'continuity of work'*, which proposes that older adults will be motivated to volunteer in an effort to achieve internal (e.g., volunteering would help to maintain a sense of identity after retirement) and external (e.g., volunteering would provide an opportunity to mix with other professionals) stability. Findings revealed that along with 'values', 'continuity of work' was rated as the most important motivational construct and predicted intention to volunteer among older adults.

Differences in motivations have also been observed between older adults, and across countries. For example, differences in motivation between older adults have been identified on the basis of volunteer organisation (Celdrán & Villar, 2017) and the availability of human, social, and cultural capital (Principi et al, 2016). With individuals with lower human and social capital (e.g., low education level, poor health, being widowed, divorced, or single) displaying a greater propensity to volunteer to enhance self-esteem, avoid thinking about personal problems, and for social reasons when compared to individuals with higher human and social capital. Additionally, Principi et al (2012) observed differences in older adults' motivation in all six of the VFI motivational domains across three European countries. Specifically, higher 'values' and 'understanding' motives were found in Germany than in Italy and the Netherlands which they speculate was the product of differing cultural scripts and welfare systems.

Benefits of volunteering

The third area of research interest pertaining to older adults' volunteerism concerns the benefits enjoyed by older adult volunteers. There is an abundance of research investigating the effect of Experience Corps, a high intensity volunteering programme where older adults (typically from underserved communities) commit to volunteering in an elementary school 15 hours per week, for a minimum of one year (Fried et al, 2013; Hong & Morrow-Howell, 2010; Morrow-Howell et al, 2012, 2014; Tan et al, 2006, 2009). In summary, compared with matched controls the programme has consistently observed significant volunteer improvements over time in multiple domains, including self-reported and objective health measurements; fewer depressive symptoms and functional limitations; increased activity within and beyond the programme; improved executive function and memory; increased confidence, knowledge, and skills; and a desire to do things outside of the home. As outlined in the preceding section, volunteerism among older adults is usually undertaken by well educated, wealthy, and healthy individuals. Against this backdrop the findings presented here are critically important as they demonstrate that, if given the opportunity, older people with poorer health, lower levels of education, and those from marginalised groups can, and do, benefit from volunteering, often at greater levels than their more privileged peers (Morrow-Howell, 2012, 2014; Tan et al, 2006).

While the Experience Corps programme is the most researched programme for older adult volunteers, research outside of this programme have produced similar benefits, including reduced mortality compared to non-volunteers, even after adjusting for covariates (e.g. socio-demographics, medical status, physical activity) (Musick et al, 1999; Okun et al, 2013; Oman et al, 1999; Harris & Thoresen, 2005); reduced risk of developing hypertension among 'frequent volunteers' (Sneed & Cohen, 2013); significantly better cognitive performance, fewer depressive symptoms, and better mental well-being and life satisfaction (Schwingel et al, 2009); and significant increase in physical activity (Fried et al, 2004). Whilst the majority of research has been conducted in North America and Europe, similar benefits have been observed in Hong Kong (Jiang et al, 2020); the Philippines (Carandang et al, 2019); Singapore (Schwingel et al, 2009); and Taiwan (Ho, 2017; Hsiao et al, 2020).

With a few notable exceptions (Schwingel et al, 2009; Carr et al, 2015; Fried et al, 2004; Parisi et al, 2014; Tan et al, 2009) this corpus of research is dominated by exclusively, or predominantly wealthy, educated, white elderly women. Thereby significantly inhibiting the generalisability of the conclusions that can be made. For example, analyses within a number of the studies identified significant differences between volunteers and non-volunteers at baseline in pertinent variables, such as number of medical conditions, years of formal education, etc. (Harris & Thoresen, 2005; Oman et al, 1999; Schwingel et al, 2009). This therefore complicates the conclusions that can be drawn – for example, it could be that having fewer medical conditions permits volunteers to volunteer in the first place but also, it could be that having fewer medical conditions rather than volunteering per se has produced the changes in outcome measures. Nevertheless, as Musick and Wilson (2003) point out, “looking at the accumulated research findings on volunteerism and well-being, it is possible to see a pattern emerging, showing a positive, if modest relationship between the two” (p. 260).

Experiential research on volunteerism among older adults

While the empirical research investigating the motivations and benefits of volunteerism among older adults has been disproportionately quantitative, there are some examples of qualitative research emerging that explore the phenomenon of volunteering from older adults’ perspectives in more depth.

Across studies, participant discussion resonated palpably with successful ageing narratives, in particular, older adults framed volunteering as a channel through which they could establish their worth post retirement (Barlow & Hainsworth, 2001; Order & O’Mahony, 2017). Similarly, Chen et al (2020) reported that volunteerism provided older people with a mechanism to mitigate the anxiety elicited by retirement and enabled them to preserve productivity and maintain a professional identity. Furthermore, the ‘giving back’ discourse was pervasive among older adult volunteers (Cousineau & Misener, 2019; Devaney et al, 2015; Narushima, 2005; Pardasani, 2018; Same et al, 2020; Varma et al, 2015), and is usually handled as a benign and normative sentiment by researchers. Although it is noted that some older adults have expressed resentment at the expectation that they must volunteer to ‘give back’ to their community into retirement (Pardasani, 2018).

Experiential research also suggests that older adult volunteers value the potential for personal growth inherent in engaging in unfamiliar roles and activities (Cousineau & Misener, 2019; MacLeod et al, 2016). For example, older adult volunteers valued opportunities to expand both inter-personal and instrumental skills (Narushima, 2005), and argue that volunteering had extended the scope and possibilities within their life which permitted continued achievements and enhanced self-identity (Chen, 2016). Relatedly, Same et al (2020) argue this expansion of older people's repertoire of skills can foster greater self-confidence and self-efficacy which can be applied not only in their volunteer role but also in other areas of life.

Furthermore, volunteering encouraged older people to reflect upon their personhood and life story and provided a meaningful opportunity for collaboration and reciprocity (MacLeod et al, 2016; Allen et al, 2016). Older adults positioned volunteering as simultaneously providing clients with an opportunity to realise the value of their lives, but also and more unexpectedly, an opportunity for personal development and reflection. For some, volunteering provided an opportunity to retell personal stories and connect with their past, but also served to preserve their own legacy and "represented a means of projecting their memory into the future" (Goth & Småland, 2014, p. 6381).

A critical perspective

This review has demonstrated that older adults frame volunteerism as a requisite for a 'productive' and 'meaningful' retirement. In so doing, whether intentionally or not, value is predicated on what a person *does* rather than who a person *is* and demonstrating productivity (i.e., volunteering) becomes a condition of being a good older person, and a good older citizen (Martinson & Helpern, 2011). It has been suggested that a consequence of this is the "truncation of the aging self", whereby productivity is elevated at the expense of other components that constitute a person's identity (Martinson & Halpern, 2011, p. 433), and leads to a homogenised expectation of ageing (Stephens et al, 2015). It denies older people the opportunity for idiographic, quieter pursuits, and erases the obstacles (fiscal, health-related, other responsibilities such as caring for grandchildren or spouse, etc.) that may inhibit some from engaging with, or valuing, volunteering (Minkler & Holstein, 2008).

An axiological consequence of this is that worth becomes contingent on a continued demonstration of productivity which further dichotomises the ageing population into either 'deserving' or 'undeserving' of respect, social acceptance, and resources (Martinson & Halpern, 2011; Stephens et al, 2015). Not only does this limit everyone's ageing experience, but it also erases structures of inequity that "position certain people to be more 'productive' than others" (Martinson & Halpern, 2011, p. 432) thereby perpetuating the unequal power relations of race, gender, class, ability (etc.). Furthermore, the civic engagement narrative is predicated on the assumption of retirement from paid work (a void that older people ought to fill with voluntary work in order to 'give back' to their community), this is simply not the reality for many older people who have to remain within the workforce due to economic necessity (Martinson & Halpern, 2011). Martinson and Halpern (2011) appeal for a theory of ageing based on mutual regard, which although not framed as such is inherently phenomenological (in line with the hermeneutic tradition). Central to this conceptualisation is a process of idiographic meaning-making that permits older people the freedom to define their own 'good life' by reflecting upon what they experience to being most fulfilling, pleasurable, and consummate to well-being. This may well include volunteering, but, critically, it attributes value to a multitude of possibilities.

Concluding remarks

In this chapter I have weaved together multiple strands of literature that serve to ground and contextualise the empirical chapters that follow. The Bereavement Supporter Project was an innovative and complex intervention that necessitated engagement with multiple literatures to gain access to a deeper and nuanced understanding of participants' lived experience. Consequently, this review has spanned literature concerned with the Compassionate Communities movement (Kellehear, 2005), volunteerism among older people, grief theories, and living within extra care housing, a merging of literatures hitherto unconsidered. Operating from within a critical gerontological perspective has been instrumental in piecing together, synthesising, and presenting such a mass of seemingly disconnected threads of scholarship. It has served as a unifying filter through which to examine, interpret, and challenge the respective fields as well as position my own research. I was particularly sensitive to notions and narratives imbued with prescriptions of how older people *ought* to live and how society *ought* to think about ageing people (Holstein, 2006) which raises questions around whose lived experiences are privileged and at whose expense. Furthermore, the problematisation of the pervasive successful ageing discourse has been an integral counter-perspective that has informed and challenged my own fore-understandings of the phenomenon under investigation and so has shaped the design, implementation, and epistemic contribution of this thesis. The subsequent chapter will attend in more depth to the philosophical underpinnings and methods employed within this research.

Chapter 3: Methodology and Methods

Philosophical and Theoretical Underpinnings

Introduction

Carter and Little (2007) posit that, the justification of knowledge (epistemology), the justification of methods (methodology), and establishing research action (methods) should be considered the foundation from which qualitative work is formed. While reflective engagement with these fundamental concepts will likely enrich the experience and process of research, Carter and Little's (2007) primary justification for such engagement is driven by its function to validate research. They argue the quality and validity of qualitative research should be assessed on the basis of the internal consistency between the three concepts rather than the reader's personal preferences. Sufficient and convincing arguments, they reason, will satisfy even the most paradigmatically opposed critic. This chapter therefore presents the philosophical principles that underpin and justify the methods employed.

The research paradigm

This research is situated within the interpretivist paradigm; characterised by its dedication to look for "culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p. 67). Contrary to positivist approaches, which are keenly influenced by the natural sciences, and therefore seek to conduct (arguably) value-free, detached observation to identify generalisable theories from which behaviour can be predicted and controlled, interpretivist approaches are concerned with understanding how an individual perceives and experiences the social world (Chen et al, 2011; Gray, 2013). Interpretivists display a commitment to the idiographic, that is, to the subjective, unique, and individual aspects of the lived experience of a phenomenon (Crotty, 1998; Gray, 2013). In recognition of the heterogeneity within the interpretivist paradigm (Chen et al, 2011; Gray, 2013; Wojnar & Swanson, 2007), it is important to signal that I will be following the philosophical tradition of hermeneutic (interpretative) phenomenology (hermeneutic and interpretative are used synonymously, 'hermeneutic' will be used henceforth).

Phenomenology

Taken at its most basic, phenomenology is understood to be the study or description of experience (Hammond et al, 1991). Rooted within phenomenological study is an ontological imperative – there is a fundamental drive to understand what 'being human' is like, and in particular, what aspect(s) of their situated experience of 'humanness' are most important to a particular individual (Smith et al, 2009). Authors frequently distinguish between the 'descriptive phenomenology' of German philosopher Edmund Husserl and the 'hermeneutic phenomenology' devised by his former pupil, Martin Heidegger (Bynum & Varpio, 2018; Chen et al, 2011; Hein & Austin, 2001; Lowes & Prowse, 2001; Wojnar & Swanson, 2007).

Wojnar and Swanson (2007) offer a succinct yet comprehensive table within their paper that helps elucidate the key differences between the two approaches (see Table 1); the philosophical underpinnings of these two approaches yield fundamentally different epistemic positions and therefore the methods that are available and traditionally employed (Lowes & Prowse, 2001).

Table 1. Key differences between descriptive and interpretative phenomenological approaches (Wojnar & Swanson, 2007).

Descriptive Approach	Interpretative Approach
1. The emphasis is on describing universal essences	1. The emphasis is on understanding the phenomena in context
2. Viewing a person as one representative of the world in which he or she lives	2. Viewing a person as a self-interpretive being
3. A belief that the consciousness is what humans share	3. A belief that the contexts of culture, practice, and language are what humans share
4. Self-reflection and conscious "stripping" of previous knowledge help to present an investigator-free description of the phenomenon	4. As pre-reflexive beings, researchers actively co-create interpretations of phenomenon
5. Adherence to established scientific rigour ensures description of universal essences or eidetic structures	5. One needs to establish contextual criteria for trustworthiness of co-created interpretations
6. Bracketing ensures that interpretation is free of bias	6. Understanding and co-creation by the researcher and the participants are what makes interpretations meaningful

The construction of positivism and interpretivism as a proxy for quantitative and qualitative research while a convenient shorthand to express often diverging epistemic, ontological, methodological, and axiological positions is an oversimplification of the philosophical and practical concerns that guide our research (Shaw et al, 2016). Indeed, Lowes and Prowse (2001) for example argue there is a misguided premise that descriptive (Husserlian) phenomenology opposes the principles of positivism which stems from a misinterpretation of the philosophical underpinnings of descriptive phenomenology. Husserl believed that our knowledge about the world accrues across our lifetime, layer-by-layer through our experiences; the role of science then becomes an unravelling of these layers allowing for an enriched understanding of the 'essence' of a phenomenon (Hein & Austin, 2001; Lowes & Prowse, 2001). Critical to this achievement is the process of 'bracketing'; through systematic examination, acknowledgement, and compartmentalisation of pre-existing beliefs, assumptions, and biases, the researcher “stands outside the research process” (Lowes & Prowse, 2001, p. 473). In other words, objectivity is assumed to be possible, desirable, and is actively pursued through the process of bracketing which seeks to reveal the ‘essence’ of experience. Thus, I concur with Lowes and Prowse’s (2001) assessment that descriptive phenomenology may actually mirror some positivist epistemic beliefs. In contrast, hermeneutic (Heideggerian) phenomenology asserts that experience can only be understood through the interplay between ‘being-in-the-world’ and the ‘lifeworld’ (Guignon, 2012). For Heidegger, our experiences do not exist in a vacuum; they are historically and culturally situated, and rather than strip away this contextualisation (for example, through controlling variables or bracketing), hermeneutic phenomenologists prioritise the examination of ‘phenomena in context’. This lens was critically important within this research which narrowed the focus to four specific ExtraCare villages in an effort to enhance understanding through an intricate examination of site-specific cultures and structures, in addition to the individual experiences of staff and residents who form these communities.

The hermeneutic circle

Heidegger argues that interpretation of an individual’s experience of ‘being-in-the-world’ hinges upon another’s - the researcher - interpretation and experience of ‘being-in-the-world’ (Lowes & Prowse, 2001); the hermeneutic circle is therefore key. Through the hermeneutic circle the researcher is actively positioned within the research process, put simply, they engage in the interpretation of their participant’s interpretation of experience (Guignon, 2012; Smith et al, 2009). It is recognised that as ‘beings-in-the-world’ the researcher and participant automatically share access to a general understanding of being human (Guignon, 2012). Yet, it is simultaneously acknowledged that every individual is a uniquely situated being, and their experiences and interpretations are moulded by their situatedness in a way that cannot be delineated. Thus, within hermeneutic phenomenology, the researcher’s assumptions, beliefs, and knowledge of the world are an intrinsic and legitimate aspect of the research process (Lowes & Prowse, 2001). Furthermore, data generation, typically a phenomenological interview, for hermeneutic phenomenologists represents a meaningful social interaction that is reliant upon the interplay between the researcher and the participant; participants therefore are agentic co-creators in the production of knowledge (Lowes & Prowse, 2001).

Phenomenon of the study

As discussed above, the philosophical underpinnings of this research grounded the inquiry with a commitment to attend to the deep-rooted meaning of human phenomena. The Bereavement Supporter Project was both innovative and ambitious in its aims, seeking to cultivate peer-led compassionate communities within ExtraCare villages. It was evident early on that unpacking the 'phenomena in context' would be critical to gaining meaningful insight into if, and how, compassionate communities can be nurtured. To do justice to the inherent complexity of this project, and consequently this research, it was critical that a multiperspectival design (Larkin et al, 2019) was embraced. It is acknowledged that this approach was conceived specifically for researchers using Interpretative Phenomenological Analysis "to capture more complex and systemic experiential phenomena through the use of multiple perspectives" (p. 183). However, it is argued that this approach can likewise serve other phenomenologically driven inquiries.

Larkin et al (2019) argue that phenomenological inquiry in psychology typically focuses on personal meaning making and prioritises "the value of the idiographic perspective in illuminating people's relationship to the lifeworld" (p. 184) which can give rise to a "one-dimensional perspective on the meaning of events and processes" (p. 184). While such an approach has undoubtedly yielded incredible insight into countless phenomena, it may also be self-limiting, particularly if the object of inquiry has a strong relational or systemic dimension. Attending to the intersubjective permits the 'location of experience' to be embedded within the process of mutual meaning-making, and therefore a multiperspectival design has the potential to produce more nuanced and persuasive understandings of phenomena. Finally, as will be discussed in more depth subsequently (Chapter 6), I conducted fewer interviews with ExtraCare residents than I had anticipated which threatened to limit my understanding of what compassionate communities mean for recipients of support. While it is acknowledged that it remains critical for these insights to be captured, the multiperspectival design of this research provided opportunities to supplement my understanding through the inclusion of additional perspectives. For example, Bereavement Support Volunteers (BSVs) were encouraged to reflect upon their experiences and understandings of the people they had supported and consider why and under what circumstances support had been provided, and what this might have meant for the support recipient. This was often difficult for BSVs who were reticent of being seen to be speaking for others, or for being self-congratulatory, nevertheless their reflections and analyses augmented understanding by providing insights hitherto undocumented.

Reflexivity

Qualitative researchers broadly, and hermeneutic phenomenologists specifically, orientate the researcher as an active agent in the research process and thereby acknowledge, and indeed value, the influence that subjective and intersubjective elements exert on our research (Finlay, 2002). Contrary to positivistic paradigms, subjectivity is not derided and dismissed as undue and undesirable bias that must be controlled and accounted for, but instead, “subjectivity in research can be transformed from a problem to an opportunity” (Finlay, 2002, p. 531). While it is argued that we can never successfully separate ourselves from our experiences and assumptions (as suggested by bracketing), ongoing engagement with reflexive exercises, such as reflexive research diaries, are nevertheless encouraged as a means of consciously, and explicitly ‘verbalising’ the evolution of our understanding and are inherently intertwined with our ‘final’ interpretative product (Finlay, 2002; Lowes & Prowse, 2001; Shaw, 2010; Spence, 2017; Wojnar & Swanson, 2007). Ideally, such efforts and exercises should be prioritised and instilled within the research process from the moment the research is conceived. As Finlay (2002) explains, reflexivity during the early stages of research can be particularly important for phenomenologists who seek to investigate a phenomenon with “openness and wonder” (p. 536). She goes on to argue, “the problem of phenomenological inquiry is that we know too much” (p. 536), in other words our own preconceived understandings, assumptions, beliefs, and familiarity with scientific knowledge limit, direct, and potentially obfuscate the nature of the phenomenon of interest and therefore the epistemic potential of our research.

The danger of leaning into these ‘common sense’ understandings is perhaps even more salient within the current research given that the experience of loss is an ontological truth; it is something that we all experience, and yet we each grieve loss in a multifaceted and idiographic way. It seems obvious that “doing death”, as Visser (2017) points out, is deeply emotional, for both the researched, and the researcher. But the notable absence of subjectivity and emotion in articles within ‘Death Studies’ reflects the dominant ontological position that, like the rest of the natural and social world, death *can* be investigated neutrally. As Robert Hertz (1960, cf Woodthorpe, 2011) eloquently expresses:

> We all believe we know what death is because it is a familiar event and one that arouses intense emotion. It seems both ridiculous and sacrilegious to question the value of that intimate knowledge and wish to apply reason to a subject where only the heart is competent. (p. 27)

By its very definition loss reflects absence, failure, deprivation, destruction, and privation. Critically, loss is additive, the more we live the more we have lost. And, I would argue, as does Visser (2017), we are all - to lesser and greater extents - insiders; loss is an ontological ring that binds us. It is from this assumption that Visser reflected upon the interplay between her research (which likewise centred on ageing and dying) and an accident her grandmother sustained while visiting her in the UK. She writes, “suddenly everything I was reading about home and mobility I was relating to my own grandmother” (p. 9). Visser explained that while this experience engendered greater empathy and rapport with participants, she was simultaneously cognisant that her personal experience frequently guided the questions she asked, and I would add, likely affected the responses she generated. Our personal experiences with the phenomena of inquiry therefore have the potential to alter the course of, enhance, and even terminate our research efforts.

As one might expect from any extended period of time, the five years that I have been immersed in this research have to greater and lesser extents been marked by adversity, loss, and indeed, death. In addition to the usual anxieties, stress, and self-doubt that seem so abundant amongst PhD candidates, my life and consequently my research were struck by the sudden and unexpected death of a family member in late February 2020. Like Visser (2017), it became difficult for me to attend to the experiences of my participants when I was flooded by my own grief. This soon became compounded when the realities of the Covid-19 pandemic gripped the collective consciousness in March of that year when death and loss literally took centre stage in a global arena. Mercifully, I was in a position to take a short hiatus from my studies to reflect upon my loss and begin healing what had become quite a fragile sense of self. In addition to yielding profound and meaningful insights, working reflexively is often uncomfortable, painful, and sometimes, lonely. Reflexivity calls us to identify and interrogate our innermost thoughts, feelings, and actions and as a consequence we are charged with making sense of and hopefully come to accept occasions when we have responded in ways that reveal our prejudice and potentially caused harm – including to ourselves. For me, while reflexivity has been challenging and painful it nevertheless has, as Shaw (2010) asserts, “facilitate[d] awareness both of the dynamic relationships between ourselves as researchers and our participants’ data and also of the way in which our research encounters change our fore-understandings to bring a fresh understanding of the phenomenon we are investigating” (p. 241).

In summary, the dominance of ‘objectivity’ within the social sciences (and beyond) stifles, relegates, and ultimately forces researchers to bury the personal and interpersonal elements of their research experience in an effort to appease positivist hegemony (Finlay, 2002). It is therefore telling that reflexivity has been used to invoke (relative) legitimacy and provide a channel through which our stories can be told and learnt from. Through reflexivity researchers have liberated their pain by giving it voice, which further emphasises and solidifies the power and poignancy of embedding reflexivity within research practice.

Quality

Epistemology is pivotal to assessing research and interpretative quality (Crotty, 1998). For positivists, objectivity, reliability, validity, and generalisability serve as the foundation to claims of high quality research (Lincoln & Guba, 1986). These four criteria, if fulfilled, obviate problems of confounding, atypicality, instability, and bias through techniques such as controlling potential confounding variables and sources of biases, randomisation, representative sampling, and replication respectively. However, as Lincoln and Guba (1986) note, meeting these requirements in social sciences research have often been impossible to achieve for both political and ethical reasons. Indeed, Yardley (2000) notes that establishing a universal, yet flexible framework for assessing the quality of qualitative work - one that is both feasible and endorsed by the heterogeneous qualitative community - has been an enduring challenge.

Within her paper, Yardley (2000) proposes such a framework which consists of four characteristics of good quality qualitative research (summarised in Table 2). First, Yardley argues, there are multiple contextual factors of research that are all of equal potential importance and consideration. Features such as, the empirical and theoretical landscape, language, social interaction and culture, and the relationship and power dynamics between researcher and participants serve as a framework against which researchers can reflect upon and demonstrate *'sensitivity to context'*. The criteria, *'commitment'* (demonstrated through prolonged engagement with the topic, competence in data generation and analysis, and immersion in the relevant data), *'rigour'* (completeness of data generation and analysis), and *'transparency and coherence'* (rhetorical power of the argument or description) are perhaps the most straightforward as they correspond to usual expectations for thoroughness in data generation, analysis, and reporting of research irrespective of paradigm. Finally, and perhaps most importantly, it is essential that research transcends into action and *'change, impact and importance'* could therefore be demonstrated through the contribution to theoretical understandings, practical applications, or socio-cultural impact. Engagement with these criteria offer researchers a tangible way to demonstrate the trustworthiness and quality of their work, as well as a scaffold from which readers can evaluate qualitative work. Indeed, these are the metrics for good quality qualitative research that have guided my own research practice, a point to which I will return in the discussion chapter.

Moreover, it has been argued that there are characteristics and abilities within the researcher that contribute to the production of good quality research (Angen, 2000; Finlay, 2002). Angen (2000), for example contends that "the researcher in the interpretive approach is the instrument through which the topic is revealed" (p. 391). It is therefore essential that as well as being meticulous, flexible, and resilient hermeneutic phenomenologists must also be creative and persuasive writers. Such craftsmanship, it has been argued, produces

> knowledge claims that are so powerful and convincing in their own right that they…carry the validation with them, like a strong piece of art. In such cases, the research procedures would be transparent and the results evident, and the

> conclusions of a study intrinsically convincing as true. (Kvale, 1996, cf. Finlay, 2002, p. 252)

While the craftsmanship of producing engaging and persuasive writing is not underestimated, Kvale's argument is perhaps a little too vehemently articulated for me. As the preceding discussion established, the heterogeneity of epistemology, methodology, and methods within qualitative traditions means that the expectations and procedures embedded within a particular approach can result in starkly different research reports. These differences may be difficult for individual readers to overcome if the author does not rigorously engage with these concepts, and transparently articulate their position. Therefore, in addition to demonstrating the internal consistency between epistemology, methodology, and methods, I was guided by Yardley's (2000) framework throughout the course of this research in an effort to remain sensitive, reflective, and responsive to factors pertaining to research quality.

Table 2. Characteristics of good (qualitative) research. Essential qualities are shown in bold, with examples of the form each can take shown in italics (reproduced from Yardley, 2000).

Sensitivity to context
Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.
Commitment and rigour
In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.
Transparency and coherence
Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.
Impact and importance
Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).

Methods

Data Generation

This section will examine the strategies for data generation and analysis employed within this research. As discussed above ('Phenomenon of inquiry'), this research sought to investigate the lived experiences of a programme designed to cultivate compassionate communities from multiple perspectives, in multiple locations, and at multiple points in time. Given these ambitions and the inherent complexity of this design, multiple strategies for generating data were employed. Attention will now be given to each in turn.

Introducing focus groups

The focus group interview was first embraced by market researchers in the 1920s, shortly followed by social scientists and psychologists in the late 1930s who eschewed traditional, directive techniques in an effort to redress the power imbalance between researcher and participant (Kitzinger, 1994). The ubiquity of the focus group observed across disciplines in the 21st Century was certainly influenced by Krueger's (1994) seminal textbook, *'Focus groups: A practical guide for applied research'*. Here, Krueger (1994) outlined six ingredients that characterise the method and served to distinguish focus groups from other group-based methods which remain salient today. In essence, focus groups produce qualitative data that capture the attitudes, feelings, perceptions, and experiences of a homogenous group(s) of people through open-ended questions or activities. In a very literal way, it is the inclusion of the 'group' that distinguishes focus groups from other qualitative methods in that during a single research encounter, multiple perspectives can be captured simultaneously (Kitzinger & Barbour, 1999). Indeed, Kitzinger (1994) has long been critical of focus group research where there is little (or no) engagement with the group work inherent in a focus group encounter, and instead the method is treated merely as being a cost-effective technique to interview many people simultaneously. She exclaimed, "reading some such reports it is hard to believe that there was ever more than one person in the room at the same time" (p. 104). In focus group research then, it is crucial that the researcher examine the context(s) of the group dynamic and the construction of conversation as well as the content.

Moreover, Wilkinson (1999) argued that focus groups avoid the artificiality of other methods because by nature they tap into conventions and social processes of communication. Krueger (1994) agreed our lives are grounded in group-based discussions, "we find ourselves invited, herded, or seduced into groups for planning, decision making, advising, brainstorming, support, and a host of other purposes" (p. 5), and argued it is through this familiarity that the assertion focus groups are a 'naturalistic' method stemmed. A focus group then, is inherently a social context through which we can "examine how knowledge and, more importantly, ideas both develop, and operate, within a given cultural context" (Kitzinger, 1994, p. 116). Attending to the interpersonal and interactive processes among participants, and between participant(s) and researcher(s), the researcher can identify normative beliefs, shared experiences, and points of tension or conflict (Duggleby, 2005; Kidd & Parshall, 2000; Kitzinger, 1994; 2005). However, there are of course limits to the claim that focus groups mirror 'natural' or spontaneous group conversations and dynamics (Wilkinson, 1999). Focus groups, like surveys or experiments, remain a research tool. They have been designed, delivered, and analysed by a researcher primarily for their purposes and so will only ever approximate naturally occurring discussion.

Focus groups in this research: practicalities, logistics, and learning

In the broadest sense, focus groups were used in this research to explore how the Bereavement Supporter Project was delivered in practice; they sought to examine the experiences and attitudes of a variety of key stakeholders (e.g., BSVs, ExtraCare staff, residents who had received support) within each of the four selected villages. I was interested in what motivated them to volunteer in this project; what skills or learning (if any) they had developed and how they applied them; the examples of bereavement support that had been provided or observed; and how the context and culture(s) of ExtraCare shaped their experience.

Anticipated timeline

For pragmatic and methodological reasons, it was agreed that we would couple the four selected sites for data generation: Sycamore Grove with Oaks Bluff, and Cedar Court with Elmwood Forest. It was rationalised that these couplings (1) permitted data to be generated in waves which aligned with the staggered delivery of the project; (2) provided senior management the opportunity to respond to participant feedback and refine programme delivery in real-time; (3) reduced the risk of having insufficient participants for meaningful focus group discussion (Kitzinger & Barbour, 1999; Krueger, 1994); and finally (4) provided a platform to examine aspects of experience that converged and diverged within, and between, villages. It was initially planned that focus groups with staff and the broader resident population would likewise be conducted through these pairings. However, staff workload prohibited this approach, and so site-specific focus groups with staff and the wider resident population were therefore conducted to maximise participation potential.

Furthermore, I had initially envisaged conducting three waves of focus groups. The first, 3-6 months post-training would largely focus on the training and if learning had been put into practice, followed by two further focus groups approximately 6-12 months apart. In taking a longitudinal approach it was intended that data would capture the unique evolution of project implementation within each of the sites from the perspective of those ‘on the ground’. However, in practice organisational restructure within ExtraCare in 2019, coupled with a high volume of staff attrition in two of the sites (Cedar Court and Elmwood Forest) disrupted village life, the delivery of the Bereavement Supporter Project, and consequently, data generation. Staff engagement with the project had ebbed, and the Project Manager struggled to motivate staff to view the project as a priority. Consequently, the paperwork to evidence support provision in these villages dwindled, and in some cases, ceased during this period. From a research point of view, I felt it was important to capture the experiences of staff and BSVs authentically in-the-moment because it could inform our understanding of the limits or challenges involved in developing Compassionate Communities. However, the apathy of both staff and BSVs was entrenched and there was concern within the management group that we would put a lot of energy into organising focus groups that would not come to fruition. It was agreed that we would postpone the second wave of focus groups to allow all villages to acclimatise to the staff restructure; to provide new staff members the opportunity to attend the training and to become familiar with the project; and where possible and appropriate, to engage with the project at a deeper level (e.g., refer residents to BSVs, apply knowledge and skills from the training). It was also agreed that we would review how, or whether, to proceed with a third wave of data collection during the first quarter of 2020.

Unfortunately, the Covid-19 pandemic made that decision for us. In March 2020, all planned data generation, which included focus groups with ExtraCare staff, and potentially further focus groups with BSVs were cancelled indefinitely. As it transpired, the Covid-19 safety measures would endure for far longer than we had initially envisaged, and for many, the aftermath of the pandemic is still being felt even at the time of writing (autumn 2022). It was prudent therefore to move forward with this thesis without the data I had initially intended to generate. While this was undoubtedly the right decision, both ethically and pragmatically, it was nevertheless a disappointment to have to cease data generation so abruptly, and under such tense and traumatic conditions. Nevertheless, I am confident that the data I had generated previously is sufficiently rich and dynamic to meet the aims of this research.

Participant Recruitment

During the recruitment periods (April/May 2018; October/November 2018; November 2019-January 2020), the Project Manager sent written invites directly to the apartments of all BSVs who had been active for at least three months. For staff, the initial recruitment period (April/May 2018; October/November 2018) was limited to staff who had attended the one-day training. Written invites to all staff members who had attended were therefore sent by the Project Manager. During the second period (February-March 2020), the Project Manager liaised with key personnel within each of the selected sites to advertise and promote the research to all staff members irrespective of their level of engagement with the project. Moreover, as the focus groups with the wider resident population were intended to be open to anyone, recruitment strategies were likewise broad-brush. Strategies included, attending Street Meetings (monthly village meetings where ExtraCare management report on matters arising and residents have the opportunity to voice issues that are significant to them) and putting up posters in each of the villages to promote the focus groups and other forthcoming research activities.

Gatekeepers

This research relied on the cooperation of multiple gatekeepers, defined here as, “someone who has the authority to grant or deny permission to access potential participants and/or the ability to facilitate such access” (King & Horrocks, 2012, p. 31). The Project Manager, who was well known within all of the sites by both staff and BSVs and had a vested interest in my capacity to successfully generate data, functioned as the primary gatekeeper. They acted as a mediator between me and the villages to ensure that focus groups were well attended and ran smoothly. This chain was fairly unproblematic in the case of research with BSVs, and staff who attended the training, as the Project Manager would contact all those eligible directly to invite them to participate in the research.

ExtraCare staff (typically the Volunteer Organiser or Dementia and Wellbeing Enabler) were often secondary gatekeepers as they were charged with relaying the information provided by the Project Manager (which I had provided to them) to the village residents and staff. The influence of gatekeepers was perhaps most salient when trying to recruit ExtraCare residents (who were not BSVs) to participate in focus groups. During one focus group (Sycamore Grove) there was evidence that some residents had been encouraged to participate irrespective of their understanding of what participation would involve, interest in participating, or proficiency in English. It is my contention that the gatekeeper was overzealous in their recruitment strategies and did not consider that their position of relative power may unduly influence participation. In some ways this was straightforward to manage, in that it was clear that these residents did not want or would not be able to participate and so I thanked them for their time, and they left to carry on with their day. Nevertheless, the moment was a little tense, and elicited further reflection and refinement of how we (the Project Manager and I) communicated the research to secondary gatekeepers. This experience speaks to Kitzinger and Barbour's (1999) warning that focus groups that are contingent on gatekeepers are at greater risk of participant selection bias as gatekeepers may, inadvertently, or deliberately, curate a pool of participants they think is most appropriate and therefore deny others with dissenting or alternative views the opportunity to participate.

Setting

Consideration of where a focus group is to be conducted is important because the accessibility, privacy, and familiarity of a space will influence who is able, or decides, to participate (Kitzinger & Barbour, 1999), and the (in)formality of the context will impact the data produced during the discussion (Green & Hart, 1999). In this research, focus groups were conducted in a suite of rooms within ExtraCare dedicated to group activities that were equipped with comfortable chairs and a private kitchen and toilet. It was also a private space that required a booking so interruptions from non-participants occurred infrequently which allowed participants to speak freely and aided the quality of the audio recordings.

Discussion guide

As recommended by Krueger (1994), a schedule of questions was prepared in advance to guide discussion (see Appendix B for example). During the first wave of data generation, questions pertained to motivations for volunteering as a BSV or in the case of staff, motivations for attending the training session; their opinions of the training; how prepared to provide support and well supported they felt; examples of bereavement support they had provided or observed; and personal benefits and challenges as part of their role. The questions for the second wave of data generation were informed by and built upon the wider data set and the interim evaluation report. Questions explored any changes that had occurred, either within the village or for them personally, since we had last met; examples of support they had provided; the significance of formal referrals for BSVs and why so few had been received; and wider conversations around ExtraCare's agenda to become a more death-friendly and bereavement-friendly community. Focus groups with the general resident population of ExtraCare centred around what, if any, bereavement support they had received or observed within the village; their awareness of, and attitudes towards the Bereavement Supporter Project; and, if improved bereavement support within ExtraCare was a personal priority, how might this be achieved.

The schedule of questions was a useful scaffold to facilitate discussion, and the process of creating, refining, and reflecting on the schedule served as useful preparation for me. However, it became evident during the first focus group with BSVs from Cedar Court and Elmwood Forest that participants viewed the focus group as a platform to air their grievances and serve their own agendas. Such that it would have been futile for me to continue to anchor discussion to the question schedule, and instead discussion was co-constructed with participants going forward. While I continued to develop question schedules ahead of research activities, these were primarily used to ground myself before entering the research encounter and served to provide a framework for conversation should it be required (i.e., if the group were quiet or preferred direction).

Introducing semi-structured interviews

The interview has become the de facto method for data generation within qualitative research (King & Horrocks, 2012). The qualitative interview is an instrument that seeks to describe and understand the meaning of phenomena against the backdrop of the individual's lifeworld (Kvale, 1983). Typically, an interview will be theme-focused; the researcher and participant will be bonded by a shared interest in, or experience of, a particular phenomenon which is to be explored collaboratively. The researcher will endeavour to elicit and direct discussion around this topic whilst remaining open to new and unexpected phenomena. Critically, the qualitative interview is understood to be an 'interpersonal situation', wherein the interviewer and the participant engage in reciprocity with one another. Kvigne et al (2002) for example, describe the interview as a "co-operative encounter" or "co-operative exploration" which through collaborative discussion, provides an opportunity for the researcher to gain access to the participant's experiences. To achieve this, Kvigne et al (2002) argue that in addition to what is verbally communicated, the researcher must attend to the nonverbal and interpersonal dimensions of the encounter to enrich their understanding of the participant's lifeworld. That is not to say that understanding is predicated exclusively and uncritically on the observations of the researcher, but rather, that the researcher's spontaneous and intuitive reflections of the encounter provide valuable meaning because "the researcher is part of the intersubjective world and may therefore understand possible meanings that body language expresses" (p. 65). Within this orientation, the researcher is not only recognised as an active agent, but they must enter the encounter with "not only an open mind, but an open heart" (p. 65).

Semi-structured interviews in this research: practicalities, logistics, and learning

Individual qualitative semi-structured interviews were employed in this research in an effort to dig deeper into the lives and experiences of BSVs. Through initial analyses of the data generated through focus groups (conducted in April/May 2018; October/November 2018) I had gained preliminary insights into the complex interplay between volunteers' personal histories, their expectations of the role, and their relationships with, and the influence of, ExtraCare as both a residential and governing structure. I observed that these factors, among others, influenced their experiences of and attitudes towards their role as a BSV, in addition to the project and ExtraCare more broadly. Qualitative interviews therefore afforded an opportunity to supplement the focus group data by attending more concentratedly on the idiographic meaning making of their lived experience as a BSV and beyond.

Participant Recruitment

During the recruitment periods (January-March 2019; October-December 2019), all active BSVs in the four selected locations who had been in the role for at least three months were sent a written invitation to their apartment via the Project Manager. The invitation outlined the core interests of the research, namely, to better understand their experiences of being a BSV through an individual face-to-face interview. In addition, I attended Peer Group and Reference Group meetings to explicate further the purpose of the interview and to answer any questions that BSVs may have had regarding what participation would involve.

Gatekeepers

As above, the Project Manager acted as the primary gatekeeper in the recruitment of BSVs to participate in the qualitative interviews that inform this study.

Setting

As others have commented (Elwood & Martin, 2000; Gagnon et al, 2015; Herzog, 2005; Sin, 2003), the setting for qualitative interviewing has historically been distilled to being a logistical consideration motivated by pragmatic participants who seek a space based solely on convenience. However, Herzog (2005) argues, "one should examine what takes place *around* the logistics of the interview and include this as part of the study, its results, and the social structuring of reality" (p. 4; italics in original). This perspective aligns with the interpretivist turn which views interviews as inherently intersubjective, interactional, and imbued with socio-cultural meaning (Sin, 2003). The location of an interview therefore can "be defined as both a physical 'space' and a 'place' where power dynamics, social relations, identities, and meanings unfold in multiple ways" (Gagnon et al, 2015, p. 2). In this way, an interview site is not merely a convenient physical space to discuss a topic - although this certainly remains a salient consideration - but a place where power, positionality, and multiple scales of social relations intersect producing 'micro-geographies' (Elwood & Martin, 2000). It is argued that careful observation and analysis of the intersections of power, positionality, and place that occur within and between participants can enhance our understanding of the phenomena under investigation (Herzog, 2005).

Within the context of the current study, while participants were invited to select the location for their interview, I included some examples of suitable spaces to mitigate participant concerns of selecting the 'right' place. The participant information sheet read, *"we want you to be as comfortable as possible so where the interviews are conducted will be up to you. It is important that we can talk freely and uninterrupted, so your apartment, or a meeting room within your village may be most appropriate."* Upon reflection, this is perhaps more directive than I intended, and framing the 'suggestions' in this manner may have been viewed by participants as the only options available to them. It was certainly the case that participants elected for the interview to be conducted in either their apartment or a bookable room within their village. Reflexive engagement and analysis of the intersections between power, positionality, and place and space within my own research has afforded deeper empathy with my participants, in addition to enhancing my understanding of the phenomenon under investigation.

Discussion guide

I was motivated to conduct participant-led interviews which permitted the opportunity for participants to tell their stories in their own way, whilst being flexible enough to simultaneously permit dialogue and an exchange of ideas between interviewer and interviewee. I therefore embraced the tradition within biographical interpretative approaches (such as the Biographical Narrative Interpretative Method; Wengraf & Chamberlayne, 2006) to start interviews with a question that invited long narration, but without the requisite commitment not to respond or interact with participants. What follows approximates that initial question posed to BSVs, *"as you know, I'm evaluating the Cruse Bereavement Project. Today, I'm interested in your experiences as a BSV. Although I have some questions prepared, I'd like to start by giving you the chance to tell the story of your experience in your own words and in your own way. So, when you're ready, please can you tell me about your* *experiences of being a BSV?"* In later interviews, by which point participants had engaged in multiple research activities, this was amended to acknowledge their previous participation to, *"…so, when you're ready, please can you tell me how things have been since last we met?"* To supplement this opening question, like most semi-structured interviews (Kvale, 1994), I developed a discussion guide in advance which incorporated guidelines typically endorsed within qualitative interviewing (McGrath et al, 2019). For example, questions were developed to avoid jargon, were organised to 'ease in' to discussion and build rapport and were viewed flexibly to respond to participants in the moment. The headings 'question', 'prompt', and 'rationale' were used as a framework through which potential discussion points could be reflected upon and refined (see Appendix C). In so doing, I was able to chart not only what I intended to ask participants but why I was asking them which helped to formalise my preconceptions and expectations going into the interview.

Reflections on researcher positionality

It was evident that the majority of participants had experienced significant challenges over the course of the project, and they viewed research activities as an opportunity to have 'their say' and 'get it off their chest'; their anger, disappointment, and disillusionment were palpable. In focus groups in particular, they 'naturally' responded to, and countered, each other's challenges and criticisms, often proposing strategies to improve their individual and collective experience. Unexpectedly, they also challenged me and invited me to participate in the discussion, *"are those little snippets of conversation really of any help to your project or did you expect something much more?" [Bernard]*. Admittedly, I was caught off guard by Bernard's direct line of questioning, and on reflection I had not yet positioned myself comfortably within the project. During these early conversations I maintained that I was an *"independent researcher"* who had planned for particular outcomes but was not moved by deviation to these outcomes. I simply reported 'what was' and did not ascribe any personal value to the outcomes, although I admitted there were practical challenges to data generation that required me to adapt the research approach in response to the informal nature of support provision.

I deliberately positioned myself as 'outside' of Cruse and ExtraCare in an effort to build trust and facilitate open discussion, despite it being clear by this point that participants were not afraid to voice their criticisms and concerns explicitly. I was also cautious about unduly influencing how participants framed their experience; having noted previously that BSVs had adopted the language used by the management group to differentiate types of support provision (i.e., 'formal' and 'informal') I was aware of the influence we exerted and was concerned this would 'pollute' participant narratives. After all, I was interested to hear *their* perspectives and experiences in their own words. Finally, my inexperience operating from multiple perspectives (evaluator, PhD researcher) simultaneously had been confusing. I struggled to make sense of the dissonance I experienced; I was actively involved in the delivery of the project (attending meetings, at times having daily discussions with the Project Manager, visiting villages etc.), and would eventually write a report that would speak to its value, yet was trying to maintain a position of neutrality and distance.

Through ongoing reflection, I have developed a more nuanced understanding of my positionality within this research. I have come to appreciate that I am not a distant observer of experience, on the contrary, I am an active, although not central, actor in how the project was delivered, discussed, and experienced. I recognise that it is not possible to stand outside of the project; I have both influenced and been influenced by the conversations I have held with BSVs throughout this research and for me, this speaks to the power of phenomenologically informed epistemic production.

Participants

Participants were successfully recruited from each of the four ExtraCare locations selected for inclusion. Written informed consent was obtained prior to participation. Focus groups were conducted face-to-face in a private room within ExtraCare. Interviews were conducted face-to-face in either a private room within ExtraCare or in the BSV's apartment according to each participant's preference. At their request, Lil and Marcus were interviewed together (in their apartment). Data were recorded and transcribed. Pseudonyms have been used in place of the real name of all participants and ExtraCare locations.

In total, 16 BSVs, three ExtraCare residents who had received bereavement support from a BSV, 23 ExtraCare staff, two senior managers, and nine ExtraCare residents; see Appendix D for further details. More specifically, this comprised of four focus groups with BSVs (n = 14); seven qualitative interviews with BSVs (n = 8); three interviews with residents who had received support from a BSV (n = 3); six focus groups with ExtraCare staff (n = 22); qualitative interview with ExtraCare staff (n = 1); two interviews with Senior Managers overseeing the project (n = 2); and two focus groups with ExtraCare residents who were not BSVs (n = 9).

BSVs were encouraged, but not required to participate in this research across multiple timepoints. Of the 16 BSVs who participated, six participated in two focus groups and an interview; seven participated in one focus group only; two participated in an individual interview only; and finally, one person participated in two focus groups (see Table 3).

Table 3. Profile of participation: Bereavement Support Volunteers.

Participant Name	Focus Group 1	Focus Group 2	Interview
Cathleen			X
Charles	X	X	
Cynthia	X		
Dawn	X		
Dorothy		X	
Elizabeth	X		
Hyacinth		X	
Lil	X	X	X
Lois			X
Marcus	X	X	X
Mary	X	X	X
Meredith	X	X	X
Nancy	X	X	X
Richard	X	X	X
Rupert	X		
Steph	X		

Data Analysis

Introducing thematic analysis

Thematic analysis (TA), as others have commented (Brooks et al, 2015) occupies a paradoxical position within qualitative psychological research. On the one hand its application is ubiquitous, both as a central technique within methodologies such as Interpretative Phenomenological Analysis (IPA; Smith et al, 2009) and Grounded Theory (Charmaz, 2008), but also as a method in its own right (Braun & Clarke, 2019). Yet, it is simultaneously dismissed as a shallow, atheoretical, positivistic analytical approach (Brooks et al, 2015) unsuited to doctoral research on the grounds that it is insufficiently sophisticated (Braun & Clarke, 2014). In their now seminal 2006 paper *'Using thematic analysis in psychology'*, Braun and Clarke themselves lamented, "thematic analysis is a poorly demarcated and rarely acknowledged, yet widely used qualitative analytic method" (p. 77). The explosive success of 'Braun and Clarke's Thematic Analysis' has seen a proliferation in the 'use' of TA in published articles across disciplinary boundaries (Braun et al, 2019) which has seen TA unexpectedly catapulted from a relatively small community of qualitative researchers into the mainstream of psychological research.

Braun et al (2019) warn that using the shared umbrella term 'TA' "obscures divergence, both in terms of procedures, and, more importantly, in underlying philosophy and the conceptualisation of key elements of the method" (p. 845). To demarcate these differences, Braun and Clarke propose a tripartite typology of TA along the 'small q'- 'Big Q' continuum (Kidder & Fine, 1987, as cited in Braun & Clarke, 2019). These 'schools' are named to emphasise the key distinctive element of the approach: 'coding reliability', 'codebook', and 'reflexive TA'. While these approaches employ broadly equivalent techniques to generate and, to a lesser extent, analyse qualitative data, divergence occurs in their underlying philosophy. ‘Coding reliability’ approaches often share the underlying logic and concerns of (post)positivism (i.e., reliability and replicability) and are positioned as ‘small q’ whereas ‘reflexive TA’ embraces situated and contextual realities, and positions researcher subjectivity as an integral component of knowledge production and thus is positioned firmly as a ‘Big Q’ approach. Finally, ‘codebook TA’ occupies a liminal space between reflexive TA and coding reliability TA. Typically, themes are developed in advance, or on a small sub-section of data, which is then applied to the larger data set (like coding reliability TA). However, the method is underpinned by Big Q philosophical beliefs (like reflexive TA) and so inter-rater reliability (and other positivistic quality markers) are not usually incorporated into the process. Each approach has a place within the family of TA. However, it is incumbent on researchers to select an approach that is most suited to their research question, aligns with their philosophical beliefs, and is performed and written about thoughtfully (Braun & Clarke, 2019). The remainder of this section will examine and explicate my rationale for using reflexive TA as the analytic method in this research.

Rationale for using Reflexive Thematic Analysis

This research was deeply rooted in hermeneutic phenomenology and sought to systematically study the experience of participating in an initiative designed to cultivate a compassionate community. In particular, this research was aligned with Heidegger’s ontological perspective that positions “existence as our experience of being-in-the-world (rather than simply our experience of being)” (Hein & Austin, 2001, p. 4). I was interested in examining not only individual meaning making of experience, but also the dynamic and engaged way that people participate in, and with, the world. Further to this, the assumption that we participate in the world with an active and engaged sensibility extends to the researcher, and to the belief that themes “are analytic outputs developed through and from the creative labour of our coding” (Braun & Clarke, 2019, p. 594). Reflexive TA procedures and practices are bound by the values of a (Big Q) qualitative paradigm – positioning the researcher as a central and active agent in knowledge production, an iterative approach to analytic practice, and an emphasis on reflective engagement with the data and phenomenon under investigation – which align with my own philosophical sensibilities. While it is acknowledged that reflexive TA is not uniquely suited to phenomenological research (Braun & Clarke, 2020), I contend that the flexibility of reflexive TA provides space for researchers to orientate their practice using an empathic lens and thereby serve an experiential focus.

Given that this research is phenomenologically rooted, it is perhaps surprising that IPA (Smith et al, 2009) was not embraced as the principal methodology. After all, the detailed examination of lived experience and how one makes sense of one’s lived experience is the raison d'être of IPA (Smith, 2011). While there is certainly overlap in the philosophical commitments of IPA and my own research orientation - both are grounded in phenomenology and embrace the double hermeneutic – there is also a fundamental divergence in our perseverance to, and prioritisation of, the idiographic. IPA is conceived as a methodology, as opposed to a method, and as such its entrenched philosophical roots direct the practices and procedures that are available to the researcher (Braun & Clarke, 2006). In order to do justice to the idiographic commitment of IPA during the analytic phases of the methodology, it is necessary for data generation to be performed with an idiographic sensibility. Such an approach did not align with the demands of project evaluation or the pragmatics of data generation and analysis within this research and so IPA was discounted.

Furthermore, while this research was exploring new terrain, theory generation was not an intended outcome, it is for this reason that Grounded Theory (GT) was not deemed to be a reasonable fit. After all, the primary motivation of a GT study is to produce a substantive theory (Sbaraini et al, 2011). This research sought to explore the experiences of people contributing to the development of more compassionate communities rather than generate theory. While this research shared some practices with GT, for example approaching data analysis with an inductive logic and performing data generation and analysis in parallel, 'theoretical saturation' was a central point of divergence. Theoretical saturation has been conceptualised as the point at which "all of the concepts in the substantive theory being developed are well understood and can be substantiated from the data" (Sbaraini et al, 2011, p. 3). However, it is more often distilled to the assertion that gathering more data would no longer yield new insights into the phenomenon (Charmaz, 2008; Low, 2019). This rendering of saturation as repetition and redundancy primarily operates as a shorthand to justify sample size and the point at which the researcher ceases data generation (Braun & Clarke, 2021), a practice critiqued even by proponents of GT (Low, 2019). It is my contention that the assumption that there is a point in data generation where 'nothing new' can be observed is a logical fallacy – there is always something new to learn. Furthermore, I was compelled by the changing landscape I had become immersed in and was likewise moved to ask questions and respond to participants in the moment. Such a fluid approach to interviewing is discouraged in GT as the introduction of different questions would dysregulate the homogeneity of participant responses and preclude the possibility of data saturation (Guest et al, 2006). It is for these reasons that GT was eschewed in favour of reflexive TA which more closely aligned with my beliefs around theoretical sampling and saturation (Braun & Clarke, 2021).

Analytic stages of Reflexive Thematic Analysis

The phases of reflexive TA developed by Braun and Clarke (2006; 2019) were followed, however, as encouraged by the authors, these phases were approached iteratively and flexibly. A summary of the general analytic process has been reproduced in Table 4. Here, I summarise my own application and reflections of performing reflexive TA in this research.

Table 4. Phases of reflexive thematic analysis, adapted from Braun & Clarke (2006).

Phases of thematic analysis	Description of the process
1. Data familiarisation and writing familiarisation codes:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Systematic data coding:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Generating initial themes from coded and collated data:	Collating codes into potential themes, gathering all relevant data to each potential theme.
4. Developing and reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2) generating a thematic 'map' of the analysis.
5. Refining, defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Writing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Data familiarisation and writing familiarisation notes

Transcription was the first step towards data familiarisation; listening to participants tell their story and engage in discussion (where applicable) was a critical way to relive and bring to life the research encounter. With the exception of one interview (whereby the participant requested for their transcript to be 'cleaned'), all data were transcribed verbatim (see Table 5 for transcription notations). While this was certainly important during the initial phases of data analysis, relistening to the audio recording also served to reinvigorate and recalibrate analysis during later phases whenever I felt disconnected or removed from the source of the data.

Additionally, reading and rereading the transcripts across the data set was critical to setting a foundation of understanding rooted in participant's own words. During the initial read through, I engaged in free coding which captured immediate and visceral thoughts and feelings; explored free association; noted connections across the dataset; and posed questions both directly to the data and to myself. Attention was also afforded to non-verbal and interpersonal aspects of communication, for example lengthy pauses, exaggerated exhalations, and efforts to persuade or challenge other participants were logged.

Ongoing engagement with the data was rewarding, cultivating curiosity and care for the data. However, it was also a time-consuming and emotionally demanding phase of the analytic process as I permitted the personal to permeate coding during this phase. Exposing personal loss and vulnerability, and safeguarding against it eclipsing participant experience was, at times, very challenging. However, giving my own experiences ‘voice’ as part of the analytical process was liberating, and I would argue, provided the release required to recentre my attention to the possibilities of meaning of the participants’ experiences that would be developed in later phases.

Table 5. Transcription notations.

I:	Interviewer
F:	Facilitator
(.):	Short pause
(number):	Longer pause indicated by the number of seconds
(…)	Indicates sequential text has been omitted
Underlined text:	Denotes emphasis
[ ]:	Indicates short interjections made by another interlocuter e.g., [I: okay] Also used to provide contextual or non-verbal information such as, [exhales] and to indicate a comment that could not be heard, [inaudible 17.23]

Systematic data coding

During this phase, data were approached with curiosity and openness. I worked systematically through each of the transcripts in the data set to produce initial codes that captured features of the data that were of interest. Codes were identified using an inductive orientation, that is, they were ‘data-driven’ rather than ‘theory-driven’ and captured both semantic (explicit or surface meaning) and latent (underlying ideas, assumptions, and conceptualisations) content. In an effort to work methodically and comprehensively, I initially approached coding line-by-line. However, given the dynamism of focus group data, and the lengthy narrative monologues of some of the interviews, approaching the data line-by-line often eclipsed contextual and interpersonal features. A more fluid ‘chunking’ strategy was instead embraced as this approach retained the depth of insight afforded by line-by-line analysis without obscuring the bigger picture.

Furthermore, I created a database on Excel to collate the extracts assigned to each of the identified codes across the data set. Codes were organised loosely based on thematic similarity. For example, the codes ‘legitimacy’, ‘validation’, and ‘disillusionment’ were clustered together as my preliminary analysis viewed these aspects of experience as informing and influencing one another. While this early organisational structure was important, in so far as it served to capture my early conceptualisations and connections of the data, it was certainly not viewed rigidly as the ‘final product’ but was rather the springboard for further, and deeper, interrogation of the data.

Generating initial themes from coded and collated data

From the comprehensive initial codes, I began to develop prototype themes. This involved mapping connecting (and sometimes contradictory) exploratory codes together to form themes which captured a coherent, insightful story about the data. In practice, this was a messy and at times overwhelming process. The use of visual aids and representations of the data were critical during this phase of the analysis. Post-it notes of different colours were used to summarise each of the initial codes, preliminary themes, and the research questions which allowed for a fluid and iterative approach to collating and connecting codes to form prototype themes. Finally, a 'miscellaneous' pile was created to house any codes that had not been placed within a theme which allowed the process to move forward without permanently closing the potential of these codes. See below ('Returning to the miscellaneous') for further explication on how the 'miscellaneous' theme was handled.

Developing and reviewing themes

Prototype themes, and the corresponding codes, were interrogated to tease out ambiguity and ambivalence, and to test that they truly reflected a meaning-based pattern, as opposed to a feature of the dataset. Attention was also given to the 'load' of the prospective themes, that is, were themes attempting to do too much? Or were there themes that were 'thin'? These considerations involved a cyclical dialogue between individual codes (and their corresponding data extracts) and the thematic patterns across the data set. This process precipitated further coding and in some cases re-coding of the data to capture the evolution of my understandings of the data and the conceptualisation of the identified themes. Inevitably, this resulted in both the collapse and expansion of themes. Visual maps (see Figure 4 for an example) of each of the prototype themes were then developed to illustrate the hierarchy and relationship between codes with the intention that these would provide the building blocks from which their story would be told.

Refining, defining and naming themes

It is during this phase that the 'essence' of each theme was identified, refined, and distilled. This was not simply a case of paraphrasing the content of the theme, but rather, consideration was given to identify what story was being told through each theme, and how this story related to, and informed the wider story being told about the data.

Organising themes into 'sub-themes' was a useful strategy to arrange and provide structure to complex themes, and to establish the hierarchies of meaning identified within the data. Each sub-theme was carefully refined to ensure it contributed meaningfully to the unfolding narrative of the theme. This was achieved by ensuring the sub-theme was anchored by its connectivity and cohesion with the other sub-themes within the theme (and to a lesser extent the other themes within the chapter) whilst simultaneously contributing new insights about the data that propelled the story forward. The ‘working titles’ for themes and sub-themes were also refined to ensure they captured and communicated to the reader a sense of what the theme is about.

Writing the report

Writing up the thematic analysis in the pages that follow energised my understanding of and relationship with the data. It was perhaps the most exciting part of the analytic process; the culmination of lengthy introspection and interrogation of the data was finally coming to fruition. To finally write the story I had been crafting for so long - the confluence of my analytic narrative with participant extracts - was a cathartic experience. It was not however without complication and challenge. The process revealed fault lines in my analysis; aspects of the data or limitations of the theme or sub-theme that had not be given due consideration which weakened the persuasiveness of the arguments presented were exposed when committed to the page. This was usually resolved quickly, but occasionally it required re-engaging with earlier steps of the analytic process to facilitate a more robust conceptualisation of the theme.

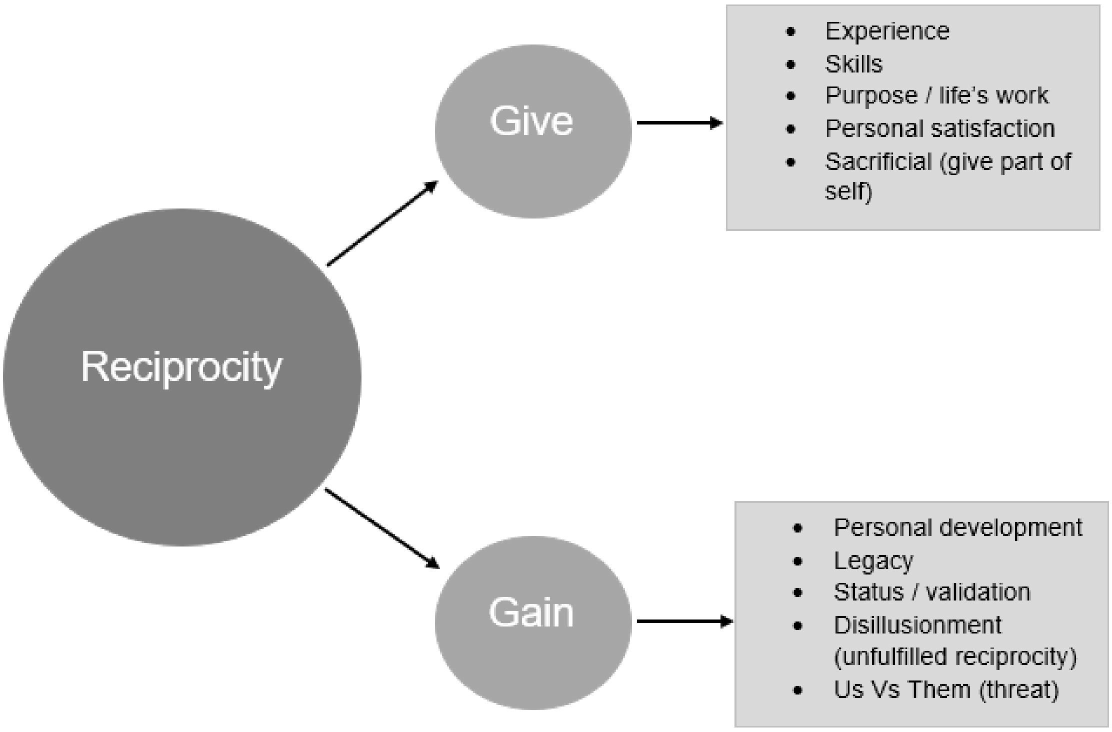

Figure 4. Visual map for the theme ‘“I want this thing to help me”: Negotiating volunteering and reciprocity’ (appears in Chapter 5).

Returning to the miscellaneous

As described above, there were codes that seemed to me to capture something important about participants’ experiences but remained peripheral to, or adrift from, the prototype themes. This, Braun and Clarke (2006) argue is to be expected and suggest analysts use the moniker ‘miscellaneous’ “to house the codes – possibly temporarily – that do not seem to fit into your main themes” (p. 90). In my case, I grouped these stranded codes under the label ‘contradictions’ as they seemed to me to speak to fissures of unease within the data that were marked by ambivalence or inconsistency that did not easily connect with the prototype themes I had constructed. I approached the data from different directions in an effort to facilitate a dialogue between these ‘contradictions’ and the themes under development and review. Ultimately though, the connections I constructed felt forced and so I moved forward without including them.

As Braun and Clarke (2019) eloquently express, “the coding process requires continual bending back on oneself – questioning and querying the assumptions we are making in interpreting and coding the data” (p. 594). And so, after a period of separation from the data, I returned to the shelved codes categorised as ‘contradictions’. I drilled deeper in an effort to unpack my own assumptions and beliefs that directed me to mark these codes as ‘contradictions’. For example, I reflected on my own grief experiences and beliefs, I returned to field notes where I had captured in-the-moment reactions to participant focus groups and interviews, and I traced back and teased out the ‘coding journey’ I had taken thus far. This process was invigorating and permitted a renewed engagement with, and perspective of, the data. However, by this point I also possessed a greater awareness of the literature pertaining to ageing, volunteerism, and CC and so it was more difficult to disconnect from their influence. Rather than struggle against this tide, I leaned into it. More formally put, I engaged in “abductive inference to the best explanation” (Hiles, 2012, p. 7) which sought to explore, and explain, the relationships between theory and data. Within ‘explanation-driven’ logic the analyst “consider[s] the data generated alongside existing theoretical concepts to help explain them further and to better understand the phenomena” (Shaw et al, 2018, p. 235). In this way, theory is neither applied to test a hypothesis (as demanded by a traditional ‘theory-driven logic of inquiry) or generated from the data (as ‘data-driven’ logics of inquiry strive to do), but rather, theory provides a “certain conceptual anchoring” (West et al, 2016, p. 1880) to aid the development of the “best explanation” of the data. It is through this dialogue between theory and the generated data that I have produced the themes presented in Chapter 6.

Presentation of Findings

As evidenced above, the data that informed this thesis was generated from multiple perspectives, and across multiple locations and time points. Rather than present discrete empirical chapters from each of the respective participant perspectives (for example, a study-based approach with an empirical chapter concerned with staff focus groups, interviews with support recipients, and interviews with BSVs respectively) I elected to preserve the dialogic nature of generated data and combine the analyses of multiple data sources. For example, in an effort to explicate the nature of bereavement and bereavement support within ExtraCare, Chapter 4 includes longitudinal data generated from focus groups and interviews with BSVs, ExtraCare staff, and senior management. This approach afforded more opportunities to attend to the multiperspectival nature of this research as it was possible to view data generated from different perspectives in parallel and identify points of convergence and divergence in their experiences. This was important to capture as participants frequently discussed other actors within their communities that affected their experience, and I was motivated to attend to features of experience concerned with the social and structural in addition to the individual. As an example, the paucity of formal referrals (particularly from staff) dominated BSV narratives and consistently appeared within staff discussions; taking a combined approach to analysis then permitted a more nuanced presentation of the factors inhibiting formal referral of bereaved residents to BSVs.

In practice, in line with the analytic strategies outlined above, transcripts were first analysed inductively and spoke to the codes and themes identified from within that particular transcript in isolation. During theme development, points of connection and contention were first identified from within participant groups (for example, I interrogated whether a particular experience or assertion was shared across BSVs or whether it was championed by a sub-set or even singular BSV and whether this changed over time) and then expanded to other participant groups (for example, Extra staff or senior management) to develop rich and dynamic themes. To preserve the multiplicity of the developed themes the three empirical chapters are presented as responses to the research questions outlined in Chapter 1. As such, they are concerned with ‘big ideas’ such as the nature of bereavement and bereavement support within ExtraCare (Chapter 4), what volunteerism means to older people (Chapter 5), and contemporary gerontological discourses and debates (Chapter 6). To orientate the reader, Table 6 precedes the first of the empirical chapters and provides a summary of the data that informed each of the respective empirical chapters, the analytic approach employed, and the research questions to which it responds.

Ethical Considerations

A favourable opinion was received from the Aston University Ethics Committee to conduct this research prior to my appointment. Nevertheless, due to the sensitive nature of inquiry, iterative engagement with the ethical implications of this research were of paramount importance. In accordance with the British Psychological Society’s (2018) code of ethics and conduct, the principles of respect, competence, responsibility, and integrity were used as a framework to guide ethical practice in this research. In practice, these principles were enacted through the consideration of, and sensitive response to, concerns of fair recruitment practices, informed consent, power relations, and participant welfare. Brief attention will be given to each of these factors in turn.

Consultation with ExtraCare and Cruse senior managers, and BSV representatives were instrumental in the development of effective, inclusive, pragmatic, and ethical recruitment practices. Through iterative consultation potential issues that may have contributed to unfair or unsuccessful recruitment processes were identified and mitigated. These largely stemmed from issues pertaining to literacy and visual impairment, but also included more pragmatic considerations. For example, one BSV cautioned that circulating the full information and consent (Appendix E) form during the recruitment phase would be too onerous to read considering the high volume of circular post residents already received. Consequently, a condensed version was created to send to BSVs (Appendix F), and for non-BSV residents material was translated to poster form (Appendix G) as it was not appropriate or practicable to send written invitations to all ExtraCare residents individually.

On the day of research activity (i.e., interview or focus group) participants were provided with a more detailed and comprehensive participant information sheet. During the interview or focus group a generous, and flexible, amount of time (typically around 30 minutes) was dedicated to reading and discussing the information sheet which summarised the nature of the research, what participation would involve, the potential risks and benefits of participation, their right to withdraw, issues pertaining to confidentiality and anonymity, and finally signposting to escalation procedures. I had been made aware prior to commencing data generation that some residents may struggle reading the information sheet independently due to physical impairment, literacy, or language limitations. To mitigate this, I read aloud the information sheet in most, if not all, focus groups conducted with residents and BSVs to establish a shared understanding of what was expected during the research process. Entering the research encounter with open dialogue not only facilitated participation in the research, but also buoyed my confidence in making judgments and recommendations for non-participation and cultivated rapport between participants and myself as we entered the research encounter. Occasionally, these initial conversations surfaced participant concerns that I had not previously encountered or envisaged. For example, one BSV communicated their anxiety that the interview would be transcribed and cited verbatim. They explained that they had participated in research in the past that used a naturalistic approach to transcription and that they had felt foolish and misrepresented when they identified their words within the written report. While I maintain that a naturalistic transcription style can provide key indicators that enhance interpretation, it is not a technique I felt so strongly about that I would jeopardise a potential participant's welfare or engagement with the research. In collaboration with this participant, I incorporated an amendment to the consent form that reflected our agreement that the transcription and citation of the interview would not include features of naturalistic speech.

Furthermore, feminist scholars have long been critical of the neutrality of power presented in social science research (Doucet & Mauthner, 2008). They have challenged the assertion that it is not only possible, but desirable, to equalise power differentials between the researcher and the researched. The researcher, it is argued, is uniquely situated to produce, and disseminate knowledge, leading to interviews that are not only inherently hierarchical but also potentially unethical. Consequently, there is a call for researchers to "display a growing appreciation of the 'dilemmas' and tensions involved in coming to know and represent the narratives, experiences, or lives of their interview subjects" (p. 348). Hewitt (2007) for example, advocates for researchers to reflect upon, and communicate, the ways in which data generation and analysis has been influenced by demographic (i.e., age, gender, social class) and contextual (i.e., personal qualities and the capacity for intimacy of the researcher and participant, the (in)formality of the research encounter, the environment) factors. As a white, well educated, (comparatively) young woman I certainly possess a lot of power and privilege within the research encounter. As I have commented elsewhere ('reflections on researcher positionality'), I was initially concerned that participants would imbue my position as a researcher with authority or 'officialdom' which would inhibit their responses. A belief that perhaps stemmed from a stereotyped representation that characterises older people as particularly acquiescent to figures of authority and power. However, it was evident early on participants were largely unintimidated by those viewed as *"management"* or *"government officials"*, including myself. In fact, participants were accustomed to articulating their views, and indeed making demands, in public forums. I likewise found participants did not hold back their critiques, and for some, the research activities were viewed as an opportunity to set their own terms of discussion in order to 'get things off their chest'. In hindsight, this lack of reverence to authority was perhaps to be expected, particularly among BSVs who were after all going against the grain by participating in a radical project centred around death and bereavement. Nevertheless, I suspect that my age, and my open and flexible approach to research, influenced researcher-participant relations, and consequently, the data that was generated. I was frequently referred to as *"the girl from the university"* and participants often expressed concern that I might not be getting what I needed from our conversations whilst simultaneously hoping that they had nevertheless been able to contribute meaningfully to my research. Additionally, participants would occasionally articulate assumptions about my lived experience of loss and grief; based on my younger age it was assumed I had not experienced deep loss personally.

This could easily have been framed as ‘you are young, you couldn’t possibly understand’ but instead participants were generous in their efforts to envelop me in their experiences, often sharing photographs and mementos to draw me into their world.

Moreover, Kvale (2006) has argued that the characterisation of an interview as dialogue is inherently misleading as “it gives the illusion of mutual interest in a conversation, which in actuality takes place for the purpose of just one part – the researcher” (p. 483). He contends that the interview is a (potentially) manipulative instrument employed by researchers to collect the life stories of others. The risk of “dangerous manipulation” within an interview context is then compounded by the quasi-therapeutic role researchers occupy which serves as a “‘Trojan horse’ to get behind the defence walls of the interview subjects, laying their private lives open and disclosing information to a stranger, which they may later regret” (p. 482). Despite my efforts to position the research encounter, and myself, outside of the therapeutic alliance there were nevertheless occasions where participants sought my reassurance that they were ‘grieving right’ or ‘doing a good job’. It therefore became increasingly important to ensure participants received appropriate signposting and support following our discussions. I incorporated significantly more ‘debriefing time’ than I had originally envisaged to buffer the transition between the interview and resuming ‘normal life’, and to gauge participants’ adjustment to this transition. Further to this, where possible focus groups were organised to coincide with the Project Manager being on-site and available to provide bereavement support if discussion surfaced painful memories that participants felt they wanted to discuss further. This was particularly important for focus groups with the general resident population as I had no fore-understanding of, or relationships with, these participants from which to ground or gauge their response to the discussion, which was inherently unpredictable as it was largely participant-led. Kvale’s axiological reservations about framing the interview-as-dialogue, and more broadly his contentions about the misrepresentation of the interview and interviewer elicited deep reflection and refinement of my practice, as well as strengthening beliefs that I already held. It was my intention during interview and focus group discussions to display a reverence to the value of participants’ experiences and welfare by encouraging them to steer the topics of conversation; question each other and me; respond to and counter my interpretations; and present my motives as transparently as I was able. While I capitulate to Kvale’s point that, ultimately, the researcher possesses the privileged position as the “big interpreter”, I nevertheless maintain that these strategies were successful in redistributing power between researcher and participant(s) within this research.

Concluding remarks

This research sought to explore community experiences participating in a Compassionate Communities project, an innovative initiative which invited a more open dialogue about death, dying, and bereavement and aimed to de-professionalise bereavement support within ExtraCare villages through peer support. As such, this research is orientated within hermeneutic phenomenology, a philosophical tradition rooted in the ontological drive to better understand our experience of 'being human'. It was important that this research captured not only individual meaning making but also attend to intersubjective and systemic elements, a multiperspectival design was therefore employed in an effort to unpack the 'phenomena in context'. To achieve this, focus groups were conducted with a range of stakeholders across multiple sites and time points, and supplemented by interviews with Bereavement Support Volunteers generated rich and nuanced data. Reflexive thematic analysis is underpinned by 'Big Q' sensibilities but remains methodologically flexible and dynamic and so was selected to analyse the data in this research. Attention will now be given to the three empirical chapters produced from this research.

Table 6. Summary of Empirical Chapters

	Chapter 4	**Chapter 5**	**Chapter 6**
Research Question(s) **(Main Research Question: MRQ)** **(Sub-question: SQ)**	MRQ1 SQ2	MRQ1 MRQ2 SQ1 SQ2	MRQ2
Reflexive Thematic Analysis	X	X	X
Logic of Inquiry	Inductive	Inductive	Abductive
Focus Groups with Bereavement Support Volunteers	X	X	X
Interviews with Bereavement Support Volunteers	X	X	X
Focus Groups with ExtraCare Staff	X		X
Interviews with Project Senior Management	X		X
Interviews with Support Recipients			X
Focus Groups with ExtraCare Residents	X		

Chapter 4: The nature of bereavement and bereavement support within ExtraCare villages

Introduction

The Compassionate Communities (CC) movement, spearheaded by Allan Kellehear (2005), asserts that over the last 150 years we have observed an unparalleled rise in ‘caring professions’ (nursing, social work, medicine, psychology and so on) which has “meant the mass abdication and referral of community care concerns to these occupations” (p. 5). Kellehear argues that this overidentification with medicine and their health care allies has resulted in the delegation of end-of-life care to truncated medicalised systems and services that frame “death as a failure of public health policies and initiatives” (p. 1). It is against this backdrop that the CC movement was born and sought to make death and dying everyone’s responsibility (Abel & Kellehear, 2016).

To achieve this, one frequently employed strategy (see Appendix A, ‘Scoping Review’) is the mobilisation of volunteer community champions to provide support to those at the end of life, their carer(s), or the bereaved, either directly or through enlisting the help of wider networks and communities. The Bereavement Supporter Project - a partnership between Cruse Bereavement Care and the ExtraCare Charitable Trust – was a pioneering public-health approach to bereavement care within retirement villages which sought to cultivate death and bereavement friendly communities through education activities, and, critically, through peer-led bereavement support.

Research investigating the impact of such volunteer efforts have found that volunteer companionship and support significantly reduced admissions to emergency and unscheduled health care services (Abel et al, 2018; Cronin, 2015), although the authors acknowledge the mechanisms that drive these findings are not yet fully understood. In addition, qualitative enquiries have found that support recipients valued the informality and flexibility of peer support (Walshe et al, 2020), as well as appreciating companionship with someone who was comfortable and competent at providing emotional as well as instrumental support which “altered the qualitative nature of their experience, even if it did not change the medical trajectory” (Pesut et al, 2018; p. 9). However, the only two randomised controlled trials currently published within the field (Walshe et al, 2016; 2018) were unable to determine the efficacy of the intervention as between group analyses were prohibited due to the study being insufficiently powered. Additionally, the authors noted that missing data and attrition due to ill health or death at follow-up also limited the claims that could be made. Nevertheless, Walshe et al (2020) cautiously observed an improvement in quality of life among those in the intervention group and a decline among those in the control group in most domains.

Moreover, as an emerging field, publications also have a demonstrable interest in attending to the experience of intervention implementation, particularly to elucidate the challenges and obstacles that researchers, organisational partners, and those delivering or receiving the intervention have experienced. Given that the CC movement is radical in its intention to disrupt the status quo that has aligned bereavement with medicalised concerns and services, it is perhaps unsurprising that ‘changing people’s minds’ is frequently presented as a significant challenge to successful implementation of CC programmes. Indeed, Grindrod and Rumbold (2018) posited that unhelpful social norms, such as the belief that dying was a private matter, or that asking for or accepting help would be viewed as socially unacceptable was one of their most significant findings. In their study, carers almost exclusively refused offers of help instantaneously, even when help was offered informally from within their network of friends, family, and neighbours. Others have commented that merely using the word “hospice” within CC programmes was a barrier to successful implementation because of widely held public belief that “hospice and palliative care is associated with imminent death, rather than living and dying well” (Pesut et al, 2020, p. 10). While productive partnership between organisations, community leaders, and citizens have been identified as the cornerstone to developing more compassionate communities (Kellehear, 2005) research has consistently demonstrated this cohesion to be more problematic in practice (Abel & Townsend, 2015; Pesut et al, 2020; Walshe et al, 2020). For example, Pesut et al (2020) argued that organisational capacity, connectivity, and continuity were paramount to achieving the intended outcomes of the Nav-CARE programme which connected adults at the end of life with trained volunteer navigators. Specially, the authors commented on ineffective linkages between communities and healthcare partners; organisational disruptions that involved changes to both resources and personnel; organisational hesitancy to follow the recruitment protocols the research team had devised which suppressed recruitment opportunities; and resistance to the programme from healthcare professionals.

While Pesut et al (2020) achieved their objective to provide a comprehensive overview of the various facilitators and obstacles to successful implementation it consequently obscured participants’ lived experience and what inclusion in the study meant for them and their communities. Moreover, while qualitative data generation techniques have been employed within the literature (Krakowiak et al, 2018; Marsh et al, 2017; Riley et al, 2018; Walshe et al, 2020) the analytic techniques employed have largely been obfuscated and yielded findings descriptive in nature. Qualitative researchers have historically, and contemporaneously advocated for a landscape of qualitative enquiry characterised by its multitudes (Yardley, 2000); such a landscape provides space for diversity in data generation and analytic techniques to flourish which consequently provides opportunities for epistemic possibility. As others recommend (Harper, 2011; King & Horrocks, 2012), it is crucial that the methodologies employed serve to answer the researcher's question(s), so I do not critique the literature in the field for the strategies they have used per se. Rather, it is my contention that, first, publications in the field would benefit from greater methodological transparency, and second, there is a paucity of qualitative research orientated within an interpretative paradigm which limits the depth and nuance of understanding of how to cultivate and live within, compassionate communities. I argue, this research is uniquely suited to respond to this gap.

This empirical chapter weaves together the narratives from multiple perspectives (BSVs, Senior Managers, and ExtraCare staff and residents) and across different locations and time points in an effort to unpack how bereavement and bereavement support are experienced within ExtraCare. More specifically, it seeks to respond to Main Research Question 1, *"what do the lived experiences of ExtraCare communities participating in a CC intervention tell us about the project of de-professionalising bereavement support and cultivating more community-orientated systems of care?"* and Sub-Question 2, *"in what ways does the culture, policy, and practices of ExtraCare as a proponent of successful ageing influence the experience and successful implementation of the Bereavement Supporter Project?"*

Results

Through inductive reflexive thematic analysis (Braun & Clarke, 2019), two main themes were constructed (see Figure 5). Through the theme *"we are all dropping off like flies, it's a fact"* it is argued that ExtraCare is a unique environment to observe the phenomenon of grief and bereavement as residents, perhaps uniquely, experience loss as an inevitable but often obscured feature of daily life. The second theme, *"it feels like a lot more, it feels like you're trying to change a culture"* explores participants' experiences of participating in the Bereavement Supporter Project. Through a series of sub-themes, it examines the observation that, contrary to expectation, bereavement support provision was largely informal, but further to this, it attends to participants' sense making processes as they reflect upon and come to understanding(s) that help to them to explain and contextualise the schism between expectation and reality. Specifically, it attends to the ways in which ExtraCare cultures, policies, and practices influenced the experience and sense making of participating in the Bereavement Supporter Project.

“We are all dropping off like flies, it’s a fact”

This theme first serves to provide foundational context to elucidate the origins, rationale, and missions of the Bereavement Supporter Project. It is through this theme that ExtraCare staff, residents, and BSVs frame ExtraCare as a site where loss is both literally, and more abstractly, all around. By attending to participants’ ‘sense making’, this theme explores how, and what stories participants constructed in an effort to make sense of the daily lived experience of loss that was all around them.

While it was acknowledged that irrespective of age, we are all vulnerable to death, death and loss more broadly were nevertheless presented as being *“closer”* to or more salient for older people. As Matthew [ExtraCare Senior Manager] summarised:

> *I mean any of us could, you know, have a bereavement, either a death or some kind of loss. But for the residents everything's a lot closer, the idea of a bereavement and the loss of a person or the loss of something, like independence or health or maybe things like self-esteem. Probably a little bit more [sic] closer to residents, older people than they maybe are for us.*

Indeed, some residents appeared grateful that the focus group provided them with an opportunity to share their experience of loss, which was typically characterised by accumulated significant bereavements and losses. The most striking examples came from the resident focus group at Cedar Court whereby the discussion about personal losses began, unprompted, before the recording device was even switched on. Within the space of a minute participants relayed an unrelenting succession of loss which appeared to escalate as each participant summarised their experiences. For example, Dolores explained, *“I was in a road accident and my friend who lived here – we’d known each other for 50 years, she died two days later”*, followed quickly by Lucille who documented her catalogue of losses, *“my husband passed away, my mum first, then my dad and then my husband all in four years and then in the same year within nine months I lost my daughter.”* These participants were effusive in their praise for the support they had received from staff following their bereavement, with Lucille going so far as to say, *“without the support that I had here, I don’t think I would have been able to cope.”*

In addition to experiencing personal, potentially private bereavements, ExtraCare residents also bear witness to death and bereavement in very public ways, as Alice [Volunteer Organiser, Oaks Bluff] noted, *“they feel like death is all around them because there are people dying, bodies being taken out (…) so they say that death is already in their face.”* Daisy [Personal Support Assistant, Cedar Court] likewise empathised with the toll that being confronted with so much death must have upon residents, *“they see more [death] so I think it’s understanding that it can – although they may not be bereft, they’re going to be grieving in some way their own mortality.”* Paradoxically, BSVs framed ‘ExtraCare’ itself as directly contributing to and compounding the experience and visibility of bereavement. While they likewise noted the more 'obvious' links between ExtraCare and bereavement - for example, bereavement or deteriorating health precipitating the move to ExtraCare, or the death of residents within the village – it was evident that BSVs had embraced the wider conceptualisation of bereavement presented in the information session and one-day training provided as part of the Bereavement Supporter Project. The training was tailor-made for this project, and designed specifically to resonate with the unique experiences of older people, as Grace [Cruse Senior Manager] explained,

> *older people out of all of the groups of society I would say are one of, if not the top group who will experience the most loss in life outside of bereavement as well so loss of health, independence, erm change in circumstance (…) so it was really important that we looked at loss in its widest context.*

This wider conceptualisation of bereavement, one that included the *"raft of other losses"* that older people may experience, was identified by both staff and BSVs as the single most important learning from the training. This definitional expansion challenged participants' sense making, it *"opened their eyes"* and provided a different lens through which to understand and respond to loss. For example, participants acknowledged that what had once seemed like a 'mundane' loss was suddenly coloured by various hues and permutations that could cascade from a single death,

> *Samantha [Care Manager, Sycamore Grove]: whoever it is, nan, grandad and then suddenly they've passed away that's a loss not just because you've lost them*
>
> *Marnie [Receptionist, Sycamore Grove]: yeah*
>
> *Samantha: but to your daily routine you think, "I've gotta do this" but then "oh no, I don't have to do it no more"*
>
> *Marnie: when you forget for a few seconds so again it's an adjustment in that way to somebody's daily life that you know that they're used to and it's almost like a loss to them.*

Here, Samantha and Marnie reflected that the experience of loss extended beyond the physical death of a body. Rather, grief may also manifest more abstractly as one must adjust to new realities; realities that are absent of important routines, roles, and relationships. Furthermore, participants such as Charles [BSV, Oaks Bluff] repeatedly argued that moving to ExtraCare compounded residents' experience of loss and grief. He referred to one person he had provided ongoing support to who had *"lost everything at once: husband, home, neighbourhood, friends, furniture because the house was big, and she moved into a small apartment. She lost everything."* By bridging the experience of bereavement with loss more broadly the training provided a new pathway to guide care, one that sought to understand the individuality inherent in the 'meaning of things' and to use this understanding to ground and guide care.

Other participants commented that older people’s bereavements were treated as an inevitable part of the life course, as something *“to be expected”*, particularly if death resulted from a protracted illness. As a consequence, they felt little attention was given to how bereavement was experienced by older people, and by extension, what their support needs might be. Matthew [ExtraCare Senior Manager] went further, he argued that older people’s support needs often go unmet because counselling practitioners have *“a kind of expectation or a kind of (.) or the idea is that older people (.) you know, it's that they're past it, they're kind of beyond any kind of point where help, that sort of help would be beneficial.”* It was precisely to counter this erroneous and damaging narrative that motivated Matthew to develop and launch the Bereavement Supporter Project within ExtraCare villages and schemes. Given the ubiquity and visibility of loss within ExtraCare Matthew lamented, *“I just don't know why we didn't really notice it before. Or maybe we did but we didn't really necessarily do much about it.”* He went on to suggest that at an organisational level, ExtraCare had historically favoured initiatives and interventions that prioritised improving or maintaining the physical health of residents, and as a result, residents’ psychosocial wellbeing had been neglected. He concluded, *“I think we do the physical health side of things really, really well (…) but maybe some of the psychosocial stuff we've not done so much of.”* Here, Matthew positioned The Bereavement Supporter Project as a rather radical departure from ExtraCare’s propensity for physical health interventions, and it was against this backdrop that the project would be introduced, compared, and ultimately, judged.

In summary, through this theme I have demonstrated that despite a legacy of health promotion and the promises of the third age, ExtraCare was, and continues to be, a space inhabited by death and bereavement in both private and public spheres. The Bereavement Supporter Project was positioned as an opportunity for ExtraCare to pivot away from interventions driven by the medical model and towards more holistic approaches which include mental health, psychological, and social facets of Being. Finally, the wider conceptualisation of bereavement (i.e., the idea that loss of all kinds can be significant and elicit a grief reaction) introduced within the information sessions and one-day training helped staff and BSVs see how residents may be experiencing, making sense of, and responding to a multitude of bereavements thereby providing a new framework to guide care.

"We are dropping off like flies, it's a fact"

- Speaks to the ubiquity and visibility of loss and grief within ExtraCare.
- Introduces social norms and practices active within ExtraCare that may historically have obscured residents' experience of loss and the availability of suitable support provision.

"It feels like a lot more, it feels like your're trying to change a culture"

- Questions the readiness of ExtraCare staff to embrace a radical, de-professionalised conceptualisation of bereavement support.
- Suggests a cultural legacy of stoicism inhibits older people from seeking bereavement support overtly.
- Explores what informal support offers bereaved residents (that formal structures cannot).
- Identifies the unqiue bereavement experiences of ExtraCare staff and their current unmet needs.

Figure 5. Summary of themes and the 'essence' of each theme' developed through reflexive thematic analysis.

"It feels like a lot more, it feels like you're trying to change a culture"

As established in the preceding chapter, the Bereavement Supporter Project was developed to respond to the unmet support needs of bereaved people within ExtraCare villages and schemes. The original model of support provision, informed by Cruse Bereavement Care's decades of experience providing support to bereaved people, envisaged support would be accessed through formal channels; that is, through self- or staff-referral (see Appendix H for model of bereavement support envisaged). In practice, BSVs received very few formal referrals through either channel, instead support was provided organically at a community level through *"casual conversations."* Through a series of sub-themes (see Figure 5) this theme attends to the unique culture and organisational structures within ExtraCare in an effort to contextualise the experiences of staff and residents participating in this compassionate communities initiative.

"It's bad enough getting older and knowing we're going to die, but we don't want to be reminded of the grim reaper all the while"

Cultivating an atmosphere where death, dying, and bereavement (DDB) could be discussed openly was one of the central aims of the Bereavement Supporter Project, as Matthew [ExtraCare Senior Manager], attested *"it feels like a lot more, it feels like you're trying to change a culture."* I was therefore keen to discuss with participants their opinions, experiences, and observations of how the DDB agenda broadly, and the Bereavement Supporter Project specifically, had been received by staff and residents in their village. In response to this line of enquiry, Dolores [Resident, Cedar Court] recalled a time when a representative from John Taylor hospice had been invited to come and talk to the residents, but *"some people were so offended by it, by the thought of discussing death that it was all finished and I thought yes, it wasn't allowed to go ahead, and I thought but I wanted to hear about that."* Dolores questioned why staff had elected to *"push it under the carpet"* rather than *"the people who didn't want to hear about it just not come to the meeting."* Marcus and Lil [BSVs, Elmwood Forest] likewise felt there was *"a lot of negative attitudes towards death and bereavement"* in their village and recalled an occasion whereby a small memorial table appeared in the village without consultation with BSVs or residents. The response had been emphatic, *"the majority of the room were completely against it, they don't want this table in a corner or a memorial table at all, they don't want anything to do with death!"* The table was subsequently moved to a far corner of the library, but at the time of the interview its fate remained uncertain as some people had said, *"we don't want to be sitting around meditating on someone who has died"* and called for its removal altogether. Staff from Elmwood Forest endorsed the idea that their residents *"in particular don't like talking about it [DDB]" [Clara, Apprentice Healthcare Assistant].* For example, Cassandra [Volunteer Organiser], whose mom lived at Oaks Bluff spoke animatedly about how they had embraced the DDB agenda there and then compared to the residents at Elmwood Forest, *"they don't wanna see it, they don't wanna hear about it, they certainly don't wanna talk about it so it's a very different village."* Interestingly, when I asked participants to explain why Elmwood Forest specifically was so resistant to the DDB agenda, staff and BSVs directed the 'blame' at one another. Cassandra identified a *"strong"* and *"bossy"* residents association (RA) as leading the charge, *"they're very bossy and if you don't fit in with their way then they can make life very uncomfortable."* On the other hand, Lil pointed to the Village Manager creating a hostile atmosphere which had caused tension among residents outside of the Bereavement Supporter Project, including within the RA.

Over the course of the interview, both Marcus and Lil frequently described the new manager's communicative style as, *"it's on a need-to-know basis, and you don't need to know"* which had, in their view, cultivated a culture of secrecy within the village that had culminated in a combative atmosphere which pitched residents against staff. I was aware that the 'new manager' had, at the time of the interview, been in post for almost 12 months, so I asked Lil and Marcus if there had been any improvements during this time. They explained that Head Office had decided to *"bring in a mediator to work with you to start afresh [laughs] so, there's no change, there's no change at all (.) and it's (.) it is frustrating."* While the atmosphere within Elmwood Forest was certainly the most explosive of the four sites, there was evidence that other villages had likewise experienced resident-staff tensions, as evidenced in the following exchange during the second wave focus group at Elmwood Forest, *Meredith: it feels like we're seen as needing to be done to*

Nancy: well! [laughs]

[all talk over each other]

Nancy: I'll tell you something, that is exactly what I was saying in the taxi over here!

[Mary and Nancy talk over each other]

Nancy: you know if you don't like it go up to your bed!

Mary: yes

Nancy: we make the decision, and you have to live with it.

In this exchange, BSVs became animated as they realised that their lived experience of *"being done to"* within ExtraCare was shared across locations, in what Nancy described as ExtraCare's *"blueprint at the moment."* BSVs were concerned that ExtraCare had accepted, and indeed were enacting, a paternalistic attitude towards residents that infantilised them and positioned them *"down the scale a bit."* And in so doing, BSVs were worried that their autonomy and dignity to make decisions for themselves was being stripped away, as Meredith concluded, *"it's worrying really, how do we maintain the conversations that we have need to be taken seriously."* Grace [Cruse Senior Manager] agreed that staff in some villages had adopted a very paternalistic approach to bereavement care, she explained, *"it was like the staff went into parent mode and we've got to protect children who are in this case the residents, "I can't let them be exposed to that.""* A view shared by Matthew [ExtraCare Senior Manager],

> *I think sometimes we have a bit of a parent-child relationship with residents in certain aspects. In a way, you know, we're the parent and that they're the child and we just give a bit of information. We'd be a bit selective sometimes with what information that we think might offend.*

The staff I spoke with over the course of this project were unwavering in their motivation to provide residents with the best care and experiences available; would often work beyond their paid hours to ensure they had met residents' needs; and demonstrated a proud work ethic to *"go the extra mile."* However, their behaviour, as evidenced by the experiences of BSVs and Matthew [ExtraCare Senior Manager], in addition to the language they used, for example, *"I think we're always trying to do what's best for them"* nevertheless reinforced a paternalistic, medicalised model of care which was difficult to overturn.

"The referral side from staff is just banging your head against a brick wall"

Indeed, some participants proposed there was a fundamental misalignment between the beliefs of some staff members and the ethos of the Bereavement Supporter Project which consequently limited its success. Marcus and Lil [BSVs, Elmwood Forest] for example explained that a conversation with a neighbour confirmed their suspicions that in addition to not referring bereaved people to BSVs, the Dementia and Wellbeing Enabler (Enabler henceforth) had not even mentioned the Bereavement Supporter Project or the services available when approached by bereaved people looking for additional support. I asked Lil why she thought the Enabler had withheld this information, she replied simply, *"from my experience being in meetings with her, I feel that that's her job and she wants to keep it to herself, that there's no delegation."* Marcus agreed, and went further, *"maybe she feels that if people see her delegating to people in the village like us then we're in a sense a threat to her job."* While from another village, Sharon [Wellbeing Advisor, Elmwood Forest] commented, *"I should probably hold my hand up because I haven't done (.) as many referrals as maybe I should have."* She continued, *"I see it [bereavement support] as part of my job anyway so I wouldn't sort of say "off you go", that's part of what I do, if I can support them I would."* Evidently, ExtraCare staff, across a number of job roles, have come to accept bereavement support as being part of their role and feel *"quite comfortable to just take it on."* When I asked Sharon *"does it [referring residents to a BSV] feel a bit (.) like you're shirking or passing on part of your role then?"* she replied, *"but I wouldn't! I don't see that I would do it. I've been a nurse for 33 years so I wouldn't."* Despite being apologetic that she had not made any formal referrals earlier in the conversation, it is clear that Sharon had no intention of doing so in the future as she viewed it as a threat to her professional integrity to delegate tasks to residents that she could do herself.

Indeed, Matthew [ExtraCare Senior Manager], who worked directly with the Enabler programme supported the view that bereavement support had seeped into the daily practice of ExtraCare staff, the Enablers in particular, *"they get involved in so many different aspects of residents' lives, and we can't always just use the EOP [Enriched Opportunities Programme] to solve everything. Because it was a very specific project designed to do a specific job [to support people living with dementia]."* Matthew viewed the project as *"a bit of a win, win"*, bereaved residents would receive support of *"genuinely good quality and that they can access quickly"* while simultaneously taking *"a lot of pressure off the EOP."* Debbie [Enabler, Cedar Court] was likewise optimistic at the start of the project she explained, *"if we had to spend time with everybody that's been bereaved there's just not [enough] Enabler[s] in the village or scheme to go around"* so she welcomed the introduction of trained BSVs to *"lighten the load."* However, as Grace [Cruse Senior Manager] pointed out, Enablers had, by and large, failed to translate this early enthusiasm into action, with "*no real consequence bar me chasing them up."*

Furthermore, the second wave focus group with ExtraCare staff from Elmwood Forest explicated some factors which address, at least in part, why staff referrals were not forthcoming. Cassandra [Volunteer Coordinator, Elmwood Forest] drove the discussion and despite attending the information session and one-day training herself Cassandra equated bereavement support with professionalised support services. Consequently, she was troubled that BSVs did not have the requisite training to support bereaved people, *"I've been asked on numerous occasions "well what training have they had?" you know they haven't had counselling; you know they're not trained counsellors and I think that people find that a barrier."* Cassandra repeatedly argued that the training BSVs had received had been insufficient and at one point, compared the BSV training to the training provided to ExtraCare residents who had volunteered to pick up litter. She explained that litter pickers had received *"a big training thing"* to ensure they wore protective clothing, could identify objects that were safe to pick up, and *"everything is signed, and I've got a folder with their things in"* which she claimed had not happened for BSVs. She went on, "*is it [BSV training] updated you know, do they have refreshers you know again like your first aid you have to have a refresher every year [Facilitator: they do have refreshers] are they doing this?"* It is evident from these excerpts that Cassandra's own beliefs about bereavement and bereavement support were fundamentally misaligned with the ethos of Compassionate Communities the project had embraced. As someone who regularly attended Peer Group meetings and project events, Cassandra had certainly heard Matthew [ExtraCare Senior Manager] and Grace [Cruse Senior Manager] argue that most bereaved people seeking support are not looking for, nor require professional bereavement support and it is *"only the absolute few who really do need that and would benefit"* but evidently, she remained unconvinced. Consequently, Cassandra did not make referrals to the BSVs in her village, nor had she (to my knowledge) spoken to them to explain why, which had resulted in Marcus and Lil feeling abandoned and left to just *"get on with it."*

Additionally, Cassandra raised concerns over the trustworthiness of the BSVs, *"I wouldn't want to share something very personal with you know, yeah you must trust that they're not gonna say anything."* She pointed out that within the village *"rumours are like wildfire"* which she argued *"our residents are very aware of that, and I think that does put up barriers into this whole thing that you're trying to do."* Alice [Volunteer Organiser, Oaks Bluff], likewise pointed out how conspicuous life within ExtraCare can be, *"you know this is fishbowl living don't you"?* She went on to explain that residents often commented on her own movements, *"they know what time I get to work every day, what time I leave, when I've been here, it's horrendous!"* and suggested this level of surveillance may prevent residents from seeking support overtly. Furthermore, some residents from Cedar Court endorsed the idea that perhaps BSVs could not be trusted to keep information confidential,

Lucille: Yes, that's right but I wouldn't like it with other residents

> *Dolores: No but that was my feeling as well*
>
> *Lucille: I mean they wouldn't have mentioned it to anyone because they're not allowed to but it's still a resident and when you see that person, it's gonna be like seeing the resident if you know what I mean? Can't explain it. It just to me it doesn't feel right*.

Here, while Lucille recognised that there was an expectation for BSVs not to disclose any information about the bereaved person she was nevertheless concerned that in practice this would not be adhered to. In addition, Lucille worried that BSVs would be judgemental, and this would cause her anxiety, *"it'd be in the back of your mind, 'I wonder what they think of me' and things like that. It isn't a nice thing I don't think."* Ultimately, many residents had established intimate trusted relationships with staff that did not extend to other residents, *"I see Debbie [Enabler] as someone who would definitely not go any further that what you've (.) you know she will keep what you've told her to herself" [Lucille].* Staff likewise felt that they, along with their colleagues, develop rapport with residents that provide them with the comfort and confidence that the staff member can be trusted with their personal information. For example, Clara [Apprentice Healthcare Assistant, Elmwood Forest] explained,

> *I think some of the residents will come to you specifically because they know you whereas some of the residents, some of the bereavement supporters here some of the residents don't know them and they won't want to talk to strangers that they don't know about things that are personal.*

Marnie [Receptionist, Sycamore Grove] agreed that in her experience, residents *"feel better talkin' to staff rather than talk to the residents themselves."* She suggested this was because older people were *"very, very private"* and that *"some of the residents think that others [residents] are very nosy"* and so perhaps cannot be trusted to keep things confidential.

It was also implied that staff possessed a greater repertoire of skills and training that provided legitimacy and confidence that they would provide bereavement support appropriately, a point that Walter [Resident, Cedar Court] contended,

> *with the number of residents that are in here, there will be a number of them who have had a career in advice, a career in support and other things and life skills and then they have got the where with all to say I want to be a resident supporter and I think it's good to have a mix of the professional and the residents.*

Walter recognised the personhood and personal biography of his peers and believed these skills could be beneficial to bereaved people within the village, supplementing the support of ExtraCare staff and professionalised services. Despite his best efforts, Walter did not succeed in changing the mind of anyone in the focus group, nor it seems, did the Bereavement Supporter Project succeed in convincing some ExtraCare staff that bereavement support could, and should be de-professionalised.

“In my opinion, the older people, they don’t give a lot away”

It was when I interviewed Richard [BSV, Oaks Bluff], around six months after the first wave of focus groups, that I began to explore the barriers to seeking formalised support within the context of this project in earnest. It was through this conversation that my own assumptions were truly challenged for the first time, and I began to appreciate the true complexity of the phenomenon I was investigating. It did not take long for our discussion to turn towards the informality of support provision, and Richard reiterated his ambivalence about what ‘counted’ as bereavement support as he had done in our previous meeting. I responded by acknowledging that he had driven this thread of conversation during the focus group and that *“it sounds to me that you’re not really any closer to kind of resolving it?”* To which he replied,

> *I don’t think it can be to be perfectly honest because err when you’re when you go down the formal route, you’re asking somebody whether it’s on a form or whether you’re asking a person, “I want support” [I: yeah sure], “I need support.”*

It seemed to me that since our last conversation Richard, at least in part, had come to accept the inherent uncertainty over what encounters could be recorded as bereavement support and what was, as he phrased it simply *“being neighbourly.”* Not because he had internally resolved what support ‘counted’ or was of value, but rather he had concluded that formal channels of support provision, which would provide him with a more tangible indictor that support had been provided, were not an appealing or appropriate pathway for his peers to receive bereavement support. In a sense, his own desire for control, legitimacy, and structure (which would be fulfilled through formal referrals) were superseded by the needs of bereaved people within his community. He went on to argue that generational differences in attitudes, beliefs, and experiences with various bureaucratic, or *“official”* systems of support provision explained why we had not observed many (and in some cases, any) self-referrals. It was Richard’s belief that, particularly among the ‘older old’, there was a cultural legacy of stoicism, or *“stiff upper lip”* that would prevent them from seeking overt, professionally framed support. He drew upon a current example to illustrate his point,

> *we’ve a chap here who’s just lost his wife, we’re goin’ to her funeral this afternoon (…) you talk to him about his wife [quieter] “don’t bother me” when you can tell it bothers him! You can tell he’s wandering about like a lost sheep!*

For Richard, and presumably most people, it would be perfectly reasonable for this gentleman, whose wife had *“done everything for him”* to be bereft after she died and to need support from his community. Yet not only did he not seek support or comfort from anyone, he claimed not to be bothered by her death, a proclamation Richard was deeply sceptical of, *“he [says he] doesn’t want help – but he does! But he doesn’t want to find help, he doesn’t want to ask for it.”* Despite clearly believing that this man was indeed bothered, Richard remained sensitive and curious as to why he presented himself in this way. He remarked that this man had been a soldier and he, like others in his generation, *"had to come through life their own way, probably a very hard life as well"* and so consequently held the attitude that they were *"much stronger than that [asking for help]."* Richard noted that this approach to help seeking was markedly different to his previous volunteer experience, a service that was predominantly accessed by middle-class families in their forties and fifties whereby there was a (relative) ease with knocking on his door and asking for help directly. There is the suggestion here that for older people, asking for help is to admit that there is something wrong with you, and there is a genuine concern that being seen to be seeking help would undermine their sense of self (a strong, capable, autonomous person who can overcome adversity independently) and how others see them. Matthew [ExtraCare Senior Manager], likewise argued that among older people there remained a culture of stigma associated with mental health, which he argued some *"residents and staff have parked bereavement in a mental health area as well."* Based on his experience in mental health Matthew argued,

> *we don't see an awful lot of older people going to things like talking therapies and I think sometimes older people maybe view those kinds of things as maybe self-indulgent or something that you only do when things are really bad.*

Moreover, it was Richard's belief that through their life experiences *"the older generation"* (he positioned himself as the *"younger of the older generation"*) had come to associate asking for help with 'officialdom'. Such that, in his opinion, it was unlikely that we would see any meaningful change in the demand for formalised support from residents.

> *Their whole life if they wanted anything, money, mortgages, rents whatever, they would have all had to go through a formal process for it and I just and it's my opinion that that puts people off from goin' on a formal route certainly older people "I've gotta fill in a form" or [whispers] "I've gotta ask for it."*

I'll admit, I was somewhat surprised by the idea that older people were more averse to formality and structure than younger people such as myself. This conversation surfaced some of my own subconscious beliefs which were rooted in the idea that older people were more reverential to those in positions of authority and valued structure and order. I developed a deeper appreciation for how differently each generation experience 'officialdom' or the structures and systems of power that determine the access we have to services and that inevitably this lived experience *"lives with you"* and informs if, and how, you engage with support services.

Over time, the BSVs began to reflect upon, and recognise the appeal of seeking support more informally. Unlike some of the BSVs Richard had received a small number of formal referrals and he explained that the conversations were often awkward in the beginning as *"you've not met the person before"* and *"the person doesn't know where to begin."* Despite knowingly entering into the conversation with the express purpose to talk about their bereavement, bereaved residents struggled to initiate the conversation and were often quickly flooded with emotion. This was a delicate moment for Richard who described, *“there is a period of time when you (.) you’ve got to listen (…) you can ask questions if you wish but you, you sometimes need them to bring it to the table.”* Within this interaction, in an effort to be person-centred, the onus of initiating and maintaining conversation is largely on the bereaved person which may be an uncomfortable dynamic for both the bereaved person and the BSV. Richard went on to compare this dynamic to informal support, *“but when you’re talking in what I call the soft side of it the conversation has already begun five minutes ago.”* What he meant by this was, informal *“casual conversations”* typically started as general ‘chit chat’ between residents centred around socially acceptable pleasantries such as *“how are you?”* or *“what are you up to?”* but through what Richard called *“natural progression”* the conversation then revealed the grief that had been lurking underneath. In this way, the ‘chit chat’ provided bereaved residents with a protective buffer through which they could build rapport and gauge the personality of the BSV before making themselves vulnerable to them. Additionally, others pointed out that bereaved people may be anxious that their interlocutor will be dismissive or avoidant of these topics and so they tentatively introduced their loss sandwiched within casual ‘everyday’ conversation in an effort to shield themselves somewhat from the potential pain of being *“shut down.”* As Cynthia [BSV, Oaks Bluff] explained to Richard in the first focus group,

> *Cynthia: the thing is though, through training etc. you was [sic] quite happy to listen to what was probably quite harrowing*
>
> *Richard: yes*
>
> *Cynthia: situation whereas other people, I guarantee would ‘ave shut her down in some way*
>
> *Richard: yeah, and made an excuse*
>
> *Cynthia: yeah, to go.*

It is implied here that bereavement, death, and ‘negative’ emotions more broadly remain taboo conversations for many residents within ExtraCare. It follows then, that bereaved residents would be particularly cautious about if, and with whom, they open up about their experiences. For Cynthia, a benefit of *“casual conversations”* was that they provide residents with a low-stakes interaction through which they can introduce taboo topics in an environment that they have some control over.

“I think it’s the informality that makes it’

While the informality of support provision was contentious among BSVs, it is noted that a small number of BSVs frequently challenged their peers’ presumption of the superiority of formal referrals throughout the process of data generation. Charles [BSV, Oaks Bluff] for example explained that when he spoke with bereaved people the sole purpose was not simply to *“listen to her reminiscences of her husband”*, but rather to demonstrate that while it is undoubtedly different to where she has come from, she nevertheless resided in a supportive community. Charles acknowledged it will take time, but he hoped that *“slowly she can make new friends”*, and one day *“she can feel at <u>home</u> in this place.”* Charles then, not only embraced but enacted, a community-driven, holistic approach to bereavement support. He was less concerned with what the support looked like ‘on paper’ or whether it allied with his expectations of the role, and was instead grounded in, and attuned to, the individual’s needs in the moment. When we met at the second wave focus group, some 18 months later, I asked Charles again about this woman and the progress they had made together. He explained that she had said that *“Birmingham is a nice place [F: laughs] and that this [ExtraCare] was a nice place, which she had never said before”*, Charles took this to reflect progress had been made as she had previously displayed deep regret at having to leave so much behind. Charles then defended informal support as being *“just as important for development”* as more traditional, and indeed professionalised, support services.

Similarly, in the first wave focus group at Cedar Court, Meredith frequently provided counter perspectives that challenged her peers’ dismissal of informal support, she suggested that *“the informal is actually more important”* as it provided an opportunity to *“take the top off the pain.”* Meredith embraced the vastness of loss, stating that, for older people in particular *“loss is a part of (.) everything really”* and so people often carry *“an awful load.”* There is evidence from the preceding theme that older people experience and must live beside loss on a daily basis, but Meredith’s empathy extended further still as she attempted to imagine what it would be like *“in the shoes of residents and what I might appreciate [if I were in that position].”* She suggested that formal, face-to-face, one-to-one support for an extended period of time would likely be an emotionally onerous proposition which may be uncomfortable for some people, particularly if it occurred in a public place. Talking informally to a neighbour therefore has the potential to ‘nip it in the bud’, in that by providing *“the opportunity to say what she needed to say”* allowed this person to move forward with their day feeling a little lighter. Indeed, this perspective aligns with the Compassionate Communities model (Kellehear, 2005), and the bereavement model that informed the development of the Bereavement Supporter Project (see, Figures 2 and 3). Within this orientation, resources are funnelled into raising awareness about bereavement and bereavement support services, and providing peer-led listening support, in an effort to prevent unnecessary referrals to professionalised services and thereby preserving these services for those with complex grief and trauma. As Grace [Cruse Senior Manager] summarised,

> *the idea is that the least number of people end up at that tier [professional support] because we've done all the awareness raising, we've got the volunteers only the absolute few who really do need that and would benefit access that because otherwise you just have a list of people waiting for support that actually they don't need and that's not helpful to them.*

The Bereavement Supporter Project, and indeed other Compassionate Communities initiatives, are ambitious in their aim to challenge the current culture of silence and stigma surrounding bereavement and bereavement support, but further to this, in their efforts to uproot the professionalisation and medicalisation of bereavement support and redirect support to local communities. The informality of support provision within ExtraCare lends itself to the reading that bereaved people have felt the absence of and seek support from within their own communities. And, as Meredith and Charles attested, the informal may in fact be more important.

"It don't get any easier, but you learn to take it in your stride"

This final sub-theme pivots away from resident experience and focuses instead on the experiences of staff. As part of its ongoing mission to cultivate bereavement friendly communities within ExtraCare villages and schemes, the Bereavement Supporter Project had dual interests in both staff and resident wellbeing. While it was intended in the original project design that each village would have staff and resident *"bereavement champions"*, this was amended following village consultation exercises and only resident champions, renamed supporters, were taken forward. Grace [Cruse Senior Manager] reflected,

> *in the original bid there was also something about having staff bereavement champions but then that sort of became apparent, again from engagement, that really wasn't gonna work and we had to have something much more fluid, and it had to be about staff culture and staff being support, about staff being able to talk about bereavement and support each other not just having a couple of individuals who were the champions or supporters.*

It is not clear what engagement activities Grace conducted, nor can I be certain of how many villages were consulted during the process, but it was evident from the interview that Grace approached the project with a deliberate intention to shape *"something that hopefully didn't just fit one village, that would fit different environments."* It was therefore somewhat surprising that staff later endorsed the idea of a staff *"champion"* and more structured peer-based support during focus group discussions. This was particularly salient in the focus group at Elmwood Forest where a number of participants shared their experiences of *"traumatic incidences"* caring for residents at the end of life, Anika [Housing Assistant] recalled,

> *Me and Kimberly [Enabler] had to attend to somebody who had passed away and we had to do CPR [cardiopulmonary resuscitation] and their family member was telling us that they did not want it and we just had to do it anyway because that is our policy. Unless I can see a DNR [do not resuscitate] I have to do CPR.*

While it was ultimately Kimberly who performed CPR, the nature of Anika's job meant that she *"had to deal with that family member quite a few times after"* which she really struggled with given the volatility of the events that had passed between them. She explained that witnessing or caring for a resident at the end of life or breaking the news to family members that a resident had died, is a qualitatively different experience than cases where she was *"not involved"* directly in the death. She found that being part of these painful and private moments uncomfortable, particularly when there was an expectation that she would maintain relationships with, and provide support to, bereaved family members, *"I do struggle with that, and I don't know how the training has helped me with that."*

In addition, Anika commented that, given her job role (Housing Assistant) it was unexpected that she would have to engage with end of life and bereavement care which she argued compounded her struggles. Others agreed that there were certainly some job roles that were more exposed to traumatic situations than others, but rather than becoming acclimated to this loss and trauma staff members were expected to carry on with the job, and consequently had to manage the weight of these experiences themselves. Tasnim [Personal Support Assistant; PSA] explained that their role required them to care intimately for residents several times per day often five days a week, which when coupled with the expectation to care for residents holistically (to get to know their family, their biographies, their life before ExtraCare etc.) resulted in forming a deep bond with residents. The death of residents then could have lasting effects, as Anika pointed out, *"before now we have had PSAs where a resident has passed away and they've actually been so close, that for months afterwards it affected them"* however, staff emphasised this was largely unacknowledged at an organisational level. Indeed, Jordan [PSA] argued that the demands of the job meant that they were expected to immediately move on to the next call and had no opportunity to reflect upon what this loss meant to them, *"it's no disrespect but it is literally "okay, well your 9 o'clock is not here anymore, we'll give you another 9 o'clock call" and that's not necessarily the point."* She went on to explain that she no longer took even short breaks after intense or emotional situations because, *"it will be like 20 million people go[ing], "where have they gone, where have they gone""* and as soon as you come back it's like *"bam, bam, bam, "where have you been?" and you just like, feel worse."* It is difficult, even in full knowledge of how stretched the care system currently is, to envisage workplace conditions where staff are not granted the autonomy and dignity to have a short break after a potentially traumatic experience, such as performing CPR that was ultimately unsuccessful. The fact that staff have deemed it to feel worse to take a break to compose themselves after experiencing something traumatic in the workplace, because the system is so strained their absence is felt immediately and is unable to accommodate even small deviations, is surely a compelling indictment for reform.

Against this backdrop it is perhaps unsurprising that staff were looking for their emotional labour, and the impact this had on their own wellbeing, to be acknowledged at an organisational level within ExtraCare and ultimately, for their conditions to be improved. Anika argued that although she and her colleagues supported each other, it would be comforting to have *"somebody who's actually meant to sit down and talk to them and spend time with them and make sure that they are okay"* and suggested a flexible, but formal debriefing process to safeguard staff wellbeing. When asked what this might look like, participants relayed a number of priorities, which culminated in the suggestion that it would be beneficial if ExtraCare could accommodate an hour per month to allow staff to attend a drop-in support group where they *"just sit and have a chat, like we have done today."* Not least because it would affirm their position within a community who share experience, that *"you're not going nuts because you do think that at times"*, and that they are not dealing with things alone, *"it's very lonely grief, it's really lonely."*

Furthermore, the Bereavement Supporter Project delivered optional staff training and information sessions with the intention that staff would not only gain a deeper appreciation for how loss and bereavement are experienced, particularly by older people, but also that it would mark the beginning of a conversation around death, dying, and bereavement and they would in turn *"take up the baton"* with the ultimate aim to *"change a culture"* within ExtraCare. Overall, staff endorsed the training, with many commenting it had *"opened their eyes"* and enabled them to observe residents' behaviour holistically and contextually, as Daisy reflected, *"it's made me look at things at a different angle or who suffers, who thinks this, why people do that."* Some staff members also commented that this learning had been helpful in their personal life. Francis for example recalled a situation where her father-in-law was in hospital and his wife became *"very aggressive with me on a couple of occasions."* Francis believed this aggression stemmed from his wife's belief that given Francis' medical background she should have been doing more to facilitate and expedite further care. Francis went on to explain, *"the training helped to put that sort of barrier there for me to be able to say, "this is not personal" (…) it was part of starting the bereavement"* which allowed her to take a step back and view the situation compassionately from someone else's perspective rather than retaliate because her own feelings had been hurt. She concluded by acknowledging, *"it was a difficult time and so I do think that [the training] did help."* Dan [Village Manager] likewise argued that the training had helped him both personally and professionally and argued the training had been a useful entry point which *"gave some space to talk around bereavement, death, and how we respond to it."* As a comparatively new village, Oaks Bluff had a *"very young profile"* of residents compared to the other villages included in this research which translated into them experiencing only a handful of deaths during their first two years. However, staff were cognisant that the village *"population sort of ages together"* and that *"unfortunately means more bereavements."* Consequently, staff at Oaks Bluff, led by Dan, viewed the training to be a *"timely"* opportunity to reflect upon *"how the village team worked"* in response to resident death and bereavement, and to talk through what *"didn't feel right and why it didn't feel right and what we might do slightly different the next time."* There was a sense that a real effort was being made to change the culture around death, dying, and bereavement at Oaks Bluff because they lived in anticipation for greater need in the future as the village aged together. And for Alice [Volunteer Organiser], there was comfort knowing that there were BSVs in place to support the community as required, she concluded, *"it's never gonna be a point where it's not gonna work."*

Others spoke more broadly about the ways in which the training challenged long-held beliefs about bereavement and grief, as Anika [Housing Assistant, Elmwood Forest] explained that in cases of protracted illness which required significant care from a spouse or loved one she had previously viewed this unidirectionally; that caring is a *"burden",* and its absence must be felt as a *"relief."* Through the training, Anika gained an appreciation for the complex and cascading effects a single death or bereavement can elicit, such that even the absence of 'being a carer' can be experienced as a profound loss in itself. While staff valued this more nuanced and empathetic approach to supporting bereaved people it also surfaced some anxiety. Staff admitted that in the past they had relied heavily on trite or clichéd sayings (*"oh he's had a hard time, he's at rest now"; "well, at least they're together"; "there, there, it's okay")* in an effort to soothe the pain of bereaved residents, and perhaps, to avoid the discomfort they felt talking openly about what can be *"a very difficult subject matter to talk about."* For example, through the training staff reflected on the importance of listening and where necessary 'sitting with silence', as Daisy [PSA, Cedar Court] explained,

> *the training itself I think opened my eyes to be fair. I think I looked at it blinkered, from my point, where I would say things like "they're in a better place now" or "just give it time, you'll come to terms with it", things like that, but now I know that don't say things like that. Keep it shut, just let them do the talking.*

Daisy frequently used the expression *"opened my eyes"* to convey the significance of the new insights revealed to her through the training, however I also considered the possibility that such an abundance of new, and sometimes radical, information could be quite overwhelming. I put it to Daisy,

> *Facilitator: I'm interested that obviously with "eye opening" that can be quite exciting, that you've learned things, but I imagine that it can also be quite difficult to be confronted with things you haven't thought about. What would you think about that?*
>
> *Daisy: I can see that because (.) it's difficult to say without saying about the particular family, but there's one lady and I think her daughter is seeing things through rose tinted glasses. She thinks it's mum and she always gets through this and she can always cope with that, but this lady's really getting on now, and struggling a little bit (…) and I'm thinking it's a difficult one, isn't it?*

Here, Daisy was conflicted, through the training she had been encouraged to approach end of life and bereavement care holistically; to consider family dynamics and roles, to contextualise feelings and behaviours against the backdrop of individual biographical histories, and to approach discussions openly without reverting to platitudes. However, in practice, being confronted with a myriad of competing priorities to consider was overwhelming and she often ruminated on, and questioned, the appropriateness of her actions. For Daisy there was a tension between maintaining *"professional boundaries"* and delivering care intuitively which had culminated in her withdrawing from residents in an effort not to upset them or 'do the wrong thing', she lamented, *"although I'll be there for people, don't get me wrong, but I tend to stand back a little bit and just let them come to me."* Across sites, staff either explicitly or implicitly registered ambivalence about maintaining *"professional boundaries"* with residents, yet the profundity of this boundary was not clearly defined and so difficult to manage. Consequently, Daisy lived in a turmoil as she oscillated from an internalised sese of 'failure' to maintain appropriate boundaries to deep sadness that she had failed residents by not supporting them effectively, *"that's the sad thing for me, is not being able to help them or say the right things."* Others however, including Daisy's manager Karen [Care Manager, Cedar Court] took a different view, she asserted that crossing the boundary was an inevitable, and even desirable, feature of care and over the course of the focus group regularly praised Daisy and her colleagues for the tremendous care they delivered, *"I think you get given the professional boundaries and I think we've got to understand that they get crossed because we care."* There was a sense for Karen that 'boundaries' were an inevitable inheritance of working within the parameters of professional governance, but in practice, there was flexibility to cross the boundary if it served the needs of residents.

In summary, this series of sub-themes has examined the ways in which the culture of ExtraCare has uniquely contributed to the experience of delivering a Compassionate Communities initiative. Specifically, it attended to the inherent challenge of introducing a radical programme intended to disrupt, challenge, and reorientate established beliefs about the nature of bereavement and bereavement support (*"it's bad enough getting older and knowing we're going to die, but we don't want to be reminded of the grim reaper all the* *while"; "The referral side from staff is just banging your head against a brick wall"; and "In my opinion, the older people, they don't give a lot away*), and argued that cultivating communities that provide informal opportunities to discuss loss was perhaps more important than the structured model of provision originally envisaged (*"I think it's the informality that makes it"*). The final sub-theme ("*it don't get any easier, but you learn to take it in your stride"*) explored how ExtraCare staff have responded to the Bereavement Supporter Project, their bereavement experiences, and the ways in which they might be better supported going forward.

Discussion

This study employed a phenomenologically orientated design in order to better understand the lived experience of residents, staff, and Bereavement Support Volunteers (BSVs) participating in a Compassionate Communities (CC) (Kellehear, 2005) project within extra care housing. Rich, dynamic, and complex data were generated longitudinally using both qualitative interviews and focus groups which afforded insights into the lived experience of CC that had hitherto been obscured. Two main themes were identified through reflective thematic analysis (Braun & Clarke, 2019) which chartered the unique bereavement experiences and needs of older people living within extra care housing (*"we are all dropping off like flies, it's a fact"*), and how participants responded to the Bereavement Supporter Project in practice (*"it feels like a lot more, it feels like you're trying to change a culture"*). Specifically, it considered the ways in which the culture, policies, and practices of ExtraCare informed, and in some cases limited, participants' experience of providing or accessing bereavement care that met their needs. This section will consider these findings against the backdrop of the wider literature.

First, participants in this research framed the experience of older people to be fraught with a level of loss greater than any other population but woefully underserved in terms of support provision as societies have positioned such losses as 'expected' or indeed, 'inevitable' features of ageing. This resonated with Kewell's (2019) reflections of providing psychotherapy to older adults wherein she condemns the societal expectation that a "certain amount of depression in older people" simply "goes with the territory" (p. 3) which she argued had resulted in older people being "objectified in society and marginalised in psychotherapy services" (p. 2). The Bereavement Supporter Project sought to counter this narrative through the educational components of the programme (i.e., the information session, one-day training, events, and workshops), by presenting a conceptualisation of bereavement that legitimised wider losses (such as loss of one's house, mobility, social position, independence, friendships, and so on) as potential triggers for grief and suggested that in order to support bereaved people holistically these wider losses must also be identified, acknowledged, and attended to. However, care was also taken not to further pathologise grief, and instead concentrated on cultivating a community attitude whereby villages maintained a dialogue about death, dying, and bereavement (DDB) and encouraged more community-led support. The normalisation of loss among older people resonated strongly with the experiences of ExtraCare staff and BSVs who incorporated these ideas into their care practice. Charles, a BSV from Oaks Bluff for example, spoke eloquently about a neighbour whose move into ExtraCare at the behest of her daughter had triggered a catalogue of losses that resulted in feelings of 'homelessness'; the experience of feeling dislocated or alienated within the physical space in which she now inhabited (Todres et al, 2009). Charles went on to explain that while they certainly discussed the death of her husband, he took care to acknowledge and validate the significance of the wider losses she had experienced which he argued were "equally important for her development." Through this humanising orientated care Charles observed improvements in her wellbeing over time, which culminated in her saying that ExtraCare now felt like home.

Contrary to expectation, bereaved people in this study typically eschewed traditional help seeking routes, that is, self- or staff-referral, in favour of more "casual conversations" that occurred naturally as part of the ebb and flow of community life. BSVs spent a considerable amount of time reflecting upon and debating the factors that may have contributed to this observation. While participants identified a number of external and contextual factors (which I will address later in this section), I will first attend to their assertion that the lived experience, social expectations, and personal beliefs of older people is qualitatively different to other generations and may help to elucidate these findings. First, participants pointed to a generational legacy of stoicism and a 'stiff upper lip' that prohibited older people from seeking help more broadly. To admit to needing help, they argued, was indicative of personal weakness and such vulnerability could not be tolerated. Bellamy et al (2014) likewise reported that older people emphasised the importance of maintaining autonomy and independence after a bereavement and remained sceptical of their need of, or the value in, bereavement support services. Similarly, older adults who exhibit high levels of stoicism are less likely to engage in help seeking behaviour in a variety of other contexts, including for pain management (Cornally & McCarthy, 2010), insomnia (Berkley et al, 2020), and psychotherapy (Hannaford et al, 2019). Enmeshed within this attitude of stoicism was the belief that, whilst progress had been made, there remained a culture of stigma around mental health among older adults that prohibited help seeking. Similar findings have been reported among older adults diagnosed with depression (Polacsek et al, 2019) who, despite overcoming their internalised self-stigma in order to seek and accept treatment, remained cautious about disclosing this 'status' with their peers for fear of being denigrated or dismissed. Moreover, participants in the current study also reported there was a palpable resistance among residents to engage with the DDB agenda. These residents were aggrieved that they were being “reminded of the grim reaper all the while” and simply wanted to enjoy the agentic active lifestyle offered by ExtraCare, and more broadly, the promises of the third age (Gilleard & Higgs, 2002; 2010). ExtraCare staff, residents, and BSVs in this research were frustrated by this attitude, particularly when a small, vocal minority of residents appeared to dictate what activities and services were available to the whole community. It was generally assumed by participants that residents who were critical of ExtraCare’s efforts to discuss DDB more openly were ‘death avoidant’ or in denial about the realities of their present and future. However, it is possible that such residents viewed ExtraCare’s reorientation away from health and wellness towards death and dying as a backwards step that reinforced the decline and loss paradigm of ageing which positioned ageing as something to be feared or disgusted by (Sandberg, 2013), and thereby established older people as a burden on society (Holstein & Minkler, 2003). Indeed, even within more ‘optimistic’ models, such as successful ageing, there is a premium placed upon avoiding disease and disability through individual choice and effort (Rowe & Khan, 1997). Critics have argued that within such a paradigm deviation from this normalised ideal becomes indicative of ‘unsuccessful ageing’ such that “‘successful’ and ‘unsuccessful’ [ageing] then become rubrics to interpret, organize, and give meaning to experience” (Holstein & Minkler, 2003, p. 788). Within this orientation, to seek help then becomes indicative of personal failure and weakness that may jeopardise your status as a ‘successful ager’ and mark your decent into the fourth age (Gilleard & Higgs, 2002; 2010). These findings highlight that community needs, attitudes, and expectations may be shaped, in part at least, through collective shared experience and generational norms. Participants in the present study pointed to generational differences that influenced their receptiveness to formalised help seeking, but of course there are other cornerstones of shared experienced (such as ethnicity, religion, socioeconomic background and so on) that should be considered and sensitively responded to by future Compassionate Communities initiatives.

Furthermore, this research identified contextual and organisational factors that influenced the landscape of bereavement support within ExtraCare. First, issues with staff retention, organisational restructure, and the appointment of new village managers posed a significant challenge to maintain continuity and engagement with the project, particularly for BSVs who frequently expressed feeling abandoned and being “left to just get on with it.” These challenges went deeper than mere ambiguity over which staff member was responsible for the project and feeling ‘out of the loop’, although admittedly, this was frustrating for many BSVs. Rather, for BSVs it spoke to a wider disregard of their personhood and autonomy as they felt their opinions and needs were not only not being listened to and addressed, but a culture where they were "being done to" had been, perhaps unwittingly, embraced within ExtraCare. Other longitudinal research within extra care housing (Cameron et al, 2019) has likewise found that changes in management, and with that, changes in managerial practices, personalities, and stycles can be deeply unsettling for residents and lead to fractious tensions between staff and residents. Within the context of CC, there are parallels between the findings of the present study and Pesut et al's (2020) commentary on the factors that influenced the utilisation of their programme, Nav-CARE. Pesut et al likewise identified organisational disruption and staff disengagement to be predictive of the discontinuation of the programme, they concluded, "the ability to sustain Nav-CARE beyond the study period was largely determined by organisational capacity" (p. 9). ExtraCare villages are dynamic and shifting landscapes and, staff retention issues notwithstanding, it is to be expected that personnel changes and restructures will occur. Nevertheless, future CC researchers should anticipate programme disruption if their partner organisation experience migratory staffing levels. Further to this, it is recommended that, where practicable, a longitudinal research approach is employed to permit the impact of such changes over time.

Moreover, this research identified a palpable disconnect between the ethos of the Bereavement Supporter Project and the beliefs of some ExtraCare staff members. Over the course of the project, I unpacked the potential reasons for this with BSVs and ExtraCare staff. BSVs hypothesised that staff were withholding referrals in an effort to preserve the status and conditions of their employment, in other words, BSVs believed that staff were concerned that devolving some of their responsibilities to residents threatened their job security. Similarly, other CC initiatives have reported meeting resistance from healthcare staff, Pesut et al (2020) for example reported that professional gatekeeping prohibited recruitment of clients in part, it was speculated, because there was "the perception that volunteers are being used to replace paid healthcare staff" (p. 11). It is likewise speculated here, that because ExtraCare staff occupy quasi-professional positions they are themselves especially vulnerable to casualisation or replacement by volunteers and the precarity of their position then may have contributed to their resistance referring bereaved residents to BSVs.

Furthermore, staff in the present study displayed an ongoing attachment to the professionalisation of grief and bereavement support and pointed out that BSVs had not received, in their view, sufficient training to provide bereavement support safely. Relatedly, Walshe et al (2020) hypothesised that their CC programme was insufficiently powered because of clinicians' "concerns about who the peer mentors were, their training, and the safety of the intervention" (p. 11) which in turn inhibited client recruitment through healthcare referrals. The authors speculated that future programmes may experience greater success if conducted outside of hospital settings. Unfortunately, the present study suggests that the professionalisation of bereavement care is pervasive among those working within medical and health and social care contexts, and the depth of these beliefs pose a significant challenge to cultivating compassionate bereavement friendly communities within settings influenced by, or established within, medicine and its allies. Indeed, Kellehear (2005) anticipated the reorientation of DDB away from medical ownership to shared public responsibility to be the greatest challenge for establishing CC, and yet, he offers little guidance to overcome this, rather profound, obstacle.

Finally, this chapter has identified that ExtraCare staff experienced a tremendous amount of loss both within and beyond their working lives which was often compounded by the conditions of their employment. Staff in this study shared examples of traumatic care situations where, for example, they had performed CPR on residents who had died, and they were then immediately expected to continue on with 'their rounds'. The relentless and inflexibility of "care runs" within extra care housing was likewise reported by Cameron et al (2020) who conclude that, while pragmatic, the organisation of care through inherently time-bound systems and practices fundamentally "undercuts ideas about flexibility and person-centred care which are at the heart of the ECH [extra care housing] ideal" (p. 401). Within the present study, staff also relayed their anxiety and unease supporting bereaved families following deaths that they had been *"involved in"* as these often emotionally fraught situations were embedded within the staff member's own lived experience which they found challenging 'to manage' alongside supporting others in their grief journey. Staff were critical that the impact of such intimate care was unacknowledged within ExtraCare and they advocated for the establishment of staff bereavement champions and more formal mechanisms for peer support; a feature of the Bereavement Supporter Project that was shelved after early consultation with staff when it was identified as being something that *"was not going to work."* Staff in other community-based long-term care facilities for older people (Rickerson et al, 2005) have likewise identified the need for additional sources of bereavement care to support them as they manage the catalogue of difficult symptoms that stem from patient death. The present study highlights the idiosyncratic, dynamic, and changeable nature of bereavement and loss experienced by ExtraCare staff. While staff members often bonded over shared experiences that they had hitherto felt alone in, their response to (potentially) traumatic care situations, as well as more 'mundane loss' was variable over time and unpredictable, even to themselves. Consequently, there was little consensus regarding what form(s) of bereavement support would be most beneficial, and in some focus groups, support for staff was not identified as a priority at all. Cumulatively, this underlines the importance of engaging staff across roles, sites, and time points to better understand their bereavement experiences and support needs, if one hopes to cultivate a compassionate and bereavement friendly community.

Strengths and limitations of this study

The present study should be viewed in light of its strengths and limitations. First, to my knowledge, this marks the first Compassionate Communities programme to be launched within extra care housing thereby providing a unique and important contribution to the evolving literature within the field. Given the legacy of palliative care within the concept of CC, the Bereavement Supporter Project marked a critical expansion for the movement as it not only moved beyond the hospice setting, but it was also designed and implemented by partner organisations that were not wedded to palliative care conventions. However, it is also acknowledged that as a result of ongoing challenges recruiting support recipients, and later, the withdrawal of access to ExtraCare staff as a result of the Covid-19 pandemic, resulted in disproportionate attention afforded to the experiences of BSVs.

Concluding remarks

In summary, this study employed a phenomenologically orientated design in an effort to better understand the experiences of a Compassionate Communities initiative from the perspective of people living and working within extra care housing. The themes identified suggest older age is uniquely positioned as a period within the lifecourse characterised in its abundance of loss, yet networks or services of support are seldom offered or accepted by older people. Furthermore, participants emphasised the qualitatively different experiences, expectations, and beliefs of older people that may inhibit them from engaging in overt helping seeking behaviour. Indeed, some BSVs argued that informal channels for bereavement support were not only more accessible and thereby provided a critical mechanism for ‘lightening the load’ of their grief, but it was also an opportunity for greater community connectivity that sparked feelings of ‘being at home’. However, there was also evidence that some staff upheld beliefs about what constituted ‘good’ or ‘proper’ bereavement support that were medically orientated. Consequently, professional gatekeeping and resistance posed significant threats to the acceptability and sustainability of the project.

Chapter 5: An exploration of Bereavement Support Volunteers' experiences of volunteering

Introduction

One of the tenets of successful ageing (Rowe & Kahn, 1997) is the maintenance of civic engagement. Given the pervasiveness of successful ageing discourse (Martinson & Berridge, 2015; Rozanova, 2010) it is perhaps unsurprising that interest in volunteerism among older adults has amplified. While definitional issues abound (Wilson, 2012), volunteerism is generally understood to refer to "any activity in which time is given freely to benefit another person, group, or organisation" (p. 215). However, it is Snyder and Omoto's (2008) characterisation of volunteerism which firmly established deliberate, structured, and institutionally sanctioned "services" as the benchmark from which volunteerism is researched. It is against this backdrop, which views older people as "a vast resource whose potential in the voluntary sector has yet to be fully tapped" (Cnaan and Cwikel, 1992, p. 126) and proliferates an expectation that older people *ought* to "give back" through volunteerism (Holstein, 2006), that the findings of this study will be considered.

A considerable amount of research attention has been afforded to establish a profile of older adults who volunteer (see Ariza-Montes et al, 2018; Bolano & Arpino, 2020; Choi, 2003; Shen et al, 2017; Warburton & Stirling, 2007) and their motivations for doing so (Clary & Synder, 1999; Ho et al, 2012; Okun & Schultz, 2003; Principi et al, 2012), yet comparatively little research has employed an experiential lens to better understand what volunteerism means for older people. This study seeks to respond to this gap in the literature by utilising non-directive techniques to gain in-depth personal narratives from Bereavement Support Volunteers (BSVs) about not only their current volunteer experience, but also to gain a holistic insight into how volunteerism is shaped by, and shapes, their identity and life-course. This empirical chapter therefore speaks most explicitly to Sub-Question 1, *"what are the motivations for ExtraCare residents to engage in volunteering? And how is this situated within their personal biography?"* but simultaneously contributes to all the research questions directing this research.

Results

This chapter examines the personal biographies of participants in an effort to contextualise and deepen our understandings of their current experiences of being a BSV (see Table 7 for a summary of participants' background). Attention will be given to what helping behaviour in general, and volunteerism within the context of the Bereavement Supporter Project specifically, contributes to older people's understanding of themselves. The themes within this chapter were informed by BSV discussions on their motivations to become a BSV *("It's* *the story of my life")* and the ways in which the tapestry of one's lived experiences establish the foundations of personal identity. It also considers the reciprocity of volunteerism (*"I want this thing to help me": Negotiating volunteering and reciprocity*), attending to the layers of 'give' and 'gain' inherent in volunteerism, and the ways in which BSVs negotiate, and in some cases, struggle to negotiate meaningful terms of reciprocity. Finally, this chapter will examine BSVs' experiences of *"being open to the "dark stuff": Unpacking the 'naturalness' of sitting with grief"*, specifically it explores the ways in which participants make sense of the *"naturalness"* of bereavement support and how this connects to their constructed identity. See Figure 6 for summary of themes.

Table 7. Background: Bereavement Support Volunteers.

Participant Name	Village	Professional history (if known)	Volunteering motivation
Cathleen	Cedar Court	Unknown	Altruism; religiosity
Elizabeth	Cedar Court	Physiotherapist	Apply professional skills
Hyacinth	Cedar Court	Nurse	Apply professional skills
Rupert	Cedar Court	Vicar	Apply professional skills
Lil	Elmwood Forest	Nurse	Apply professional skills
Marcus	Elmwood Forest	Unclear – related to computing	"Newbie" to bereavement support; wanted to do more
Meredith	Elmwood Forest	Counsellor	Apply professional skills
Steph	Elmwood Forest	Police Officer	"Newbie" to bereavement support; wanted to do more
Charles	Oaks Bluff	Unknown	Respond to need observed in the village
Cynthia	Oaks Bluff	Nurse	Apply professional skills
Dorothy	Oaks Bluff	Unknown	Unknown
Lois	Oaks luff	Homemaker	Altruism; religiosity
Richard	Oaks Bluff	Unknown – related to computing / tech	Apply professional skills
Dawn	Sycamore Grove	Unknown	Support other bereaved people
Mary	Sycamore Grove	Nurse	Altruism; religiosity
Nancy	Sycamore Grove	Unclear – related to finance	New learning opportunity; support community

"It's the story of my life"

During the initial discussions with BSVs (in May 2018), participants were explicitly encouraged to reflect upon their motivations for becoming a BSV as it was hypothesised that this line of questioning was a neutral point to initiate discussion, would cultivate an understanding of participants' lived histories, and would facilitate rapport amongst the group.

It was immediately striking that volunteers possessed extensive bereavement support experience and expertise within both primary care and charity sectors. For example, five of the participants had worked as a nurse or within an allied health profession, one had worked professionally as a relationship counsellor, one had volunteered as a counsellor supporting those affected by alcohol and drug misuse, and one was a former vicar who had supported countless bereaved parishioners. Participants enthusiastically shared the details of their *"working life"* with their peers within the group, often cataloguing the prized details of their professional journey and signposting accolades they had received within these posts. For example, as Lil explained:

> *I worked in [name] Hospice about nine years both on the wards and as a tutor and I taught care of the dying and bereavement to a whole variety of people (…) I also ran erm a bereavement support group in my local parish with our parish priest (…) and erm I used to visit people in the homes at the request of people and the priest*.

Participants presented the rich details of their professional lives matter-of-factly, often reeling off decades' worth of professional competencies within mere seconds of dialogue, *"I've been involved in counselling for donkeys' years, training and err enabling counsellors to be alert to err the underlying issues that err people may bring" [Meredith]*. Participants appeared keen to impress their credentials upon their peers but were careful not to appear too boastful or self-aggrandising. This was a difficult balancing act to strike, and some participants strayed into the realms of 'humble bragging', *"they used to tell me that I was so good (…) I was head hunted by other hospitals (…) I was even head hunted by the bank because I'm so brilliant with money" [Cathleen]*. Here, Cathleen's professional proficiency comes across as potentially fantastical as she described scenarios where she is sought out directly by numerous agencies across sectors for her comprehensive competencies. However, irrespective of the verity of these claims it is striking that Cathleen, and indeed the majority of participants included in this study, used these discussions as an opportunity to share, and relive, valued achievements from their *"working lives."* There is the implication here that participants' current experiences were marked by the absence of working, to the extent that paid employment represented a different life; a distinct, and for many a meaningful, period that has now ceased but is recalled with nostalgia. It is perhaps rather obvious, given that participants live in a 'retirement village', that paid work would no longer be a central feature of their lived experience (although it is noted that some residents remain employed in paid work whilst living within ExtraCare). Nevertheless, the automaticity of framing their current volunteerism through the lens of professionalism was revealing. The remainder of this theme will explore potential readings into the ways in which participants' rich working lives serve, detract, and distract the cohesion of their (BSV) identity.

As intimated above, participants quickly established a central link between their biographical history and their motivations to volunteer within this project. They did not simply cite a history of volunteerism or an interest in, or experience with the topic, nor did they rely solely on vague notions of 'wanting to help others' or 'giving back' (although these discourses were certainly featured within their narratives), but rather, participants asserted their legitimacy by enumerating examples to demonstrate their commitment to lifelong learning and personal development, and direct 'professional' experience specifically within the field of death, dying, and bereavement. These positions -nurse, vicar, counsellor- unambiguously hold cultural significance and communicate a shorthand that confers respectability, status, and worth. Having held these positions for many years, participants in this study would have enjoyed, and perhaps become accustomed to, the privileged status afforded to those who hold traditionally middle-class occupations. It is argued that the immediacy with which these experiences are drawn upon produced (perhaps inadvertently) a hierarchy within the cohort of volunteers, whereby volunteers with direct, institutionally sanctioned, and often paid experience of bereavement support were elevated above those without. For example, when asked for their opinions of the training they had received Lil asserted, *"one day [training] is not sufficient to especially for someone like Marcus it is not sufficient to expect people to go out and be bereavement support."* Framed through concern, Lil used the authority afforded her as a retired nurse to speak on behalf of those she had identified as less experienced. Through this statement Lil clearly demarcates between those she considered to have sufficient credentials to successfully (and safely) provide bereavement support, such as herself, and those who do not, such as her husband Marcus. It is suggested that organising BSVs hierarchically on the basis of experience may also serve to uphold and affirm Lil's own credentials which would be threatened if bereavement support could be provided by, or taught to, anyone. In later discussions for example Lil repeatedly questioned whether another, less experienced volunteer could have handled the referral she received with a resident who was very angry and who, Lil assessed, required *"professional help."* The boundary marking that Lil introduced permeated group discussion henceforth. Influenced by Lil's dichotomy, Steph immediately positioned herself as inexperienced, *"I can't say I've got any experience I'm like Marcus I'm just sort of these two [Lil and Meredith] are the experts"* and began to undermine her capacity to support bereaved people, *"I think that she's [Dementia and Wellbeing Enabler] chosen the right two people for the ones [referrals] that have come through to be honest and I just wouldn't know what I was going to do."* While Steph's experience, and ultimately her disillusionment with the BSV role and the project was complex (and will be explicated in greater depth in the theme *"I want this thing to help me": Negotiating volunteering and reciprocity*), it is argued that establishing a hierarchy of experience that positioned volunteers in reductionist dichotomous terms so early in the discussion reinforced Steph's feelings of inadequacy and provided her with a convenient narrative to explain to herself and to others why, in her view, the project had been unsuccessful.

Against the backdrop of lifelong volunteerism and a commitment to 'personal development' it is perhaps unsurprising that a number of the participants included in this study could be described as 'serial volunteers'. That is, volunteerism characterised by engagement across the life course that oscillates in response to contextual factors (such as employment status, health, birth of children etc.) and is conducted across multiple organisations (Hogg, 2016). Over the course of data generation, participants would continue to pepper discussions with anecdotes demonstrating a history of volunteerism, with Lois concluding that 'helping people', channelled through volunteerism was, *"the story of my life."* In addition to volunteerism within external and religious organisations a number of participants demonstrated an ongoing commitment to volunteer for multiple and often diverse activities within their own village. Nancy for example explained,

> *I mean I do volunteering I do the book club, the cinema, erm (.) I volunteer for activities when they have any functions, I'm at the door taking the tickets and raffle err and I volunteer for bingo if there isn't anyone there to call the numbers.*

Even Marcus, who had steadfastly been positioned as inexperienced, later revealed in an interview that he had volunteered for the Samaritans, and within ExtraCare he provided IT workshops to other residents and volunteered in the gym. Like for Marcus, the move to ExtraCare often acted as a catalyst that ignited greater levels of volunteerism among residents. As an organisation ExtraCare is reliant upon volunteers to deliver services and activities that are enjoyed by current residents but are also used to illustrate the vibrancy of community life to prospective residents. In this way, residents are encouraged, and to a degree expected, to volunteer to demonstrate true citizenship within ExtraCare. As evidenced by the variety of volunteerism activities undertaken by Marcus and Nancy, volunteerism 'opportunities' are ubiquitous within ExtraCare villages. Historically, there has been a prioritisation of volunteer activities that contribute to community cohesion and social connectivity, as Nancy's list of engagements can attest. While participants in this study in no way indicated that these roles were unfulfilling, there was a palpable sense that they were looking for something more. The appeal of the Bereavement Supporter Project then becomes apparent, here was a more demanding volunteering role implicitly imbued with greater capital and status within the community. Within the context of other volunteer activities within ExtraCare the BSV role was in many ways unique; not only was it concerned with mental wellbeing and bereavement, both of which are imbued with cultural taboo, but it was also an overt effort to re-distribute the overwhelming workload of key members of staff (such as the Dementia and Wellbeing Enabler and Wellbeing Nurse) and so inherently conferred (pseudo)professional status. Consequently, the BSV role was viewed as 'special'. These factors likely appealed to residents who had previously held professional occupations as it presented an opportunity to re-enter the 'professional sphere'; to apply the skills and expertise accumulated during paid work within a new context and to *"identify as someone"*, in this case a volunteer, engendered with elevated status once again.

As others have pointed out (Cnaan and Cwikel, 1992; Martinson & Halpern, 2011), the dominance of successful ageing narratives has led to an expectation that older people volunteer during their retirement, with some arguing that the worthiness and value of older people then becomes contingent on their continued contribution to 'productivity' (Holstein, 2006; Martinson & Minkler, 2006). Unlike previous research in volunteer motivation amongst older adults, participants in this study rarely used phrases that have become saturated within successful ageing discourse (such as 'giving back'). Nevertheless, there were echoes of successful ageing discourse, for example participants frequently cited 'personal development' as driving their volunteerism which capitulates to the successful ageing directive to maintain "interpersonal relations and productive activity" (Rowe & Khan, 1997). Furthermore, there was more overt evidence that participants nevertheless had absorbed, and indeed perpetuated, discourses informed and elevated by successful ageing narratives:

> *Hyacinth: it's the older ones who are coming up to late 80s who are volunteering [others agree] and the younger ones are not doing it. You know early 70s or 60s you don't see them*
>
> *Lil: we've had a few people moved in who said, "well we haven't come here to volunteer" [Hyacinth: yeah exactly] we don't come here to do work, we've done that all our lives and now we just want to you know, they just don't want to do it*
>
> *Nancy: another thing is some of the residents who are moving into our village they can't help themselves and I said "well where is the volunteer? Because you're saying you need volunteers, but the people you're bringing in can't help themselves"*
>
> *Hyacinth: because the volunteers give them another couple of years and they're not going to be volunteers*
>
> *Nancy: no because you work the volunteer to death!*

In this exchange we see long-standing residents Lil, Nancy, and Hyacinth lament the loss of active volunteers within their respective villages over the course of time. Their combined hypotheses suggest that there has been an upsurge of residents within ExtraCare who either don't want to or can't volunteer. Hyacinth for example pointed to generational differences between those in their late seventies and eighties to those in their sixties and early seventies, with those in the former demonstrating greater willingness and dedication to volunteering. Lil extended this argument with the assertion that the new, younger residents have a fundamentally different conceptualisation of volunteerism and life within ExtraCare to her and her cohort. Here we see the beginnings of a backlash against the notion that, despite decades of paid employment, there is an expectation for older people to demonstrate their worth through volunteering. Although Lil's train of thought goes unfinished, it is implied that newer residents have moved to ExtraCare 'simply' to have fun and to enjoy life on their own terms. These residents appear to have embraced the freedoms and possibilities promised by the third age whilst simultaneously resenting and eschewing the expectation of reciprocity through actions such as volunteerism. Nancy on the other hand pointed to the disabilities of new residents as a major contributor to the fall in volunteerism, surmising that *"you cannot bring people into the village to live if they're in a wheelchair, they've had a stroke, they can't help themselves."* While Nancy is careful not to make explicit accusations there is nevertheless an undertone that ExtraCare are purposively *"bringing people"* to the village with greater care needs. As a consequence, established volunteers, such as Nancy, are becoming resentful as they bear the weight of preserving activities and events that are inherently reliant upon volunteers but are insufficiently recognised and supported at an organisational level.

In summary, this theme has established that BSVs possessed a wealth of experience, skills, and expertise pertinent to the experience of grief and bereavement support. This was primarily accumulated through professions allied with health or social care or through institutionally sanctioned formal volunteerism. It is argued that the BSV role was inherently imbued with elevated status which may have appealed to those who had previously held middle class professions as a vehicle through which they could reassert a valued identity and the privileged status such an identity affords. As a consequence of the preponderance of retired professionals within the cohort of BSVs, distinctions, boundaries, and hierarchies of experience, legitimacy, and aptitude amongst the participants were quickly established.

"It's the story of my life"	"I want this thing to help me"	"Sitting with grief"
• Speaks to volunteer motivation and the situatedness of volunteerism within the lifecourse.	• Considers the reciprocity of volunteerism, attending to the layers of 'give' and 'gain' fundamental to participant experience.	• Examines the 'naturalness' of bereavement support and how this intersects with their identity.

Figure 6. Summary of themes and the 'essence' of each theme' developed through reflexive thematic analysis.

"I want this thing to help me": Negotiating volunteering and reciprocity

This theme speaks to BSVs' conceptualisation of volunteerism as an inherently reciprocal practice; the challenges volunteers have experienced negotiating reciprocity; and the ways in which such a conceptualisation informs our understanding of ageing and identity.

As mentioned in the preceding theme *("It's the story of my life"*), the notion that volunteering provides older people with an 'opportunity' to 'give back' to their communities is ubiquitous within the corpus of volunteerism literature. Holstein and Minkler (2003) argue that decline and loss paradigms of ageing have framed older people as a 'burden on society', and, perhaps in an effort to counter these harmful politics, the proliferation of the 'giving back' narrative has become particularly potent among older adults. It was therefore somewhat surprising that over the course of this research participants very rarely explicitly reduced their BSV experience as being a passive exercise in 'giving back'. Certainly, they echoed the sentiment of, and value in 'giving', but this was instead framed as an act of empowerment, that they elected to bestow the assets of their experience to enrich their community. As Rupert summarised, *"it's always been an area where I've felt I had something to offer."* Participants enumerated the various positions and skills they had developed over the course of their *"working life"* and were evidently proud of their professional credentials. Further to this, participants explicitly viewed the BSV role as a way to leverage their skills and expertise to gain personal fulfilment and purpose, *"it gives me erm a reason to continue thinking, to working but at the same time I enjoy myself" [Richard]*.

There is an implication here that Richard feels the absence of intellectual challenge post-retirement acutely and given the paucity of intellectually demanding volunteer opportunities within ExtraCare, the BSV role was particularly appealing. Similarly, Nancy asserted, *"we [sic] using the skill that we've got makin' sure our brains are not dormant, there are skills there that we are using to support one another."* These statements reveal that while participants did not resort to the banal and shallow refrain of 'giving back' there is nevertheless a propulsion to preserve an appearance of productivity. Participants demonstrated a fear of dormancy, specifically the decrepitude and decline produced by dormancy, and viewed activity (in this case volunteering) as a mechanism to stave off decline. While slightly repackaged, these sentiments nevertheless echo the promises of successful ageing and the third age more broadly; that the maintenance of physical and cognitive health and the pursuit of lifetime ambitions through volunteerism is not only desirable, but essential if one is to resist the 'gravitational pull' of the fourth age (Gilleard & Higgs, 2010).

Moreover, participants also reflected on the vulnerability inherent to volunteerism, not simply in terms of the giving of time or resources but offering part of oneself in the service of others. Cathleen suggested,

> *it's a question of what you can do and knowing that if you take a task on that you've got to see it through to the end. So, you can't take extra tasks on and give part of yourself if you know what I mean.*

Here Cathleen was responding to a question that asked whether she would be able to identify becoming overburdened within the role, and what steps for mitigation or recourse she might employ. She argued that volunteerism, and helping behaviour more broadly, required an intimate and self-appraising understanding of the self in order to become attuned to one's capacity. She suggested that the act of giving extends beyond the mundane notions of giving time or money to a more abstracted, theological, and sacrificial conceptualisation where part of oneself is given. The cost then of taking on too much becomes far more significant. The risk of becoming overburdened is perhaps heightened within the context of bereavement as grief was frequently framed as a load that required unburdening. Indeed, Nancy spoke of *"shouldering"* other people's pain as a means of *"helping them along"*, and Meredith explained,

> *she carried an awful load (.) so you know I was the privileged person to be there and I'm quite good with a bucket! [both laugh] because I've learnt the art of not carrying it so yeah it was (.) it was good.*

In this rather whimsical statement Meredith extends the metaphor of 'grief as a physical burden' to conjure an image wherein she is on hand, with a bucket, to siphon off some of the load the bereaved person is carrying, thereby allowing them to engage in life more freely and fully. However, unlike Nancy, Meredith quickly clarified that she does not then absorb this burden into her own load. Instead, she hinted to the therapeutic skills acquired through her *“working life”* that shield her from becoming overburdened with the pain of others. Likewise, Richard claimed his career enabled him to *“build up a resilience”* that protected him from absorbing others’ pain, *“I’m not cold, I’m not a cold-hearted person but I can find the way to offload that easily.”* These examples justify participants’ assertions that they possess a unique profile of skills and experiences that enable them not only to be available and receptive to the pain of others, but to be in a position to help bereaved people to *“offload”* without the personal vulnerability of becoming overburdened. For Meredith and Richard, the acquisition of these skills is intimately tied to their status as former counsellors which taught them *“the art of not carrying”* other people’s pain. Consequently, they are both careful to reassure their interlocutor(s) that they have maintained ‘appropriate boundaries’ by employing learned strategies that serve to protect their own resources and wellbeing. On the other hand, Cathleen and Nancy appear to embrace the necessity of some personal sacrifice and burden in the service of helping others. Unfortunately, Nancy and Cathleen did not reflect upon or explicate the source of these beliefs further, nor did they dwell on their pre-retirement career which may have informed or influenced the ways in which they frame ‘work’ and ‘retirement’, albeit in a different way to Richard and Meredith. It is therefore difficult to draw conclusions to explain the differences between BSVs described based on their biographical history alone. Nevertheless, I suggest that the parallel between ‘work’ and the ‘BSV role’ was largely absent for Nancy and Cathleen. Indeed, Nancy frequently corrected me when I framed being a BSV as a ‘role’. For her, she *was* a supporter, it was not a part to play, or a function performed to confer professionalised status, she stated simply, *“I don’t class it as bein’ a job, I’m classifying it as being a supporter but not a job.”* Cathleen was equally unconcerned about the ‘status of being a BSV’ and during the interview recounted numerous examples of supporting the community outside her capacity as a BSV with no hint of hierarchy or judgements about what was more valuable or valued. For Nancy and Cathleen then, volunteerism stood apart from work and instead spoke to a deeper drive to contribute to the ‘common good’.

Relatedly, Nancy argued that being a BSV necessitated *“putting yourself out there for them [bereaved people].”* Within the context that this extract has been drawn, Nancy described her duty to attend the funeral or memorial services of deceased residents as a marker of respect and an outward indictor of condolence to the family. While Nancy repeatedly positioned herself as *“outside the Church”* the way in which she framed her *“duty”* to volunteer and help others nevertheless possessed an undertone of servitude and personal sacrifice often associated with religious teachings. Furthermore, being visually and spatially present confers mutual mourning and an implicit openness and availability to ‘be there’ for a person in need. However, Nancy’s language also speaks to the vulnerability and personal sacrifice of these moments. At a basic level, attending the funeral of someone that you may not have known particularly well requires the BSV to accept a certain level of inconvenience (for example, in time, travel, and expenses). But additionally, it necessitates being at ease with stillness; being in the moment, sitting with grief, and reassuring others that they are safe to sit alongside you. By being *“out there”* BSVs must reconcile not only the challenges inherent in sitting with grief, but also the possibility of rebuttal or rejection. Such vulnerability, rather than being indicative of unsuccessfully established boundaries, is framed as being part of the territory; a personal sacrifice in service of a ‘greater good’.

While participants initially framed the value of volunteerism exclusively around ‘giving’, as the discussions unfolded participants emphasised the importance of ‘gaining’ something from volunteering as being equally important. When participants were asked directly whether volunteering had elicited any personal benefits, BSVs typically referenced the feeling of personal satisfaction that came from helping others, Richard for example associated feeling energised and accomplished with volunteerism, *“I still get the same buzz by helpin’ other people.”* Richard’s somatic language characterised volunteerism as an embodied experience; the experience of helping others is marked within the body with an energy that restored and reaffirmed vitality. Meredith likewise agreed that in helping others *“there was certainly a feeling of satisfaction.”* However, when discussion about their experiences was more organic, participants focused less on simplistic pronouncements that coupled ‘doing good’ with ‘feeling good’, and instead positioned volunteerism within their rich, complex, and ongoing, life journey. Participants challenged the notion of retirement as a cliff-edge, and instead presented this period of life more broadly, and living within ExtraCare specifically, to be marked by opportunities to enrich and develop their skills.

> *I’m gonna start again right so my life was like, yeah this is another journey. I got on a plane and I’m goin’ to a different island and that was part of [village name] so starting and taking up different things, I’m involved in different things erm in that sense, in that sense, so it’s still a journey for us. [Nancy]*

For Nancy, the ‘adventurous horizons’ promised by ExtraCare citizenship was deeply appealing, whilst the transition to ExtraCare living is presented as a radical upheaval it is nevertheless imbued with an exotic and exciting quality. Nancy’s characterisation of the opportunities available suggested an openness to try new and different things, and that she is receptive to veering off course and changing the trajectory of her journey. Unlike many of the other BSVs Nancy relished relinquishing her *"working life"* in order to make space for new opportunities that more closely aligned with her current priorities.

> *when I left I used to do finance (…) first thing I did was get rid of my computer, I didn't want it, that part of my life was going, off it went [laughs] (…) what I did, just like a computer you store information in, well delete those [Richard; hmmhmm] and said "I'm gonna start again" right so my life was like, yeah this is another journey.*

Nancy frequently expressed gratitude at being included within the Bereavement Supporter Project as she had gained a lot of new knowledge and insights into how bereavement is experienced through both the requisite training programme, and through the interactions she had with bereaved people. She described being a BSV as *"a learning curve for us as well as supporters in that sense it's not just about giving support it's about us receiving some sort of information in a sense from them."* Similarly, Cynthia positioned the BSV role as an opportunity for further learning, *"I wanted to come to see how things move over, theory with regards to bereavement etc. you know, it alters over time like everything, so I found that side you know interesting."* As a former nurse Cynthia would certainly have possessed both theoretical and experiential knowledge about bereavement and bereavement support. Nevertheless, she acknowledged there may well be gaps in her understanding as inevitably there have been developments in research, as well as shifting societal values and norms, since she was immersed in the field. In these cases, reciprocity was easily negotiated; BSVs found meaning and satisfaction not only through the act of helping others, but also gained new knowledge that advanced and enriched their understanding of the world.

However, some BSVs were disappointed that their expectations for reciprocity had been unfulfilled. In a particularly candid moment Rupert explained, *"but I want it to be the other way around, I want this thing to help me and encourage me and give me more opportunities but they're not coming."* Through this statement Rupert flips the script on volunteerism reciprocity, particularly within the context of older people. Contrary to the wider literature, which historically positioned altruism as the cornerstone of volunteerism, and more recently has adapted to concede the importance of reciprocity (whilst usually still favouring the 'receiver') in facilitating meaningful and valued volunteer experiences, Rupert's experience is directed by the elevated status of his desire for personal enrichment and purpose. I suggest that there was a fundamental disconnect between Rupert's expectations of the BSV role and his lived experience, a tension which ultimately brewed discontentment and disillusionment.

A recurring source of discontentment among BSVs was the lack of formal referrals they received, and despite their claims that it wasn't *"overly important"*, or indeed that *"in an ideal village you wouldn't need a referral system because it would all be done informally as we live together as a community" [Rupert]* it became a rather contentious, and circular, discussion topic. Culminating in Rupert, Elizabeth, and Steph all threatening to withdraw from the project. Participants repeatedly dismissed any informal support they had provided as something they *"would've done before"* leading them to conclude that *"nothing much has happened."* Despite the efforts of key personnel from both Cruse and ExtraCare, some BSVs could not be convinced to think differently about informal support,

> *I feel like I'm wasting my time because I'm not actually doin' anything, and they say well if you have a casual chat with somebody who has been bereaved but I don't, but I would've done that anyway [Rupert: yes] so I don't see that as part of this [Steph].*

Certainly, the informality of the support provision was unexpected and presented markedly different interpersonal demands on BSVs; no longer were 'support sessions' structured, boundaried, and tangible, instead they permeated daily life through *"casual conversations"* and as such they were often fleeting, unpredictable, and difficult to quantify. During my preliminary analyses of these early focus groups, I hypothesised that participants' professional background had, in some cases, established rigid expectations and judgements about what 'counted' as 'good' or 'proper' bereavement support. Consequently, participants experienced an irreconcilable rift between their expectations and their lived experience which threatened their sense of self and their efforts to reclaim a privileged status position. For Rupert, Steph, and to an extent Lil and Marcus, there was an expectation that participation would involve greater stakes, both in terms of what would be required of them and in what they expected to receive in return. They intimated that they were looking for something 'more', something greater than the everyday, perhaps, something imbued with status that would restore their professional identity. However, towards the end of the first focus group a brief exchange between Elizabeth and Steph hinted that this interpretation was incomplete,

> *Elizabeth: I might as well carry on with what I was erm doing before because I'm not living up to what this wanted erm [Steph: yeah] somehow*
>
> *Steph: that's how I felt like a failure*
>
> *Elizabeth: yes, I feel that have felt that.*

It was saddening that BSVs not only viewed the project but themselves as a failure, especially when, from my perspective, they had been repeatedly reassured by the project developers that informal support, while unexpected, nevertheless had the potential to be both meaningful and impactful for support recipients. Regrettably, these comments came right at the end of the focus group and, mindful that we had already exceeded the agreed time and picking up on nonverbal signals that some participants were eager to leave, I did not have the opportunity to explore this further. The collapse of the formal referral structures had a lasting impact on BSVs; indeed, I cannot think of an occasion where I met with them that it was not discussed at length. Yet, it was not altogether clear why for some BSVs the success of the project, and their own personal success at 'being a BSV', hinged on formal referrals. Unpacking the significance of formal referrals therefore became a priority during the later phases of data generation. It was during the interview with Marcus and Lil that my continued efforts to pursue this line of enquiry revealed new and significant insights.

> *Interviewer: I might be wrong and do correct me is that I suppose that if you say, if someone says "nothing is going on" then there's value in the formal and that is seen as important and something that isn't being fulfilled and I didn't fully understand why some volunteers found the formal so important or is it something that they really want and I suppose that was my rationale for asking you (…)*
>
> *Lil: I don't think of it as the important thing [I: hmm] but sometimes you just feel out on a limb, what am I supposed to be doing? (…) because if you have a formal erm (.) thing err referral then it's almost got to go and sit down with them and it's almost like a counselling session in a sense, I know we're not counselling but you know what I mean, it is more formal [I: it's tangible] yeah.*

It is evident from this exchange that, for Lil, the appeal of formal referrals was that they offered a clear marker that they are 'doing' something; formal referrals require an explicit agreement between two people regarding the purpose for the conversation that quickly establishes their respective roles and the boundaries of the interaction. The paucity of formal referrals has therefore made it difficult for Lil and Marcus to gauge whether or not they are doing the 'right thing', or indeed, anything which potentially undermined both the 'give' and 'gain' components of reciprocity for them. Lil had an underlying fear that they were failing at volunteerism, which was exacerbated through unfavourable social comparison, *"they were getting residents erm referred to them and err they were visiting people and helping people (…) I found it embarrassing that our village was [Marcus: so far behind]."* An unintended consequence of the Peer Group events, and to an extent the research activities, was that rather than being an opportunity to pool knowledge and experience, they became a space for social comparison that dichotomised volunteers as either 'successful' or 'unsuccessful'. Overall, across all locations, formal referrals were infrequent and, in most villages, virtually non-existent so it was unclear how Lil had built up an impression that other BSVs were in receipt of great volumes of referrals. It is true however that a number of BSVs at Sycamore Grove were very proactive; contacting bereaved families directly, attending funeral and memorial services, and *"putting themselves out there"* in an effort to keep apprised with community life (and death). Additionally, these volunteers retained a positive outlook with regards to how the project operated within their village, as well as the role(s) that they played, and have embraced the essence of the project whilst adapting their practice to align with their beliefs, values, and personal traits. A flexibility that Marcus and Lil struggled with.

Furthermore, Lil and Marcus framed the breakdown in staff referrals as being indicative of a general mistrust and malaise that had developed between staff and residents within their village. Lil reflected,

> *I sometimes wonder, and I must be quite wrong, that the staff see us that we're not staff so really, we [Marcus: should be kept out of it! [laughs]] you know we shouldn't be told or [I: interesting, I don't] I mean I might be wrong but sometimes that's what I pick up, you're a volunteer and you're a resident, you're not a member of staff [I: hmm] it's a bit them and us kind of thing.*

Lil explained that she had met with a number of bereaved neighbours who had been meeting regularly with the village Dementia and Wellbeing Enabler and who expressed surprise when Lil informed them that she and Marcus had received bereavement training to support their peers and had been available to support them the whole time. While Lil and Marcus used examples pertinent to the Bereavement Supporter Project to support their argument that staff had developed an *"us and them"* mentality, they nevertheless emphasised that this issue permeated much deeper into village life. In this way, not receiving staff referrals was interpreted (by Lil and Marcus) as a purposeful effort to withhold information, reinforce boundaries between staff and residents, and inferred that staff viewed residents as being less trustworthy and capable. It is possible therefore that some BSVs revered, and longed for, staff referrals as they had become an indicator that staff not only acknowledged, but valued, their personhood.

A final aspect of reciprocity identified from BSV narratives pertains to the idea of legacy. While supported by a relatively small number of participants it nevertheless merits some consideration here. It was somewhat surprising, given the nature of their role and their eagerness to dismantle what they viewed as a taboo around death, that BSVs rarely reflected on their own mortality. One exception to this was Lois, who drew parallels between a bereaved gentleman she observed sitting alone every day in the reception area of her village and her husband, Ken. Lois explained that Ken was unable, or unwilling, to have conversations about illness, death, and dying and so she was concerned that if she died before him, he would withdraw from life. Lois' narrative was at times meandering and confusing, so she provided, nor sought, a resolution to her concerns but reconciled that it was enough, for now, to lay them bare. Furthermore, like many of the BSVs, Lois was pragmatic about the inevitability of death within the village, and perhaps because she was the oldest BSV in the group, she experienced the proximity to death keenly, *"I know you can [die at] anytime but when you get to our age you've got to accept that it might be happening haven't you."* On a number of occasions Lois appeared to reflect upon, and evaluate, the 'worthiness' of her life by making comparisons first with her siblings and later with her peers in ExtraCare.

> *you know I haven't got many attributes but [laughs] well, I wasn't because my sister and brothers they've all got degrees and had careers and, and I didn't (…) I wanted to (.) have a family and I wanted to be a good mother (…) They've [other residents] got degrees or had jobs, managing this and something to do with that and you think well [laughs] "where've you been?"*

Lois has lived a modest life, prioritising raising a family and volunteering, and when compared to her peers and siblings who obtained degrees and entered professional fields, she assessed herself harshly. However, when invited to share her experiences of volunteerism throughout her life, Lois concluded by saying *"I've always got that"* which suggested that it was through the kindness of her actions that she remembered most fondly and hoped to be remembered for. It seemed important to Lois that she had left an imprint on the earth, a sign that she had lived and made a difference, and it was through her volunteering that Lois could claim a legacy. While Lois expressed regret that she had not been able to do more during her time as a BSV, she remained hopeful that this was just the beginning,

> *the longer it goes on the longer these people are going to die because there must be, I don't know 20-30 of us in our 80s so there's going to people die here and then I think we'll be glad we've got counsellors. I think that time will come.*

Here, Lois framed the Bereavement Supporter Project as part of their legacy, that they were developing the capacity of residents to support the bereaved before it was fully needed so that when the oldest residents die there will already be an established core group of residents who can provide bereavement support. Lois drew comfort from the *"wealth of knowledge"* her peers possessed and that they will use these skills after she herself has died, *"I'm one of the oldest now because I'm 89, but those that are younger will be here when people like me die."*

In summary, this theme has examined the complexities of reciprocity as it pertains to volunteerism experience and identity. It has presented the argument that the duality of 'giving' and 'gaining' are fundamentally important if volunteerism is to elicit a personally meaningful and rewarding experience; a feature largely absent in the literature focused on older adults.

Being open to the "dark stuff": Unpacking the 'naturalness' of sitting with grief

BSVs often framed the ease with which they were able to initiate and hold conversations about death and bereavement as *"natural"*, as Richard explained, *"from my perspective it's a natural thing anyway in order to be able to talk to her if she wants to talk about erm her loss."* This theme explicates the multiplicity of the use and meaning of the *"naturalness"* of bereavement support, how this shapes BSVs' experiences, and what implications such a framing has upon the conceptualisation of bereavement support proposed by Compassionate Communities.

As intimated in the preceding chapter (*"the nature of bereavement support"*), the informality of *"casual conversations"* elicited tension for some BSVs as they attempted to unpack what 'counted' as bereavement support and what was 'simply' what they, or indeed anyone, would do in that situation. Richard was particularly motivated to untangle what was counselling, or bereavement support, and what was *"being neighbourly."* To illustrate his dilemma, he provided an example which I will briefly summarise. Richard and his wife had gone down to their car where they met two other couples who were talking. They said *"hello"* which developed into *"chit chat"* that lasted over an hour. During this time, one of the women drew close to Richard and spoke at length, and in detail, about the death of her father with whom her relationship had been quite fraught. Richard recognised *"now she would never be referred because she doesn't feel like she needs to be referred* <u>*but*</u> *she does need support."* He appealed to the group, *"is this the sort of thing I should document?"*

Overwhelmingly, the answer was yes. Cynthia for example asserted, *"the thing is though, through your training etc. you were quite happy to listen to what was probably quite harrowing [Richard: yes] situation whereas other people, I guarantee would 'ave shut her down in some way."* Here, Cynthia suggested that the training cultivated an openness to talk about the 'dark stuff'; a strength and confidence to listen and empathise with someone's pain on a deep level without judgement, and without flinching. She challenged Richard's extrapolation that just because talking about the 'dark stuff' came *"naturally"* to him it does not necessarily follow that it is easy for their peers, or for society at large. Indeed, she intimated that their peers remained uncomfortable and avoided talking about death and bereavement and suggested that BSVs in fact possess unique and valuable attributes that permits subtle bereavement work to flourish. Cynthia, along with a number of BSVs, credited their ease and confidence talking about death and bereavement to the training they received, *"the benefit is that you're trained, you know what to look for (.) it's a learning process and [I] was privileged to do that" [Nancy]*. The training not only advanced their knowledge about bereavement and enhanced their therapeutic skills but it also *"backed them up"* by bestowing their actions with legitimacy and authority.

The ubiquity with which participants framed their openness and capacity to support bereaved people as *"natural"* was striking; it was evidently a salient descriptor for BSVs. During my initial readings I therefore carefully considered what this word choice might communicate, to me it connoted; ease or comfort, normalcy or 'what's expected', an innate attribute or quality, conforming to the course of nature, being outside of external influence, an essential quality.

Consideration of the context and intent of participants' usage supported these interpretations,

> *"It seemed natural for me to become or want to become a supporter." [Richard]*
>
> *"Counselling was a natural part of the ministry and I felt it was a natural part that could be continued in the village." [Rupert]*

Here participants used the word *"natural"* to communicate an essential quality about themselves, they imply an inevitability to following this path given the skills and attributes they innately possess. Yet, this interpretation obscures the years of bereavement training and experience so many of the participants accumulated through their *"working life."* This is not to say that participants were purposefully downplaying their learnt skills in an effort to portray themselves as being uniquely capable. Rather, it resonated with the concept of 'praxis'. Notwithstanding the definitional elasticity of the term, praxis is here understood to refer to knowledge that has emerged through the application of theory into action, or practice (Penney & Warelow, 1999). The notion of praxis may therefore help to reconcile the apparent contradiction of participants elevating the status and skills accumulated through their *"working life"* while simultaneously presenting their skills and capabilities as *"natural"* or innate. In that, the repeated rehearsal of practice not only obscured the effort inherent to the practice, but also severed the link that connected the practice to theory resulting in the possession of practice that appears innate. Or, put another way, "praxis or 'doing action' effectively dissolves the traditional theory-practice gap by making theory and practice mutually dependent on one another" (Rolfe, 1993, p.176). This certainly resonated with the difficulty participants experienced when encouraged to reflect upon specific examples of bereavement support and unpack the relative contributions of their personal characteristics, the skills and knowledge developed through their *"working lives"*, and the theoretical knowledge and therapeutic skills obtained from the training. Meredith for example found it impossible to untangle, *"I think probably because I bring so much work experience it's difficult to evaluate that [I: yes, to separate it out] to separate it out."* She explained that she had become attuned to matching her response to the in-the-moment needs of the bereaved through *"donkeys' years of experience."* However, when asked how BSVs without her counselling background would cope in comparable situations Meredith was quick to redress the implication that hers was the only, or indeed most desirable, route for knowledge acquisition, *"some of the folk [in her previous organisation] who were just superb even from early on they put their foot in the door and you just thought "I've got gold dust here and I better hang on to it!""*

BSVs demonstrated a deep ambivalence about whether theirs was a role contingent upon their unique profile of characteristics and skills, or whether there was space for anyone to do it. The continuous circling back to their professional acumen certainly pointed to the belief that they are particularly, if not uniquely, capable to fulfil this role. Cynthia for example explicitly asserted *“not everybody has got the experience that could come into this role”*, and Lil frequently questioned whether volunteers with less experience than herself could handle the support situations she had encountered. Dorothy went further still and proposed gatekeeping the role; cautioning against taking on too many, or inappropriate additional volunteers, *“don’t you think though Richard that we should watch the amount of volunteers that we take on?”* In response to this, Richard conceded that they joined because *“they have the right characteristics to do the type of support that is needed”*, but suggested that as the village had recently seen an *“influx of new residents”* there may well be more people who would be suitable on the basis of experiential or professional knowledge, *“they themselves might have gone through similar things like you have Dorothy, or people like myself who have already, and like Charles have already been in a support environment anyway.”* In lieu of professional knowledge, participants often claimed to possess the *“right characteristics”* as a means of claiming what they perceived to be the requisite legitimacy and authority to perform the role. With the exception of establishing trust through the reassurance of confidentiality, participants seldom interrogated what specific characteristics and skills they possessed, and indeed whether or not these could be learned.

In summary, BSVs frequently referred to their capacity to provide bereavement support as *“natural.”* This theme has presented a number of possible readings into the salience this phrasing held for participants. It considered what this language connotes and conceals, as well as exploring how BSVs characterise the ‘BSV role’ and consequently how this reflects upon their own identity.

Discussion

This study embraced an interpretivist orientation to explore the lived experiences of Bereavement Support Volunteers (BVSs); older adults living in ExtraCare Charitable Trust (ExtraCare) villages who were trained, as part of the Bereavement Supporter Project, to provide bereavement support to bereaved people within their communities in an effort to cultivate more bereavement friendly, or Compassionate Communities (CC) (Kellehear, 2005). This study aimed to gain a deeper understanding of what volunteerism means to older people, specifically, it sought to unpack the role volunteerism plays in the construction of self-identity, ageing, and the life course. To achieve this, non-directive qualitative techniques were employed which produced rich and dynamic narratives of the experiences, challenges, and biographies of BSVs. Data were then analysed using reflexive Thematic Analysis (Braun & Clarke, 2019), through which three themes were constructed *“It’s the story of my life”*, *“I want this thing to help me: Negotiating volunteerism and reciprocity”*, and

“Being open to the “dark stuff”: Unpacking the ‘naturalness’ of sitting with grief.” Attention will now be given to situate the findings of the current study within the landscape of volunteerism among older adults, and the CC movement.

Rather than approach participants with predetermined and prescribed motivational categories from which volunteers chose to endorse, this study encouraged spontaneous and self-directed discussions to emerge thereby positioning it as somewhat unique in the field of volunteerism among older adults. Contrary to previous findings (Celdrán & Villar, 2007; Chen & Morrow-Howell, 2015; Ho et al, 2012; Principi et al, 2012), the discourses of ‘giving back’ and ‘humanitarian values’ were rarely stated explicitly in this research. Certainly, participants echoed these sentiments, particularly when responding to direct questions about their motivations early on in the research encounter, but these rather shallow refrains were not salient to their experience overall.

Participants framed volunteerism not as a mundane, discrete, or isolated action but rather a mode of being that aligned, influenced, and was influenced by the legacy of their lived experience, and their values for the future. Participants frequently emphasised their respected, skilled, and productive *“working lives”*, a delineation from their current lived experience which implied the present was marked by the absence of purpose and status their (largely) middle-class professional occupations afforded them. Indeed, participants reported their professional background had paved the way to this juncture and they were therefore compelled to become a BSV to honour this facet of their biography and personal identity. Other research has similarly identified a link between volunteerism and the maintenance of professional identity. Chen et al (2020) for example reported that older adults felt anxious about losing their professional identity and status during retirement and so leveraged their skills and professional knowledge in an effort to preserve their ‘productivity’.

To explicate their findings, Chen et al (2020) drew upon the continuity theory of ageing (Atchley, 1999) which uses a life course perspective to define ‘normal’ ageing. The theory posits that older people attempt to preserve consistency in their activities, values, and relationships in order to adapt to, and cope with, their changing physical, mental, and social status. Retirement in this context is positioned as a potential threat to an individual’s internal (their beliefs, ideas, and personality) and external (their relationships and social roles) structures which may destabilise their self-concept and lifestyle, particularly among those who derived meaning and pleasure from their *“working life.”* Consequently, these individuals seek activities, such as volunteering, that maintain their internal and external structures thereby stabilising the continuity of their identity. Continuity theory certainly chimes with the context and content of BSV narratives within this study; these were older people who had possessed, or revered, the status and expertise afforded those in middle class occupations and explicitly framed the BSV role as a continuation of previous roles. However, such an interpretation obscures the normative assumption and expectation that continued ‘productivity’ is not only universally possible, but that it is universally desirable.

Indeed, Rudman and Molke (2009) caution that the proliferation of ‘productive ageing’ discourses within policy making, health care, and the media have established a moral convention that drives older people to be “forever productive.” More broadly, Katz (2000) argued that the “ideal of activity”, perpetuated by neo-liberal and market-driven policies, has conditioned society into believing that “to be functional, [bodies] must be busy bodies” (p. 149). For older people, continued activity is then reframed as an ‘empowered’ effort to avoid stigma and evade decline and dependency. This narrative was identified within the current study as participants frequently presented their volunteerism as a mechanism for demonstrating ‘productivity’ and staving off ‘dormancy’. Further to this, participants became heated in their discussion about the decline in volunteerism within ExtraCare, where they policed their peers’ activities and capacities, and admonished them for eschewing volunteerism. Indicative of a deep-rooted belief that continued activity, as demonstrated through volunteerism, is a marker, and perhaps even a requirement of ‘successful’ citizenship.

Other research within extra care housing has likewise identified volunteerism (West et al, 2017), and “keeping busy” more broadly (Johnson et al, 2020) to be explicit strategies employed by residents to stave off decline and delay dependency (in the form of accessing or increasing care provision) in order to preserve agentic independent living. However, these studies also speak to the apprehension of older people that they soon will no longer be able to resist the ‘gravitational pull’ of the fourth age (Gilleard & Higgs, 2010). If indeed issues of illness, availability, or the geography of the scheme had not already precluded their participation in health, social, or volunteer activities (Johnson et al, 2020). The participants described by West et al (2017) for example displayed dogged perseverance to maintain volunteer activities despite their own “waning energy” and “what appeared to be a lack of enthusiasm or interest on the part of other residents” (p. 1886). Nevertheless, more experientially orientated research is required to build confidence in this interpretation, and to further unpack the confluence of individual meaning-making and wider societal discourses and norms related to ageing expectations and identities.

Moreover, participants in this study framed volunteerism as a negotiation between ‘giving’ and ‘gaining’ which emphasised the salience of reciprocity to their volunteer experience. Other research has likewise demonstrated that older adults endorse both altruistic and self-orientated motivational categories simultaneously (Chen & Morrow-Howell, 2015). Within this model, being motivated to 'help others' or 'leave a legacy' are aligned with altruistic motivations whereas increasing one's own well-being, receiving social recognition, and personal development are aligned with self-orientated motivations. While participants provided spontaneous responses to open-ended questions, Chen and Morrow-Howell's (2015) paradigmatic orientation steered them away from analysing the data generated through an experiential or psycho-social lens and instead they employed reductionist techniques to impose discrete categories for the purpose of statistical analyses. It is therefore unclear what these motivational categories mean for older adult volunteers, how this contributes to their concept of self, or what such understandings contribute to conceptualisation and expectations of ageing.

Within the present study, participants viewed volunteerism as a mechanism for 'giving' the skills and knowledge they had accumulated throughout their lives. In so doing, participants championed their own life experiences, skills, and knowledge and some argued that through this they were empowered to challenge ageist stereotypes which obscure older people's rich past, as well as limiting their potential for the future. Cousineau and Misener (2019) likewise reported that participants conceptualised volunteering as a means of "making a difference" on two levels; an individual level where their own sense of self worth and self-concept was enhanced, and a community level where satisfaction was derived from community development and enrichment. Findings from survey-based research have also identified a correlation between volunteerism and a concern for community among older adults (Chong et al, 2013), particularly among those who had lived in the community for a longer period of time (Lee et al, 2008). However, as was the case in the present study, the meaning and satisfaction participants derived from volunteering hinged on their perception of how successfully they had 'performed', as one participant in Cousineau and Misener's (2019) study explained, "you just need to have affirmation that you are, or confirmation that you are of value to someone, and you're making a difference because otherwise, what's the point?" (p. 71).

As intimated above, participants in the present study were initially drawn to the BSV role as they viewed it as an opportunity to apply the skills and knowledge they had accrued through their *"working life"* which would simultaneously *"make a difference"* to both their community and their own sense of self-worth. For some, the informality of support provision threatened the duality of reciprocity as volunteers elevated formalised support above informal *"casual conversations."* The lack of formal referrals became a predictable, and at times tumultuous, feature of discussions with BSVs. This tension showed no signs of dissipating despite the accumulating evidence that formal referrals were not forthcoming, nor was it mollified by the project managers' efforts to persuade BSVs of the value of the informal support they were providing. Given the salience of this distinction for BSVs, and the draw of formal referrals in particular, it became integral to this research to attempt to unpack and explicate the significance of formal referrals.

It is argued that, for BSVs the value of formal referrals is multifaceted. It would be unfair to suggest that BSVs' preoccupation with formal referrals was solely an attempt to reassert a revered status position within ExtraCare although this certainly may have played a part. Formal referrals operate as tangible, easily quantifiable, and structured interpersonal interactions and so were valued because they validated both the 'work' of individual volunteers and more broadly the role of BSV. Participants explained that informal support was often transient, ad hoc, and the boundaries between what constituted support were blurred, so they struggled to demonstrate their 'productivity' as volunteers. It is suggested that a consequence of this was that BSVs were denied the societal and personal recognition afforded to those engaged in socially desirable and sanctioned volunteerism and so the conditions of reciprocity were not met.

Participants in other CC initiatives have likewise struggled to gain satisfaction within their volunteer role due to role ambivalence (Pesut et al, 2018). Like in the present study, the authors comment that participants found it challenging "to construct criteria by which to measure how well they were performing in that role" and were concerned they were not "doing more for clients" (p. 6). Nevertheless, the authors assert that, over time, volunteers reassessed what 'counted' as support; they developed an understanding of their role that appreciated the value of "helping people navigate this time of life on an emotional level" (p. 6), rather than focus exclusively on instrumental support. However, given that volunteers in Pesut et al's (2018) study were matched with clients, whom they had regular contact with over time, it is argued that the volunteers had more opportunities to observe the impact of their support efforts and build meaningful rapport and connectivity over time compared with the Bereavement Supporter Project where support largely consisted of ad hoc, informal, *"casual conversations"* which remained difficult to measure. Nevertheless, it was certainly the case that some BSVs valued, and in some cases privileged, the significance of informal support over time and enjoyed the reciprocity afforded by volunteering in the programme.

Furthermore, BSVs regarded the paucity of staff referrals as being indicative of a more general organisational malaise characterised by deep division and conflict between staff and residents. Participants suspected that staff were purposefully holding back referrals out of mistrust and a disregard for their personhood and lived history. They gave the impression that formal referrals had come to symbolise an atmosphere of trust and reciprocity between staff and residents; an olive branch that they clung to and remained hopeful to receive.

Indeed, other CC interventions (Abel & Townsend, 2015; Horton et al, 2015; Pesut et al, 2020; Walshe et al, 2020) have likewise encountered resistance from staff operating within organisations participating in, and in some cases, implementing the intervention. It has been hypothesised for example that this resistance stems from healthcare professionals struggling with the concept of a public health approach to end-of-life (Horton et al, 2015); concern about who the volunteers are, their training, and the safety of the intervention (Walshe et al, 2020); lack of appreciation of the skills and contributions of volunteers (Pesut et al, 2020); apprehension that volunteers are being used to replace paid healthcare staff (Pesut et al, 2020);and medical, risk averse organisations being a poor setting for such purposively radical interventions (Abel & Townsend, 2015; Walshe et al, 2020). The field would therefore benefit from more experientially orientated research to unpack, elucidate, and mitigate the lines of resistance to successful implementation of CC interventions.

Strengths and limitations of this study

The present study should be viewed in light of its strengths and limitations. First, volunteer experiences were situated within rather unique conditions, both in terms of the physical space and the nature of the project itself. With a few notable exceptions (for example, Kahana et al, 2013; Leedahl et al, 2017; Pardasani, 2018) there is a paucity of research exploring older adult volunteerism within retirement villages or care homes, this study therefore represents an important addition to the field. Retirement villages are, in many ways, unique, and differ to 'community dwelling' in a number of keyways. For one, they are often self-contained and self-sufficient communities, equipped with amenities to encourage leisure, health, and social activity internally, in addition to the provision of care packages to those who request (and can pay for) it. Consequently, the village is a hub of activity, including opportunities for volunteerism, unparalleled to typical residential streets. For many participants in this study, volunteerism is embedded into the fabric of life within ExtraCare, indeed, West et al (2017) suggested that volunteerism had been accepted by residents as part of their democratic duty and civic responsibility of ExtraCare citizenship. Volunteers in this study then are part of a unique culture, which particularly venerates volunteerism, that may not be comparable to other settings and communities.

Additionally, the Bereavement Supporter Project was an innovative and unique public health approach to supporting bereaved older people, consequently, it traversed unchartered territory. As has been discussed at length, the informality of support provision was an unexpected, and for some an unwelcome, feature of the BSV role and presented residents with a significant challenge to negotiate and reconcile their volunteer identity, and their expectations of reciprocity. This aspect of experience undoubtedly dominated discussions, with a small number of participants repeatedly steering conversation back to this point, perhaps as a consequence, other salient features of BSVs' experience were eclipsed. It is possible that if the Bereavement Supporter Project continues and evolves volunteer recruitment will then be predicated on the understanding that the role is largely dominated by informal helping which will perhaps mitigate the dissatisfaction and disillusionment palpable in the present study.

Concluding remarks

In summary, this study embraced a phenomenologically orientated design in an effort to better understand the lived experience of BSVs – older adults living within ExtraCare who had been trained to provide first contact listening support within their communities. Further to this, it refocused attention away from survey-led designs and concerns and instead strived to elicit participant-focused and directed narratives and discussions. In so doing, this study was uniquely positioned to situate the motivations, experiences, and identities of older adult volunteers within their personal biographies, societal expectations and stereotypes, and the dialogue between the two. The themes identified suggest that successful and productive ageing discourses linger, with older people expressing a propulsion to volunteerism in an effort to present themselves as active combatants of decline and dormancy. Furthermore, volunteers emphasised the importance of reciprocity, in that they expected not only to 'give' but to 'gain' from their experience. The context of this research was unique and so may not reflect the broader experience of older adult volunteers, more phenomenologically orientated research in this field is therefore welcomed.

Chapter 6: Right idea: Wrong place, wrong time?

Introduction

This chapter builds on the two preceding empirical chapters. The first, ‘the nature of bereavement support’ orientated this research within the compassionate communities (CC) movement (Kellehear, 2005) which seeks to make death and dying “everyone’s responsibility” (Abel & Kellehear, 2016) by mobilising and uplifting community networks to supplement professional end of life and bereavement care. I recently conducted a scoping review to synthesise CC intervention strategies (see, Appendix A) which argued that enlisting, training, and deploying volunteers to provide instrumental, emotional, and informational support to patients identified to be at the end of life and/or their carer to be a central model for interventions in the field. While drawing upon a similar volunteer model to other interventions in the field, the Bereavement Supporter Project was unique for a number of reasons. First, it translated the ‘community champion’ model from the dominant purview of death and dying to a more holistic approach which included bereavement. Second, it was developed and implemented by organisations outside of palliative care, and to my knowledge, is the only CC intervention conducted in extra care housing. Finally, the project embraced the idea of ‘peer support’ and so volunteers were recruited internally within ExtraCare with the view that Bereavement Support Volunteers (BSV) would provide support within their own village community. The ‘nature of bereavement support’ chapter takes a granular view using the lived experience of community members to explore not only what participation meant for them but what these experiences tell us about the implementation of CC interventions more broadly. The second empirical chapter, ‘identity’, drilled down further and centred closely on the lived experience of BSVs. Specifically, it considered the meaning of volunteerism for older people using their personal narratives as a backdrop from which to consider the ways in which pervasive societal discourses, namely successful ageing (Rowe & Khan, 1997) and the third age-fourth age dialectic (Gilleard & Higgs, 2010), colour their experience and how they make sense of the world.

The intention of the present chapter is to zoom out from the idiographic and enter into a more explicit and intentional dialogue with the broader conceptual and theoretical frameworks at play. The data generated within this research acted as a springboard from which to consider and challenge higher concepts such as the epistemological tensions within CC interventions, specifically the misalignment between the intention to drive forward community-orientated and driven initiatives and the practice operating within the demands of professionalised spaces; the third age-fourth age dialectic (Gilleard & Higgs, 2010) as it pertains to death discourse; and finally, that the master narrative, ‘it’s good to talk’ has axiological implications upon the acceptable parameters of grief and imposes limitations on how we ought to age (Holstein, 2006). To achieve this, this study moved away from the data-driven logic of the two preceding empirical chapters and was orientated within an explanation-driven logic, which used 'abductive inference' (Hiles, 2012) to explore and explain the relationships between the data generated and salient theory (see 'Methodology and Methods' Chapter for more details on the analytic process). This empirical chapter therefore serves as a response to Main Research Question 2, *"what can the findings of a CC intervention contribute to wider gerontological discussions and debates?"*

Results and Discussion

Through abductive Reflexive Thematic Analysis (Bruan & Clarke, 2019) three main themes were constructed. First, I draw upon West and Glynos' (2016) concept of *"'death talk' / loss talk'"* in an effort to better understand the differential treatment of, and engagement with, two ExtraCare initiatives (the Gold Standards Framework and the Bereavement Supporter Project) that, on the surface at least, appear united in their efforts to invite conversations around death, dying, and bereavement. Within the second theme, *"even the volunteers are expecting very formal referrals"* I examine the ways in which the Bereavement Supporter Project, and specifically, the BSV role, have been (re)framed over the course of the project. Further to this, I unpack the potential reasons for, and implications of, the discursive shift which saw the role of the BSV transform from being 'counselling adjacent' to being *"real community leaders."* Finally, the theme *"it's good to talk"* applies a critical gerontological lens to challenge the maxim that 'grief work', and specifically, the impetus to disclose and discuss one's grief is an inherently 'good' or 'adaptive' grief response.

'Death talk' / 'loss talk'

As discussed in a preceding chapter ('the nature of bereavement support'), two years after the introduction of the Bereavement Supporter Project, ExtraCare began their Gold Standards Framework (GSF) accreditation which sought to "improve the quality, coordination and organisation of care leading to better patient outcomes in line with their needs and preferences and at greater cost efficiency through reducing hospitalisation" (goldstandardsframework.org/about-us). The GSF was often framed by staff as operating in symbiosis with the Bereavement Supporter Project as both programmes encouraged a more open dialogue about death, dying, and bereavement. As illustrated in the following exchange between staff at Oaks Bluff.

> *Francis: there's a big section on that, about bereavement, and how we will support relatives' erm friends following you know the bereavement really and erm that, that we've got to monitor that as well as part of the Gold Standards Framework accreditation so it's all*
>
> *Dan: it's all linked, it all works very well together. [Focus Group, Staff Oaks Bluff]*

Staff were demonstrably proud and reverential that ExtraCare were to be accredited by the GSF, and thereby recognised as leaders in quality end-of-life care that culminated in the 'good death' of residents. As Daisy [Cedar Court] testified, *"I'm incredibly proud of the staff team that I work with (…) because they do support somebody with their end of life in such a fantastic way because it's how they choose to die."* Here, Daisy placed an emphasis on resident choice and autonomy, not only in the way they live, but in the circumstances of their death. Being chosen as the site for, and witnesses to dying was then framed as a privilege; a charge which Daisy accepted and treated with the utmost respect. As the following anecdote, which describes the final moments of one of Daisy's *"favourite"* residents, attests,

> *I held her hand and she smiled at me, and she was tucked in, but she pulled her hand out and she got my hand and pulled it to her and went like that. I put my hand there and she just smiled at me and then within an hour, I think, of that they told me that she'd passed, and I thought, oh my god, I could have been one of the last people to see her. How lovely was that for me. [Staff Focus Group, Cedar Court]*

Yet, I was struck that the same deference and diligence was not afforded to the implementation of the Bereavement Supporter Project, and indeed, there was in fact evidence of open resistance to the project among some staff members (see, Chapter 4 'The nature of bereavement and bereavement support') in a way that was not observed, at least overtly, in relation to the GSF. There was discursive evidence within staff narratives that framed the GSF as mandatory policy and practice that was not mirrored in their attitudes or efforts towards the Bereavement Supporter Project. For example, staff frequently described bereavement support as a compulsory component within the GSF that they were required to monitor, work towards, and evidence in order to receive accreditation.

> *"We've got to monitor that [bereavement support]." [Francis, Staff Focus Group, Oaks Bluff]*
>
> *"Bereavement is a big thing in there [GSF] obviously so we've offered everything, we've put stuff around." [Sharon, Staff Focus Group, Elmwood Forest]*
>
> *"We were all really on board with that and everyone was revising all of our papers you know and making sure we knew exactly what we was [sic] talking about." [Alice, Volunteer Organiser Interview, Oaks Bluff]*

Staff accepted that the GSF *"isn't optional, that is happening"* and so had perhaps *"taken it on board"* for pragmatic and self-protective reasons. After all, this was a directive over which they had to concede; it would have been futile, and potentially self-sabotaging, to resist a programme that had so quickly, and seemingly easily, been incorporated into the suite of opportunities available within ExtraCare. To some extent then, staff performance was contingent upon demonstrating significant progress towards GSF markers. In contrast, not engaging with the Bereavement Supporter Project led to *"no real consequence bar me chasing them up"* [Grace, Cruse Senior Manager], and so perhaps, staff felt criticism in this context was more permissible. While this explanation is certainly plausible it is not wholly convincing, for one, staff did not appear to be inhibited in voicing their criticism of ExtraCare. For example, Francis and Patrick [Oaks Bluff] led an impassioned duet that railed against an earlier training session (outside of the Bereavement Supporter Project) on death and dying led by ExtraCare that Patrick concluded was *"just appalling (…) and it was scaring people."* Alice [Oaks Bluff] likewise spoke candidly about being overworked, *"we're so inundated with things every single day with so many of us working silly part-time hours for full-time roles or expecting full-time results from part-time hours."* Second, while outwardly both programmes ostensibly sought to elicit a richer and more transparent dialogue about end-of-life issues and bereavement, it is argued that these talking points were fundamentally different. And it is the crux of this difference that surfaces and contextualises the contradiction at play.

West and Glynos' (2016) delineation between 'death talk' and 'loss talk' provided a useful lens through which to interpret the 'contradiction' between the differences in acceptability of these two, seemingly similar, programmes. The authors argue that through pervasive policy and public health discourses the possible permutations of 'death talk' have been diluted to concerns of extending life and preventing disease. Specifically, 'death talk' is presented as on opportunity to pacify people's fear of the dying process; fears of a 'bad death'; and more broadly, fears of mental and physical illness and incapacity. It is then through choreographed conversations about our expectations and choices surrounding dying that we can plan, control, and ideally defer, the dying process. West and Glynos go on to argue that this circumscribed concept of 'death talk' embodies the desires of the 'third age' which cleave to the capacities that afforded productivity and independence during the exalted 'second age'. And in so doing, "'death talk' here works to avoid confronting the losses implied in old age" (p. 230), and indeed, reproduces distaste for, and avoidance of, the dreaded 'fourth age'; a "black hole" where "power, status, and citizenship can no longer be enacted by who are identified by it" (Gilleard & Higgs, 2010, p. 121). 'Loss talk' then stands in contrast to (bad) 'death talk'; it is moored to "the ever-present possibility of loss in life itself (…) and crucially, what those losses imply for our identities" (p. 236). By inviting individual (or collective) subjects to publicly recognise and integrate loss into "one's collective or individual life", West and Glynos suggest 'loss talk' "is the kind of affective practice that can 'make a difference to our outlook'" (p. 235).

Returning to ExtraCare, I assert that the differential implementation of the GSF and Bereavement Supporter Project reflect the fissure between 'death talk' and 'loss talk' respectively. As an exemplar of 'death talk' the GSF operates within a professionalised lens of end-of-life care concerned with the early identification of people at the end of life (O'Callaghan et al, 2014) and an (over)emphasis on improving end of life care through the implementation of advanced care planning (Mullick et al, 2013). The discourse surrounding advanced care planning is prefaced on the philosophy of “hoping for the best and planning for the worst” (Gold Standards Framework, 2013) and is therefore, unsurprisingly, principally focused upon managing what is to be done to unruly bodies once they are stripped of capacity and have therefore entered the “black hole” of the ‘fourth age’ where the full power and status of citizenship has receded, irrevocably, from view (Gilleard & Higgs, 2010). Within ExtraCare, staff appeared to have embraced the necessity of these conversations and embedded them within their practice. For example, Karen [Staff Focus Group, Cedar Court] explained,

> *With the GSF we are not promoting death, that’s the wrong way, but we’re promoting the fact that you can plan and have advanced planning in place so that you are moving to a village where you’re going to spend the end of your life and your end days, so we’re looking at more for the individual of can you be here for the rest of your life and how do you want it to be?*

Here, Karen appeared to be spontaneously responding to the criticism that the GSF is *“promoting death”*, which given that this had been absent from our previous discussions had presumably been raised historically by residents. Karen was careful to quickly pivot away from death-focused discussion towards the more reassuring notion of *“the rest of your life”* and the reinforcement of the principles of independence and individualism inherent to the promises of the third age. While Karen falls short of stating it explicitly, it is inferred that planning is protective, and that once the paperwork has been completed, death has been deferred and *“the rest of your life”* can be enjoyed. Indeed, Karen and her interlocuter Daisy could not fathom the notion that residents may come to ExtraCare anticipating the death of others, let alone themselves,

> *Daisy: they’re not going to move into an environment thinking they’re going to die. They’re moving into the next stage of their life, if you like, and going to have our golden years here.*
>
> *(…)*
>
> *Karen: But I don’t think anybody moves somewhere thinking, “I’m going to see lots of people die” because you just wouldn’t think that would you?*
>
> *Daisy: You couldn’t come here, would you? [Staff Focus Group, Cedar Court]*

Given Karen and Daisy’s idealised presentation of retirement and ExtraCare living as the *“golden years”*, a period of life apparently divorced from illness and death, it is perhaps striking that they have seemingly reconciled this vision with the incorporation of the GSF. Nevertheless, others did express concern over potential tensions between the promises of a happy, healthy, independent retirement and the spectre of death, particularly in more established ExtraCare villages. But this tension was quickly attenuated by ExtraCare’s intention going forward to have the GSF in place in new villages *"from the very beginning."* As Patrick [Staff Focus Group, Oaks Bluff] asserted, *"if it's introduced then right at the word go that would be easier, rather than here's your happy life, here's your show home, and by the way, death!"* It is suggested here that establishing 'death talk' early on is advantageous because it is then absorbed into the administration of relocation, it is simply another piece of paperwork that must be completed before you enter your *"golden years."* Whereas for residents in more established villages, where successful ageing messaging has obviated any concession to living with illness and the process of dying, the introduction of 'death talk' poses a greater threat to the age-less agentic identity ExtraCare residents have embraced and reproduced. The GSF then provides staff with an approach to 'death talk' that emphasises "the ideal of mastery and control embodied in the image of the third age" (West & Glynos, 2016, p. 233) and is therefore firmly aligned with the teachings and practices of their profession. This, West and Glynos would argue, exemplifies 'bad death talk', "insofar as they do not allow the subject to countenance fully the potential loss of identity and thus the possibility of constructing a new mode of being" (p. 236).

In contrast, the Bereavement Supporter Project can be seen to align, at least in part, with the spirit of 'loss talk'. The project purposefully conceptualised bereavement as *"loss in its widest context"* in an effort to acknowledge that older people *"will experience the most loss in life. Outside of bereavement as well, so loss of health, independence, change in circumstance"* [Grace, Cruse Senior Manager], and that it is important to recognise and reconcile this *"raft of losses"* as part of the lived experience of ageing. 'Loss talk' is therefore rooted in the ontological experience of embodied loss, and the challenge many of us experience of living after a significant loss. Within this orientation it was intended that the Bereavement Supporter Project, and the BSVs in particular, would provide the necessary conditions - "a publicly shared recognition of loss; and an appropriate context within which loss can be processed and creatively integrated into one's individual and collective life" - to foster genuine 'loss talk' within ExtraCare (West & Glynos, 2016, p. 235). However, in practice this was rather more challenging, for both staff and residents, to engage in. To do justice to the multi-perspective approach taken in this research, a subsequent theme (*'it's good to talk'*) will consider resident experience in relation to the wider literatures, and this theme will continue to attend to staff experience.

As part of the Bereavement Supporter Project, ExtraCare staff were invited to attend a one-day loss and bereavement awareness training session. Their experiences of this training, both within and beyond the classroom, were particular foci of the first wave focus groups. These discussions revealed that the training had challenged and shifted staff conceptualisation of bereavement to include losses which could be termed non-death bereavement (e.g., loss of mobility or independence, loss of previous home and furniture, loss of social opportunities etc.). As Lydia [Staff Focus Group, Sycamore Grove], who worked in sales commented, *“[there are] many different ways of losing things and grievin’ for things without people.”* She went on to say that while she had always been cognisant of the stress that residents may experience whilst moving, she had not fully considered the parallels between these losses (e.g., downsizing, leaving a house they had lived in for many years, etc.) and grief. She conceded that she does not regularly have contact with residents after they have moved into a village, and so would be unlikely to offer them direct bereavement support, the training nevertheless resonated with her experiences and encouraged her to attend to the individual experiences of residents. Lydia’s experiences are a good illustration of how having increased knowledge and awareness of loss and bereavement can pay dividends for every role within ExtraCare. A point succinctly, and effectively, made by Marnie [Staff Focus Group, Sycamore Grove], *“so we’re all dealin’ with different sort of bereavements really, she’s in care, you’re in houses, and I’m in reception so we’re dealin’ with it in different ways.”*

However, discussion with staff also surfaced some challenges to, or tensions around, talking openly about death, dying, and bereavement. Threaded throughout the discussions were concerns about saying or doing the ‘wrong thing’, and it was evident staff were ambivalent about whether or not there is a ‘right way’ to talk about and respond to residents’ grief. Some, like Samantha, asserted that shifts in language (for example, ‘how are you?’ as opposed to ‘are you ok?’) provide residents with the space to *“open up”* and facilitate a culture that centred the “active engagement in mourning or loss talk as part of life” endorsed by West and Glynos (2016). While not necessarily a product of the training, Samantha recognised that the training reaffirmed this approach to eliciting conversation from residents. In contrast, Daisy felt frustrated and sad that there are no words she can say to alleviate residents’ pain, *“that’s a sad thing for me, is not being able to help them or say the right things.”* Jordan likewise pointed out that ‘sitting with grief’ ran counter to her role as a carer where, *“normally with care, you know, you’ve got somebody you have to action it, whereas if somebody is just talking, it doesn’t necessarily need an action.”* While Jordan framed this positively, it provided an interesting insight into why other staff members, such as Daisy, may be saddened or frustrated in not being able to *“action it.”* Unlike the GSF and other examples of ‘death talk’ which are underscored by tangible, but distal actions, the Bereavement Supporter Project was committed to sitting with these *“uncomfortable conversations”* with no promise of resolution. This could be deeply uncomfortable for staff operating within a system entrenched in nursing culture and practices; where “action” to improve physical health outcomes had historically been the purview for intervention, as Matthew [ExtraCare Senior Manager] acknowledged.

> *A lot of kind of our senior team at the time were nurses and kind of like nursing backgrounds, so I think again that very kind of physical health was always a priority for extra care, but maybe some of the psychosocial stuff we've not done so much of.*

Despite being presented as working in symbiosis, it is my contention that ExtraCare staff responded differentially to the GSF and Bereavement Supporter programmes. Approaching this 'contradiction' using the concepts of 'death talk' and 'loss talk' proposed by West and Glynos (2016) provided a compelling lens through which to view and unpack this contradiction. In summary, it is suggested that the GSF exemplified the concept of 'death talk' in that it is primarily concerned with enacting choreographed conversations intended to secure "control of the dying process" such that "confrontation with the idea of death itself is deferred" (p. 230). In contrast, the Bereavement Supporter Project was motivated to encourage genuine discussion centred on the *"raft of losses"* we experience as we age and their effects upon inter- and intra-personal identities. Further to this, I assert that 'death talk' in the guise of the GSF was more easily absorbed into ExtraCare's professional culture as it aligned with the principles and practices of nursing whereas the Bereavement Supporter Project was more radical in its commitment to surface "the ever-present possibility of loss in life itself" (West & Glynos, 2016, p. 2366) which staff resisted.

"Even the volunteers are expecting very formal referrals"

The informality of support came to be emblematic of the struggle faced over the course of the Bereavement Supporter Project. It was particularly contentious among BSVs for whom the more structured model of support originally envisaged promised a bridge back to occupying the privileged status of 'the professional' (see Chapter 5); a mechanism for reciprocity where volunteerism provided a meaningful opportunity to give and gain; and finally, the referral system became a shorthand for BSVs' ongoing longing that staff would recognise their personhood and 'all they have to offer' (see Chapter4). A number of BSVs were unyielding in their pursuit of formal referrals, with a pocket of volunteers withdrawing from the project when it was evident referrals would not be forthcoming. Conversations with BSVs, both within and outside of data generation contexts, came to be characterised by a circular narrative that hinged on cultivating a structured model of bereavement support. This, admittedly, became a little tedious; although I was determined to unpack the significance of formal referrals for BSVs, part of me harboured some frustration that BSVs could not, or would not, move on and embrace the informal and make the most of things. At this point, engaging in a dialogue between the data, or more specifically my interpretations of the data and gerontological literature once again challenged the root of my interpretations and provided an alternative lens through which to interpret BSVs' lived experience. Studying the discourse of my own interpretations, for example my insistence that BSVs should simply endeavour to *"make the most of things"* and move forward with the project, I was confronted by my perpetuation of the third age demand for proactive and positive ageing (Asquith, 2016). Here, I reflected that perhaps my frustration in BSVs doggedly persevering in their dissenting discourse about the informality of the project was rooted in an unconscious belief that one must 'bounce back' from personal adversity by drawing out opportunities to re-frame the experience within a positive orientation. In other words, I was projecting an expectation of resilience that emphasised "the importance of personality characteristics such as flexibility to adapt to change or a realistic outlook" (Wild et al, 2011, p. 7) that stripped away critical contextual factors and in so doing placed responsibility for 'success' squarely on the shoulders of these few individuals. This analysis served as a useful reminder to actively engage in the multiperspectival approach of this research and to make space for "what lies between" the participants and myself (Larkin et al, 2019, p. 187). By re-examining the data and reflecting on my own participation within the project and with this renewed perspective I was invited into a more concerted analysis on the significance that 'time' held in the ways in which the project was (re)constructed and experienced. Retracing the steps we had taken to develop, deliver, and evaluate the project provided a springboard from which to consider the temporal mechanisms that underpinned and, at times, undermined participant experiences. The remainder of this theme will attend to these critical contextual factors which had hitherto been obscured through viewing the data, unintentionally, within a vacuum.

There was an impression among project senior management (including among the research team, myself included) that *"because of their ex-professional roles some of them [BSVs] would prefer real structure"* [Grace, Cruse Senior Manager]. It was inferred that BSVs had imprinted their former professional role onto the role of BSV that persisted despite the efforts of senior management to ground their expectations within the informal orientation of the project. As Grace reflected,

> *I think some of the volunteers although I feel like we couldn't be any clearer in the training and in the follow-up training and the information that they receive that expectation although we constantly pass on that message that it will be informal for a lot them there is still the expectation that it will only carry value, or it will only work if it's formal referrals.*

However, this representation belies, and indeed, re-writes the history of the project. As I have reported elsewhere (see Chapter 4, 'The nature of bereavement and bereavement support') the envisaged pathways to support were informed by referral processes characteristic of Cruse's previously established model of support provision. Despite its success elsewhere, time has revealed this to be a model misaligned with the ExtraCare context. But it is important to remember that at the beginning of the project it was expected that the referral pathways would yield support that would be structured and tangible, and indeed, this is reflected in the original evaluation protocols. Further to this, the one-day training ExtraCare staff and BSVs attended, while tailored to ensure *"the content was relevant to older people"* nevertheless presented grief and bereavement through the lens of a professional bereavement organisation. For example, the training examined various models of bereavement, such as Kübler Ross' stage process (Kübler-Ross, 1970), continuing bonds (Neimeyer et al, 2006), and the dual process model (Stroebe & Schut, 2010), and privileged therapeutic skills such as active listening and boundary setting. It is important to acknowledge that attendees, staff and BSVs alike, valued the learning they gained from the training, *"I said the benefit is that you're trained, you know what to look for, it's a learning process and was privileged to do that"* [Nancy, BSV, Sycamore Grove], and commended the creative and engaging presentation of the material, *"it was providing tools but without providing 600 word theory behind it which made it a little bit easier to grasp and easier to retain"* [Patrick, Volunteer Organiser, Oaks Bluff]. Its potential for education notwithstanding, it is my contention that because the training was orientated within the traditions of counselling it framed bereavement support as (quasi)professional, and, perhaps inadvertently, contributed to the expectation that the BSV role was 'counselling adjacent'. Indeed, one BSV asserted there was an over-emphasis in the training on listening and proposed the value of *"a training session based on how to use our experiences of bereavement to help people beyond just listening"* [Rupert, BSV, Cedar Court]. While the project senior managers maintained that part of what was unique about the Bereavement Supporter Project was that it valued the experiential wisdom of residents who *"can maybe empathise with the resident more maybe than a member of staff can"* there was a misalignment between this ethos and the kinds of bereavement support and skills legitimised through the training.

Moreover, there was a concerted effort initially to engage with ExtraCare staff and residents to develop the project, as Grace [Cruse Senior Manager] reflected, *"it was really important that residents kind of had ownership and felt like "this is ours, and that it's not you coming in and saying you must do this" that it was more "we can shape it.""* Grace explained that the name of the volunteer role was changed from *"champion"* to *"supporter"* in response to resident feedback that they *"can't relate to it, champion implies something else"* which she presented as an early indicator of the ways in which the project had adapted in service to community need. She also emphasised the importance of continued engagement as the project was rolled out into new villages *"so that we were shaping something that hopefully* *didn't just fit one village."* During data generation senior managers frequently emphasised the importance of BSVs finding *"their own way"* with the project, and the importance of collaboration between staff and BSVs to cultivate more 'bereavement friendly' communities. However, once again, the training did not nurture the atmosphere or requisite skills for community action, arguably this was because over the course of the project the messaging shifted in response to the informality of bereavement support observed. In other words, there was a pragmatic and prudent discursive shift in how the project, and the BSV role, were characterised by management as it became evident that formal referrals were not forthcoming in any of the sites. While the project had always been underpinned by public health approaches to end of life and bereavement care, the salience of community mobilisation inherent within the CC movement had hitherto been peripheral. As bereavement support came to be characterised through *"casual conversations"* attention pivoted to the potential of the BSV role as a grassroots movement and the discourse of community action emerged. BSVs from Sycamore Grove, who were described as *"real community leaders"* and *"assets"* were hailed for their ability to embrace and *"run with"* the project. They were encouraged to *"carry on with that leader role but just upskilling them with training and a bit of structure"* whereas other BSVs, from more established villages, were viewed as *"a little bit inflexible about anything new coming in [to the village] so that was a challenge because the project was seen as something new"* [Grace, Cruse Senior Manager].

Further to this, some participants noted the rigidity with which the project broadly, but the Peer Group sessions more specifically, were conducted. In principle, the purpose of Peer Groups was twofold. First, to provide an opportunity to refresh, refine, and enhance BSVs' learning, for example, sessions would often include an invited speaker to address issues identified by BSVs as being salient to their work. Such as the link between bereavement and mental illness, and so a representative from the local chapter of the mental health organisation Mind led one of the sessions. Second, Peer Group was viewed as a platform to bring together BSVs from different villages in an effort to share and learn from one another's experiences, connect to 'a bigger picture', and more light-heartedly, socialise with one another. However, Alice [Volunteer Organiser, Oaks Bluff] noted,

> *some of the feedback I've had from volunteers, and I think personally, is that they've found these kinds of things really rigid, so they've got like a really tight agenda and there's hardly any room to talk and it's like "oh, room for one" or "two more minutes*."

Nancy [BSV, Sycamore Grove] likewise sought opportunities to *"keep the connection going instead of when we meet up having information or a meeting."* The implication here is that Peer Group sessions, or indeed, any of other engagement activities embedded within the project maintained a degree of formality and structure that inhibited BSVs from making meaningful connections with one another and stifled opportunities for community-driven discussion and action. These events were organised and delivered by senior management and so it was their priorities that were privileged. While it was not addressed directly during data generation, through my own participation in these sessions it is my impression that management maintained a firm grip on the agenda in an effort to limit BSVs using the session as a soapbox from which they could rail against ExtraCare - which was viewed as being outside of or irrelevant to the project - or repeat well-worn criticisms and challenges implementing the project. And in so doing, it was intended that the sessions would be more productive in driving the project forwards. However, a schism emerged within the project wherein it was claimed there was an ethos, and indeed an expectation of community-directed action which did not translate into the everyday practices of project implementation.

It is important at this juncture to extend the analysis outwards further still and consider how the Bereavement Supporter Project, and more specifically, the contradictions and tensions addressed here, sit within the landscape of the CC movement (Kellehear, 2005). Others, like Abel and Townsend (2015) have similarly acknowledged an epistemological tension between their core ethos and the training provided to volunteers within their community mobilisation intervention. They reflect that as a product of operating within a risk-averse corporate understanding of volunteering their training focused on a professionalised understanding of what being a carer is rather than being orientated by the lived experience of carers. Consequently, the training provision was not as aligned with the principles of community participation and engagement as they would have liked. Parallels are easily drawn with the Bereavement Supporter Project where the aim to de-professionalise bereavement support and reorientate it within the domain of the community were, to some extent, undermined through training practices that, perhaps inadvertently, reinforced and privileged the beliefs and skills of the counselling profession at the expense of nurturing the integration of experiential knowledge into bereavement support.

Relatedly, Pesut et al (2020) reflected that at the mid-point of data generation volunteers identified “confusion around boundaries and the need for further education and mentorship led to adaptations in Nav-CARE implementation” such as “more structured educational content around topics such as boundaries, self-care, and medicalised assistance in dying” (p. 12). Here we glimpse the potential risk that CC programmes may unintentionally deepen the medicalisation of care of the dying and bereaved rather than facilitating movement away from it. Echoing the hierarchy established among BSVs predicated on their counselling experience identified in this research (discussed in Chapter 5), Pesut et al reported a tension among some volunteers who proclaimed, “I think taking volunteers from wherever, is not adequate. They do need to have some experience behind them” (p. 12) by which they meant experience in palliative care as a healthcare provider. There is a danger here that early CC initiatives to facilitate community mobilisation, most of which employ a broadly equivalent model of volunteerism and are implemented by and within palliative care organisations (see Appendix A, 'Scoping Review'), will prematurely settle the meaning and orthodoxy of intervention in the field. Resistance to the de-professionalisation of end of life and bereavement care, even among those genuinely invested and engaging in the intervention, speaks to the challenge inherent within movements that intend to shift societal beliefs and practices. Flexibility and adaptation are critical to successful intervention implementation and so it behoved Pesut et al (2020) to revise the educational content and incorporate additional skills that would better serve their volunteers. However, care needs to be taken not to develop a CC model of volunteering that has been sculpted to the preferences and demands of (former) healthcare professionals. As Walshe et al (2020) argue, a greater effort needs to be made to engage communities that are not directly aligned with, or accountable to, medical professionals if the CC movement is to gain traction. But further to this, I would argue that movement away from the medical and allied health professional arenas may shield the movement from perpetuating the professionalisation and medicalisation of death, dying, and bereavement that it seeks to dismantle.

It's good to talk

As intimated above, referrals either directed by the individual themselves or via a staff member did not materialise in the numbers anticipated in any of the ExtraCare locations, and indeed, dwindled to zero in most villages over the course of the project. In preceding empirical chapters I presented the arguments made by ExtraCare staff and BSVs to explain this discrepancy which included the suggestion that the project was not visible enough, there was a lack of accountability and responsibility among staff for moving the project forward, and staff resistance to the project. However, there was a handful of occasions whereby BSVs questioned more fundamentally whether it was worthwhile to direct energy into *"broach[ing] a subject that to some people is a no-go area" [Richard, BSV Oaks Bluff]* particularly when, *"the age group that at the minute I am in probably would seek or be likely to seek less help than the coming up age groups as it were" [Meredith, BSV Elmwood Forest]*. There was an implication here that older people were unassailably opposed to discussing death, dying, and bereavement and were incalcitrant in their resistance to help seeking. I bristled at this suggestion, first because it seemed to me to perpetuate pervasive stereotypes that older people are resistant to change (McGregor & Gray, 2002) or are unable to learn and engage in new activities or ideas (Ory et al, 2003), which my own research had encouraged me to challenge, and indeed the data I have presented thus far contradicts. And second, I countered that while we were not observing a *"traditional idea of* *help seeking"*, through discussion with staff and BSVs we nevertheless had accumulated evidence that supported the assertion that older people were in fact open to talk about death, dying, and bereavement albeit through *"casual conversations"* as opposed to overt help seeking. As summarised in the following anecdote after one of the BSVs had asked me directly whether I thought the project was appropriate for older people,

> *I was struck because someone else in this focus group that I referred to earlier said "older people don't want to talk about these kind of things" but then (.) a few minutes later they said, "if I was writing down every conversation I had I'd be here all day" [Nancy: hmm] and I was like "well then, they do want to talk about it!" [laughs] [others murmur agreement] [Meredith: exactly] but they just don't necessarily want to talk about it in a way that would be easy to evaluate! [laughs] [Facilitator, Second Wave BSV Focus Group]*

While I still hold space for these interpretations, by attending to the features of the data I had characterised as a 'contradiction' I noticed a thread that had hitherto been obscured. Across the data set, irrespective of participant group, I noticed a pattern of unease talking about death, dying, and bereavement and further to this, I identified a questioning tone among some participants that challenged one of the underlying principles of the Bereavement Supporter Project, that it is inherently 'good' and 'helpful' to talk about one's grief. This thread could not easily be interpreted, and perhaps dismissed, as evidence of death avoidance or older people's resistance to change that needed to be challenged and ultimately, overcome. For example, among the ExtraCare residents who had received bereavement support from a BSV, two (of three) reported that the support they had received had not helped them much. As I have not previously presented their narratives, I will briefly summarise a distillation of their bereavement experiences.

Mrs Law had prefaced our interview by explaining that she still felt *"very raw"* about the death of her husband but was adamant that she wanted to participate in the research. Although Mr Law had experienced a number of health complications in the past including a heart attack, hip replacements, and dementia, his final diagnosis -cancer- acted quickly and aggressively; *"he was in the bed for four days, he only had four days poorly."* After almost sixty years together, Mrs Law moved into ExtraCare alone and found coping with her grief incredibly challenging. Her grief was palpable, and although she had loving and supportive family, friendships within the village, and activities and events she engaged with she remained utterly bereft, she lamented, "*I really am doin' my best (…) but there's somthin' missin' [quietly] I don't know what it is, I don't know what it is."* Mrs Law had spoken to a BSV which she initially described benignly, "*she was helpful, and I cried and she was nice, she listened"*, however as our conversation continued Mrs Law asked me beseechingly, *"I just wondered you've been through a lot, you've done a lot of this, is there anybody in this place that's worse than me"* with whom she could talk to and connect with over their shared loss. I responded that I had not spoken with many bereaved people in her village, but that many of the BSVs had experienced personal loss and perhaps they could help her, to which she replied, *"but I've had them here haven't I? and I don't feel any different when they've gone."*

Like Mrs Law, Mrs Laverty was utterly devastated when her husband died and she threw herself into various activities and excursions in an endeavour to occupy herself, *"last year, the various things I was doing, I was sort of buffeting myself, almost running away from it."* Feeling that she couldn't *"keep on, and on, and on with, with your friends because it's old news"*, Mrs Laverty agreed to meet with a BSV. She met with Lil on one occasion who encouraged her to reach out if she wanted further support, however Mrs Laverty explained, *"I just didn't feel she was the right person to speak to."* When asked if the support was fulfilling in any way Mrs Laverty replied, *"not for myself no. Probably for other people yes, I think not many people will have had the sort of trauma that I had (…) it's not a criticism in any way, shape, or form."* While care must be taken not to extrapolate too liberally from two cases, the experiences of Mrs Law and Mrs Laverty certainly challenged my assumption that it's inherently 'good to talk'. Indeed, these insights encouraged further examination of the data generated with ExtraCare staff and BSVs. In particular, I was struck by the hunger with which BSVs in particular engaged in the project, as Patrick [Volunteer Organiser, Oaks Bluff] and Joyce [Care Supervisor, Oaks Bluff] joked,

> *Patrick: they're almost gagging for customers [all laugh] and I don't know how I can provide for them really [all laugh]*
>
> *Joyce: we'll have to watch out for their food! We'll have to put a safeguarding in against Patrick! [all laugh]*

Here Joyce teased that Patrick would have to resort to poisoning residents in an effort to meet BSVs' unsatiated demand for people to support, and while this was certainly spoken in jest, it nevertheless spoke to the fervour that some of the BSVs were operating within. BSVs were impassioned in their belief that it was good to talk about loss and grief, and to not do so was indicative of avoidance or death denial, as Lil summarised, *"it's almost a denial of death in a sense (…) there's a lot of negative attitudes towards death and bereavement here."* Staff likewise frequently endorsed the belief that it was 'good to talk', going as far to say that non-disclosure contributed to prolonged grief.

> *Don't you think that's healthier in a way, to talk about it. [Lisa, Dementia and Wellbeing Adviser]*
>
> *Let them talk because they're the ones who actually need to get it off their chest. [Kimberly, Dementia and Wellbeing Advisor, Elmwood Forest]*

> *Even within a village there will be people say that don't understand, so why are they moaning about something that's trivial to one person but actually no that's really important to them, but other people trivialise it so then they'll get withdrawn so bereavement lasts longer because people aren't supported. [Lisa, Dementia and Wellbeing Adviser]*

Within the context of bereavement, the truism that it is 'good to talk' stems from the concept of 'grief work' which demands we engage in "a cognitive process of confronting the reality of loss, of going over events that occurred before and at the time of death, and of focusing on memories and working on detachment from the deceased" (Stroebe & Stroebe, 1991, p. 479) in part, through disclosure and discussion. Within this orientation avoidance, blunted affect, nondisclosure, and at the other end rumination are pathologised as maladaptive grief responses. Indeed, Lindstrøm (2002) argued the concept of 'grief work' has "served as an almost axiomatic fundament" (p. 12) within the grief literature and therapeutic intervention such that it has become accepted wisdom among healthcare professionals, and perhaps more significantly, among the general population. Despite the existence of accumulating, and potentially undermining, critiques levelled against it, not least the paucity of supportive evidence within an abundant landscape of literature extolling its virtues, 'grief work' discourse remains pervasive. Nevertheless, more contemporary models of grief have circumvented some of the more contentious aspects inherent to 'grief work' in an effort to evolve theories of grief to align with current evidence. The idea that one must 'break the bond' with the deceased for example has been reimagined through the 'continuing bonds model' which "emphasises the adaptive function of retaining bonds with the deceased, rather than relinquishing them" (Neimeyer et al, 2006, p. 716). Similarly, the 'dual process model' (DPM) challenged the pathologisation of avoidance among the bereaved and countered, "it is arduous and exhausting to grieve, respite at times is recuperative" (Stroebe & Schut, 2010, p. 275). Indeed, the DPM accommodates both loss- and restoration-orientated bereavement stressors neither of which are conceptualised within the binary of 'adaptive' or 'maladaptive' but instead, "oscillation between positive and negative affect/(re)appraisal is understood to be an integral part of the coping process, and to be a component of both loss- and restoration-oriented coping" (p. 279). Yet, the insistence that talking about our loss is desirable and perhaps even essential to adaptive bereavement retains its grip on the cultural conscious.

Yet, there is accumulating evidence to challenge the universality of this belief. Emanuel et al (2004) for example found that 49.6% of patients and 44.9% of caregivers reported that talking about death, dying, and bereavement offered them little to no help. Further to this, a narrative review synthesising the evidence on whether social support and emotional disclosure facilitate adjustment post-bereavement concluded that there "is little evidence that social support moderates the impact of bereavement on psychological health and/or accelerates adjustment to the loss" (Stroebe et al, 2005 p. 409). Within the context of ageing, the argument that talking about our grief is something we should all be doing has echoes of the "double oughts" that concerned Holstein (2006) who cautioned against master narratives with an "overarching, totalising tone" that impose limits on "how we ought to age and how society ought to think about its ageing members" (p. 21). There is certainly evidence within the present study that those who do not want to be *"reminded of the grim reaper all the while"* have been maligned as *"avoiding death"* which is perhaps an early indicator that talking about and planning for death will become another behaviour that older people 'ought' to engage in. Furthermore, the inclusion of 'prolonged grief disorder' in the DSM-5 has established a precedent for what might be considered (ab)normal grieving (Boelen et al, 2020). Indeed, there already exists emerging evidence that the public endorse the inclusion of (prolonged) grief as a mental disorder (Breen et al, 2015) that hinges on erroneous beliefs about bereavement and mental illness (Penman et al, 2014). Wakefield (2016) therefore cautions that the inclusion of 'prolonged grief disorder' in DSM-5 "has high potential for false positives and for transforming our relationship to this basic human emotion, especially as grief becomes targeted for medication development" (p. 121). This move, which further entrenches bereavement within a medicalised sphere, is particularly salient for older people who are already more likely to be prescribed pharmacological treatments for common mental illnesses (Cooper et al, 2010) and less likely to be offered talking therapies (Cooper et al, 2010; Pettit et al, 2017) than younger people. The reductionist notion that it's good to talk about and through one's grief is therefore not only untenable, but the insistence that its universally 'good' to talk automatically positions those that do not engage as 'bad grievers'. Of course, I am not suggesting that those who do not talk about their grief, those positioned as *"death avoidant"*, will be automatically marked as pathological, nor indeed am I suggesting that there are not some among their midst that may benefit from additional sources of support. Instead, I advocate for more nuanced and compassionate discourse around death, dying, and bereavement that holds space for the adaptive potential of non-disclosure and imposes fewer limits on what is considered to be 'normal'.

Approaching this theme from a different angle, it is worth returning to the observation that the participants in this study, and indeed CC initiatives and bereavement support programmes more broadly, continue to privilege traditional help seeking and counselling at the expense of more community-driven support systems and skills. This is particularly striking in light of recent evidence that bereaved people most value and seek support from informal (defined as friends and family) and community sources of support rather than from professional services (Aoun et al, 2018). The benefits of informal and community support were threefold: it deepened emotional bonds; it provided tangible practical assistance with everyday tasks; and cultivated a sense of belonging. In contrast, it was striking that 46% of people who had received support from a psychiatrist, and 41% of people who had received support from a bereavement support group rated it as unhelpful, with one responder going as far to say that a psychologist “appeared to hold back recovery” (Aoun et al, 2018, p. 1384).

Other CC interventions have likewise identified that informal support “was not always easy to pinpoint or articulate” but it was nevertheless valued and meaningful, as one participant summarised, “the friendships. Being able to chat with people. And the garden itself, it’s wonderful” (Marsh et al, 2017, p. 113). Relatedly, participants in Pesut et al’s (2018) study, who admittedly provided more structured support than in the present study, appreciated the flexibility of unstructured conversations as this permitted support to be “more fitting of my needs each time” and “it’s not so much about the medical; it was putting things in context” (p. 8). It therefore behoves the Compassionate Communities movement to engage communities more directly to cultivate and collaborate on opportunities to mobilise more support from within their existing informal and community networks.

In summary, this theme has challenged the firmly held belief that ‘grief work’, and specially the mandate that one must disclose and discuss their grief may, perhaps inadvertently, contribute to prescribing how we *ought* to grieve and lead to policing the grief of others. In so doing, a dichotomy is established between ‘normal’ and ‘abnormal’ grief that has the potential to pathologise bereaved people who do not grieve in a socially sanctioned way. Furthermore, I have argued, there is a misalignment between the aims of the Bereavement Supporter Project and other CC initiatives to mobilise community volunteers to enhance the support networks of bereaved people and the model of support provision within which they operate. In other words, these programmes perpetuate traditional models of overt help seeking which consequently obscure the value and enhancement of informal and community support channels which previous research has demonstrated is most valued and sought by bereaved people.

Concluding remarks

This study employed a phenomenologically orientated design in order to better understand the lived experience of residents, staff, and Bereavement Support Volunteers (BSVs) participating in a Compassionate Communities (Kellehear, 2005) project within extra care housing. Rich, dynamic, and complex data was generated longitudinally using both qualitative interviews and focus groups which afforded insights into the lived experience of compassionate communities that had hitherto been obscured. Data were first analysed inductively using Reflexive Thematic Analysis (Bruan & Clarke, 2019) as has been described elsewhere (‘methodology) which produced a catalogue of miscellaneous codes housed under the label ‘contradictions’. These codes were explored further, orientated within an explanation-driven logic, which used ‘abductive inference’ (Hiles, 2012) to explore, and explain, the relationships between theory and data. Within ‘explanation-driven’ logic the analyst “consider[s] the data generated alongside existing theoretical concepts to help explain them further and to better understand the phenomena” (Shaw et al, 2018, p. 235). Through this iterative process, three themes were constructed *“’death talk’ / ‘loss talk’”*, *“even the volunteers are expecting very formal referrals”*, and *“it’s good to talk”* which capture a dialogue between the generated data and critical gerontological literature and the compassionate communities movement.

These themes endeavour to unpack and explain moments of unease identified from participants’, and in some cases my own, experiences. Using this lived experience as the springboard, they zoom out, and using pertinent literature as an anchor, they speak to, and challenge, the fundamental principles underpinning the Bereavement Supporter Project. First, I argue that the differential treatment of the Gold Standards Framework (GSF) and the Bereavement Supporter Project within ExtraCare can be better understood using West and Glynos’ (2016) distinction between ‘death talk’ and ‘loss talk’. As a proxy for ‘death talk’ the GSF obviates true engagement with the lived reality of dying and bereavement by limiting dialogue to efforts that uphold “third age fantasies” (p. 237). That is, the idea that death can be planned, controlled, and deferred in order to permit the *“golden years.”* It is suggested that the resistance to the Bereavement Supporter Project by some members of staff may be explained by their discomfort in engaging in ‘loss talk’ which seeks to accept and incorporate loss as part of life. Second, I argue that there is a misalignment between the principles and practices of the Bereavement Supporter Project, and indeed other compassionate communities initiatives. Specifically, I draw out the ways in which the BSV role was framed changed over time - from pseudo-professional to “community leader” – and the impact this had upon BSV experience and project success. Finally, I examine the principle underpinning the Bereavement Supporter Project, that it is “good to talk.” Here I challenge the universality of this belief and drawing upon critical gerontological literature caution against the promotion of ideals and discourses that limit the possibilities for ageing.

Chapter 7: Discussion

Introduction

Imagining once again the shape of a funnel, this discussion chapter widens its scope. Through the discussion sections in each of the three empirical chapters I have identified the key findings from my studies and engaged in a localised dialogue with the extant literature. The discussion here then serves a different and wider purpose, that is, to consolidate the three empirical chapters by proffering 'bigger picture' commentary on how this research contributes to the field and wider gerontological discourses. Specifically, I draw upon implementation science and participatory action research methodologies to argue that Compassionate Communities (CC) (Kellehear, 2005) interventions would be enhanced by a more concerted appeal to behaviour change theory. Second, I will consider the contributions of this research to wider gerontological discourses, namely those pertaining to successful ageing. I will conclude this thesis by reflecting on the research process.

Revisiting the aims

Broadly, this research sought to explore a range of stakeholder experiences (ExtraCare staff, residents, and BSVs) of the Bereavement Supporter Project, a peer-to-peer bereavement support initiative aligned with the CC movement. By concentrating on culturally and historically situated lived experience and meaning making, this research aimed to:

- Explore the impact of the Bereavement Supporter Project within the context of ExtraCare.
- Explicate the challenges and successes of the Bereavement Supporter Project with the intention to inform and enhance intervention implementation within the CC movement.
- Explore the lives and experiences of older adult volunteers delivering peer bereavement support to other residents within ExtraCare.
- Identify residents' motivation for engaging in volunteering generally, and within the field of bereavement support specifically.

The impetus for this research was driven by the paucity of rich and dynamic phenomenologically orientated research within the respective fields to which it is engaged. That is, the CC movement, critical gerontology, critical death studies, and volunteerism among older adults. Motivation also stemmed from the funder's request to evaluate the Bereavement Supporter Project. While no limits were imposed by the funder in terms of the scope or commentary of this thesis, pragmatic concerns (availability of time and resources for example) precipitated that the demands of these two motivating factors must be met through a single strategy. That is, the data generated would serve both this thesis and the project evaluation. A phenomenologically orientated multiperspectival (Larkin et al, 2019) approach was employed that generated rich and nuanced data which could then be analysed differentially to serve the particular demands of doctoral research and programme evaluation respectively. Returning to the objectives of this research, Chapter 4 responded to objectives one and two, and Chapter 5 responded to objectives three and four.

Trying to change a culture: How can the Bereavement Supporter Project inform and advance the Compassionate Communities movement?

A synthesis of the main findings will now be discussed with the view to enhance the implementation of interventions within the CC movement.

Obstacles to success

An initial analysis of the findings identified that the lives of older people are often marked by loss and grief. The accumulation of experiences, including loss, comes with the territory of ageing but during old age the rapidity of successive losses accelerates; often marked by the deaths of one's partner and lifelong friends. Participants in this study embraced the wider conceptualisation of loss presented by the Bereavement Supporter Project as it deepened and resonated with their own experiences of non-death related loss and provided a useful framework to better understand and empathise with the experiences of their peers. There was recognition that older people's bereavement support needs were inadequately met, and there was a sincere drive to redress this. However, whether or not the Bereavement Supporter Project was successful in responding to older people's bereavement support needs was more contentious. Each of the three empirical studies revealed an array of challenges that threatened the successful implementation of this CC intervention, for brevity I will focus here on the three most salient challenges.

Organisational ambivalence

Despite their initial enthusiasm for the project, the ExtraCare staff assigned to be responsible for the project failed to "pick up the baton", to take ownership and drive it forwards with little to no repercussions from senior management. Other research more broadly within 'extra care housing' has likewise identified tensions arising between staff members regarding the remit and limits to their respective responsibilities (Tinker et al, 2008; Wright et al, 2011). These studies tend to focus on the ways in which staff delineate between personal and domestic care tasks for residents in receipt of a 'care package', and specifically what was and was not 'their job', rather than the management of a new initiative. Nevertheless, they speak to the complexity of negotiating an accepted and feasible programme of duties for staff to perform which is likely to be compounded through the introduction of a new initiative such as the Bereavement Supporter Project.

It is also contended that organisational restructure and a high turnover of staff, including management positions, diminished the attention and priority afforded the Bereavement Supporter Project as villages responded to significant upheaval, insecurity, and the redistribution of workloads. Others researching extra care housing have likewise commented that high staff turnover, specifically turnover of management creates instability and can elicit feelings of uncertainty among residents, particularly when residents felt the new appointments disrupted established activities or were viewed as uncommunicative or unresponsive to resident needs (Cameron et al, 2019; Netten et al, 2011). Indeed, the effects of organisational restructuring and the disruption of resource availability and allocation has been noted in other CC interventions. Pesut et al (2020) for example, reported that three of the six sites they were operating within experienced significant organisational disruption that entailed changes to both resources and personnel which "influenced the resources available for implementing a new program(me)" (p. 9) and ultimately resulted in the discontinuation of the project in four of the sites.

These considerations notwithstanding, I argue there was a more fundamental misalignment between the beliefs about bereavement and bereavement support upheld by ExtraCare staff and the ethos of the Bereavement Supporter Project. Staff displayed unease regarding the appropriateness of BSVs providing peer-led bereavement support and purposively withheld referrals as a consequence. Staff cleaved to the idea that bereavement support necessitated professional care and were critical of what was, in their view, insufficient training of BSVs. Consequently, it was implied that BSVs did not possess the requisite professional acumen or skills to provide bereavement support such that permitting them to do so posed a threat to the welfare of residents. Again, there are echoes of staff resistance to the de-professionalisation of end of life and bereavement care within the wider CC literature. For example, Abel and Townsend (2015) reflected that many professionals in their study struggled to shift from the automaticity of responding to care needs through professional, that is medical, practices and priorities, to focus on enhancing and empowering pre-existing naturally occurring networks to care for those at the end of life. Unfortunately, Abel and Townsend do not unpack the potential reasons for this, concluding simply that health and social care professionals were threatened by the incursion of volunteers 'doing what they do', "which in turn questions their role and their value" (p. 19).

Similarly, Pesut et al (2020) suggested that healthcare professionals viewed the proliferation of volunteers to be a cost-saving exercise as volunteers were, in their mind, being drawn in to perform duties previously undertaken by paid healthcare staff. Like Pesut et al, Walshe et al (2020) reported disappointing collaboration with clinical partners and hypothesised four potential factors which may have limited their success recruiting clients to the study: (1)

clinicians' concern about the appropriateness of peer mentors and the safety of their patients; (2) clinics may not be the most suitable recruitment location for non-clinical interventions; (3) it may be difficult to accept peer support within a clinical environment; and (4) a peer mentor intervention may not meet patients' perceived needs. The authors argue that alternative recruitment strategies, such as social and traditional media advertising, could be utilised in the future as it is more "congruent with the mutuality of a peer mentor intervention" (p.11).

In contrast to the evidence drawn from other CC interventions however, ExtraCare staff do not occupy medical positions akin to staff in clinical end of life settings. Indeed, proximity to medicalisation is rather more complex within ExtraCare as it is on the one hand conceived as being "housing not residential or nursing care" (Riseborough & Fletcher, 2003, p. 14) whilst simultaneously operating adjacent to nursing and health and social care traditions, philosophies, and practices. For example, in their most recent corporate strategy (The ExtraCare Charitable Trust, 2022), ExtraCare set out four core values - empowering, compassionate, collaborative, and transparent - to guide operations and behaviours within the village which map onto the professional standards of practice and behaviour for nurses, midwives, and nursing associates (Nursing & Midwifery Council, 2018). Consequently, many staff positions are imbued with quasi-professionalisation, and staff have absorbed the expectation to uphold 'professional standards' and 'boundaries' within their respective roles. Perhaps then their resistance to the project was not solely motivated by a jealous guarding of professional values and standards but instead speaks to a more general precarity of employment or position within ExtraCare.

Culture of stoicism inhibits help seeking

Second, and relatedly, it was acknowledged that trying to change long-held social norms and beliefs about overt help seeking more broadly, but bereavement support specifically may be an especially ambitious aim among older people. ExtraCare residents suggested that a generational legacy of stoicism and a 'stiff upper lip' prohibited older people from seeking help overtly in fear that it conveyed weakness. This is a common theme within gerontological literature, with authors reporting an association between older adults who exhibit high levels of stoicism being less likely to engage in help seeking behaviour in a variety of contexts, including for pain management (Cornally & McCarthy, 2010), insomnia (Berkley et al, 2020), and psychotherapy (Hannaford et al, 2019). Smith et al (2007) argue that the association between help seeking and perceived weakness or stigma may be particularly acute for older men. They explain that the narratives of older men in their study were consistent with hegemonic constructions of masculinity wherein having control over one's health was used to characterise the male ideals of strength and independence.

Consequently, many participants reported avoiding or delaying help seeking; (in)action that profoundly frustrated significant others in their lives. This drive for independence and control was heightened when they discussed the ageing process, and their fear that cognitive or physical incapacity precluded the possibility of ‘successful ageing’ and positioned them as a ‘burden’ to others. Within the context of extra care housing others have similarly commented that older people display a sense of unease at the prospect of needing, and accessing, personal care (Cameron et al, 2019; Shaw et al, 2016). Given that these are communities where residents are contemptuous of those with more demanding care needs and critical of “management’s failure to rejuvenate the resident population” (West et al, 2017, p. 1891) it is perhaps to be expected that some residents may be reticent to seek help overtly.

Returning to the CC literature, Grindrod and Rumbold (2018) likewise reported that carers’ reluctance to accept help offered by family, friends, and neighbours was one of the most significant findings from their CC intervention. The authors comment that refusing help appeared to be an automatic response “made without considering the merit, and irrespective of whether support was needed” (p. 76) and outlined three main reasons given for not accepting help. First, was the desire not to be a burden. Second, the belief that dying was a private matter. And third, that needing support inferred their inability to cope and so was viewed as socially unacceptable. Grindrod and Rumbold emphasise that to modify these ‘unhelpful social norms’ intervention efforts must be “grounded in concrete examples of achievable activities” (p. 77), however they proffer no specific behaviour change model to meet these aims.

Is education enough to change behaviour?

Third, it is argued that in many respects the Bereavement Supporter Project hinged on the educational components of the intervention. I have already discussed above that the project’s efforts to ‘convince’ ExtraCare staff that bereavement support could and should be de-professionalised and pivoted towards peer-led support was largely unsuccessful. Furthermore, the training for BSVs while effective in expanding residents’ understanding of bereavement (for example, the wider conceptualisation of loss and theories of grief such as the Dual Process Model) it did so at the expense of nurturing or empowering volunteer capacity and pre-existing skills, and in so doing the BSV role was imbued with pseudo-professional status. For example, the training modelled structured systems for support provision and elevated therapeutic skills such as active listening and avoiding giving advice which established the role as ‘counselling adjacent’. Of course, as an innovative initiative there was little precedent to inform the development of the intervention and so I do not wish to critique the project unjustly from the lofty tower of hindsight. None of those involved in the development of the project, including myself, anticipated that residents would largely eschew the formal routes to support provision in favour of a more grassroots approach, typified through ‘casual conversations’.

However, project coordinators frequently espoused, from inception, that an advantage of peer-support was that BSVs would be able to connect with their bereaved peers through their shared lived experience. And yet, the training did not equip BSVs with the necessary skills to incorporate their experiential knowledge into the conversation, nor did it effectively cultivate a sense of ownership and empowerment among BSVs to “put their own stamp” on the project. There were opportunities to at least begin to redress this over the course of the project, for example through additional training within peer group sessions, that were not taken. Like other CC interventions, it is argued that the Bereavement Supporter Project struggled to effectively mobilise community action because it operated, perhaps unintentionally, within a lens of ‘working on’ as opposed to ‘working with’ communities.

An appeal for more theoretically driven Compassionate Communities interventions

To greater or lesser extents CC interventions are developed through consultation with the Compassionate City Charter (Kellehear, 2005). The charter asserts that “the best approach to health care and end of life care must be a partnership between the efforts of formal health services and the concerted efforts of the rest of the community. This is no more or less than the recognition that end-of-life care is everyone’s business” (p. 76). The charter demands a commitment from local government or other community bodies to enact social changes within their community whether that be within micro-communities or across significant geo-political areas such as cities, towns, and villages. Kellehear (2005) places an emphasis on driving change at the policy level and specifies key institutions (such as schools, religious centres, and museums and galleries) to exemplify the expectant changes in policy and practice to cultivate more compassionate communities. Further to this, Kellehear argues the charter performs a number of important social and political functions for the promotion of a public health approach to end-of-life care which can be summarised as:

(1) educating/raising awareness about possibilities and responsibilities for end of life care.
(2) promoting social innovations and collective responses.
(3) mobilising local political and social action.
(4) creating new alliances for end of life care.
(5) a fillip for national change (pp. 82-84).

Given that the notion of CC is predicated on responding to the public health needs and strategies identified by and for communities a universal blueprint for the development of CC would be inappropriate. Kellehear therefore emphasises that these are not to be viewed as directives or the limits to what is possible or desirable, but rather intended to inspire and provide a scaffold from which to build. However, Kellehear’s springboard for action provides sparce guidance on responsive methodological practices and provides no theoretical framework(s) to justify how the proposed activities and policies will elicit social change. Consequently, CC interventions struggle to present compelling evidence that their programmes ‘work’ which in turn makes it difficult for programme developers to know what to focus their efforts on. Others in the field have likewise criticised public health approaches to palliative care, such as CC, on similar grounds (Hazelwood & Patterson, 2018). They identify a number of significant challenges that impede the progress of the CC movement which include, but are not limited to the breadth of the CC agenda; the paucity of evidence demonstrating the efficacy of CC interventions; the difficulty translating the exhortation that “palliative care is everyone’s business” into practical actions that are sufficiently flexible to respond to, and be relevant for, a range of contexts and communities; operating within risk averse organisations; and the difficulty measuring attitudinal and behaviour change longitudinally, not to mention demonstrating causality. While Hazelwood and Patterson, among others (Collins et al, 2021; D’Eer et al, 2022; Librada Flores et al, 2020; Quintiens et al, 2022), endorse future CC interventions and research efforts to examine the mechanisms of the intended behaviour change(s) there appears to be some hesitancy in making explicit and specific recommendations. Perhaps they fear that such an approach will prematurely settle the meaning and orthodoxy of intervention in this field? What I am about to propose may therefore be met with some resistance in the field, but I proceed in the hope that it may provide future researchers with a framework for developing more theoretically driven CC intervention. The COM-B model is introduced here as a starting point for examining the necessary conditions to drive change in behaviour (Michie & West, 2013), with the caveat that it is not claimed to be the only model, nor may it be universally applicable within the CC context.

The COM-B theory of change model

The COM-B model provides a framework for understanding behaviour. It is a system of interactive elements (Figure 7) which positions ‘capability’, ‘motivation’, and ‘opportunity’ as necessary conditions for a given behaviour. Behaviour can likewise influence these three factors and capability and opportunity influence motivation (in addition to behaviour). Each of the three sources of behaviour can be further divided into two types, capability can be physical (the physical strength to perform the action for example) or psychological (having the requisite knowledge, skills, psychological resources); motivation can be reflective (self-conscious planning and decision making) or automatic (in the case of habits or emotional reactions); and opportunity is afforded by the physical environment (resources, locations, physical barriers) or the social environment (concepts available in language, social norms and beliefs). This model positions the nature of the behaviour to be changed at its centre; working outwards one can then systematically examine which factor(s) “would be necessary, practicable, and acceptable to achieve that change” (Michie & West, 2013, p. 7). The COM-B system forms the hub of a ‘Behaviour Change Wheel’ (BCW), an expanded ‘behavioural system’ intended to provide a comprehensive, coherent, and theoretically attuned framework for developing behaviour change interventions (Michie et al, 2011). Often depicted as three concentric circles, the BCW consists of the COM-B components at its centre, followed by nine intervention functions (education, persuasion, incentivisation, coercion, training, restriction, environmental restricting, modelling, and enablement), and seven policy categories (environmental/social planning, communication/marketing, legislation, service provision, regulation, fiscal measures, and guidelines). Michie et al (2011) emphasise that the three layers of the BCW are not to be viewed as linearly, but rather the “components within the behaviour system interact with each other as do the functions within the intervention layer and the categories within the policy layer” (p. 6). Once an intervention function(s) has been selected, this can then be mapped onto more specific Behaviour Change Techniques (BCTs) (for example, goal setting, behavioural information, graded tasks and so on) (Michie et al, 2008). This taxonomy of techniques is linked to theoretically derived behavioural determinants intended to support more robustly designed interventions that not only elicit the intended behaviour change but also facilitate an understanding of the underlying mechanisms and conditions for change.

I will now return to the Bereavement Supporter Project to unpack the utility of the COM-B model further.

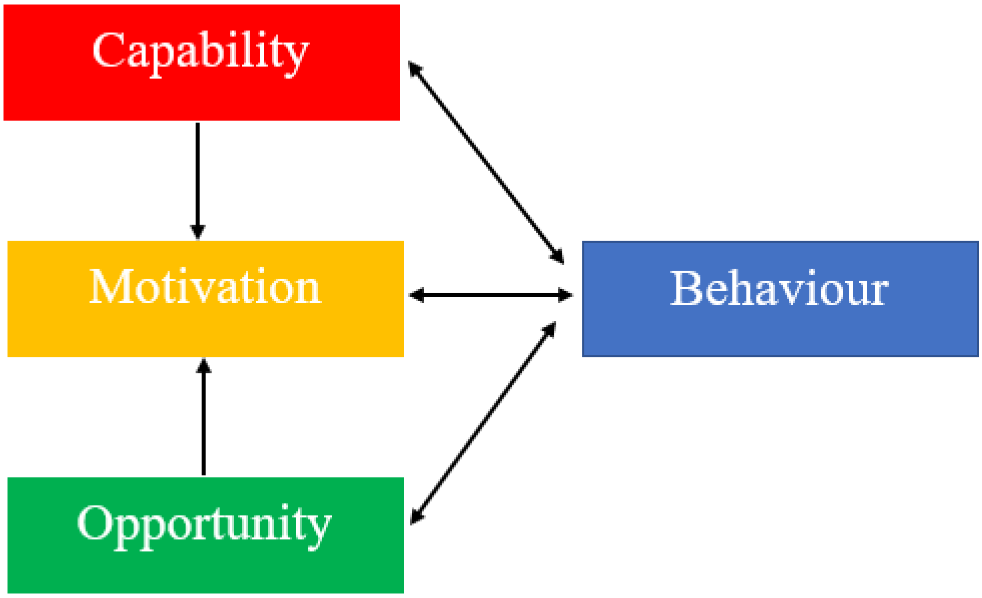

Figure 7. The COM-B framework for understanding behaviour (reproduced from Michie et al, 2011).

While the Bereavement Supporter Project was multi-faceted in approach, the central behaviour to be changed was that bereaved residents would access support from their peers in lieu of ExtraCare staff. To achieve this, ExtraCare residents -BSVs- were recruited, trained, and deployed to provide first contact listening support for their bereaved peers. In addition, but peripheral in focus were optional information and awareness sessions for ExtraCare staff and residents, and sporadic cultural events (such as ‘Dying Matters Week’, and remembrance bauble decorating workshops at Christmas). It was intended then that ‘education’ and ‘environmental restructuring’ would serve as the primary functions of the intervention (Michie et al, 2011). Such that it was assumed that simply offering an opportunity to access bereavement support from an ‘educated’ BSV would be sufficient in reorientating the provision of bereavement support from ExtraCare staff to BSVs.

Using the COM-B as a lens, one can easily start to unpack factors that are likely to be important to successful behaviour change that were insufficiently targeted, operationalised, or even considered, to the detriment of the project. For example, circling back to the main obstacles to successful implementation I outlined earlier in this chapter, the training provided to BSVs favoured ‘education’ (increasing knowledge or understanding) at the expense of ‘training’ (imparting skills) or ‘enablement’ (increasing means/reducing barriers to increase capability or opportunity). Consequently, when support pivoted from the structured model of support provision envisaged to ‘casual conversations’, perhaps better understood within a grassroots community orientation, BSVs were not equipped with the skills or self-belief to adapt to a role that was now centred on community leadership and advocacy. It is beyond the scope of this discussion to conduct a full behavioural analysis in line with the COM-B recommendations. Rather, it was my intention to introduce a systematic behaviour change framework that could serve future CC research to elucidate the active ingredients required to drive the social changes that the movement seeks.

A note on Compassionate Communities methodology

The majority of CC research, including the present studies, have employed methods that uphold the traditions of the paradigm that they are operating within (see Appendix A, Scoping Review). That is, surveys and psychometric scales are used within a positivist orientation, and qualitative interviews and focus groups are used within an interpretivist orientation. However, some scholars have proposed that Participatory Action Research (PAR) can be understood as a "new paradigm of science" (Baum et al, 2006), one that advocates for 'the researched' to be actively involved in the research process as opposed to being mere 'participants', 'respondents', or 'subjects'. PAR has resisted calls to establish codified step-by-step guidelines, and instead has accommodated common underlying values to direct practice, summarised by Bennett (2020, p. 23):

1. The problem originates in the community itself and the problem is defined, analysed, and solved by the community.
2. The ultimate goal of research is the radical transformation of social reality and the improvement of lives of the people involved.
3. The community are actively involved in the research process from beginning to end.
4. Participatory research involves a whole range of powerless groups of people.
5. The process of participatory research can create a greater awareness in the people of their own resources and mobilise them for self-reliant development.
6. It is a scientific method of research in that the participation of the community in the research process facilitates and more accurate and authentic analysis of social reality.
7. The researcher is a committed participant and learner in the process of research.

I argue therefore that the guiding axiological and philosophical principles of PAR mirror the ethos of CC which above all else is "seeking for ways for how caring responsibilities in societies might be distributed and assigned democratically (…) and also to ensure the greatest possible participation of citizens in this assignment of responsibilities" (Kellehear, 2005, p. xiv) making it a uniquely suited methodology for CC endeavours. Indeed, researchers have already begun to capitalise on the synergies between PAR and public health approaches to palliative care, examples include employing a PAR approach to explore the role of education in building palliative care capacity in four First Nations communities in Canada (Prince et al, 2019); to understand the support needs of Pacific family carers with the aim to develop culturally appropriate resources (Williams et al, 2021); and to develop a multi layered model of impact development to capture and evaluate individual and group development, action-orientated impact, and strategy-orientated impact (Kleijberg et al, 2022).

Furthermore, I argue that rather than being an atheoretical approach removed from the wisdoms of the academy, PAR can be embraced alongside behaviour change models such as the BCW. Indeed, a recently published intervention protocol (Bielinska et al, 2022) described the development of an intervention to increase advanced care planning among older adults following hospitalisation using a blended research design. By combining knowledge drawn from both PAR and BCW approaches Bielinska et al (2022) have designed a novel intervention in the field which they rationalise is not only theoretically robust, but critically, is also grounded by community needs and priorities therefore maximising the acceptability of the intervention. There is also emerging evidence from other fields, including increasing upper limb exercise in stroke rehabilitation (Connell et al, 2016); transforming social norms to end female genital mutilation (Barrett et al, 2020); and identifying barriers to the educational role of midwives in Cyprus (Middleton et al, 2022) that PAR and the BCW can operate in symbiosis to inform robust community-centric interventions that yield positive outcomes.

It is acknowledged that operating within a PAR paradigm is not without its own methodological and axiological concerns (Bennett, 2020), nevertheless it is my contention the application of PAR within the field of CC holds a promise for developing programmes that actually serve the needs of the community and present a genuine opportunity to mobilise and empower communities to support each other at the end of life.

Volunteer identity

Volunteer mobilisation is a key facet of the CC movement, with Kellehear (2005) going as far to say that all CC programmes should involve a community effort in some capacity. It is therefore unsurprising that a primary function of a sizeable proportion of CC interventions is the development of ‘community champions’, volunteers who receive training that covers the fundamentals of palliative care and/or bereavement and are then deployed to support people in their communities (see Appendix A, Scoping Review). Research with volunteers within the CC literature has been largely focused on evaluation metrics such as, the feasibility of meeting recruitment targets, feedback pertaining to the quality and content of training materials, and the benefits they had observed in their clients. It is understandable for a field in its infancy to prioritise evidencing the ability of these early interventions to meet targeted outcomes and employ a descriptive modality to distil programme achievements and challenges. However, as a consequence the idiographic experience and meaning making of volunteerism is obscured. By this I mean, what volunteerism in a CC initiative means from an individual perspective - how volunteerism aligns with their beliefs and personal biography for example – is side-lined in favour of an approach that targets volunteers as a collective vehicle through which to make claims about intervention efficacy and the value of the CC movement more broadly. To my knowledge, there is no research within the CC field that draws upon the wider volunteerism literature to deepen and expand their understanding of volunteer mobilisation within the movement.

Quantitative research with older adult volunteers has demonstrated that older people are more likely to be in better health and possess greater resources than non-volunteers (see among others, Amilon & Larsen, 2020; Ariza-Montes et al, 2018; Choi & Chou, 2010; Dávilia, 2018; Dury et al, 2015, 2016; Haski-Leventhal, 2009), and that they are motivated to volunteer because it is a practice that aligns with their 'values', will provide personal 'enhancement', enable them to better 'understand' the world or apply their skills (Ho et al, 2012; Okun et al, 1998; Principi et al, 2012), and support a sense of internal and external 'continuity' (Brayley et al, 2014). It is evident from qualitatively orientated research that volunteerism is firmly embedded into the cultural script of ageing, in that it has become a key mechanism through which older people demonstrate their continued worth and productivity post retirement (Barlow & Hainsworth, 2001; Order & O'Mahony, 2017; Cousineau & Misener, 2019; Devaney et al, 2015; Narushima, 2005; Pardasani, 2018; Same et al, 2020; Varma et al, 2015), and to ameliorate the anxiety elicited by retirement and the reality of ageing (Chen et al, 2020).

Historically, the narratives of older adult volunteers are saturated with successful ageing discourse as they frame their volunteering as a means of 'giving back' and thereby leveraging their continued value and contribution to society. This has largely been handled benignly by researchers who, whether implicitly or explicitly, have embraced the 'ideal of activity' (Katz, 2000) fundamental to the values and conceptualisation of ageing championed by the successful ageing agenda (Rowe & Kahn, 1997). Katz (2000) problematised the ideal of activity arguing that through this prism volunteerism is positioned as a universal good within individual control which drives older people "to be active to avoid the stigma and risks of dependency" (p. 136). As I will now expound this has significant implications for how older people view and live within the ageing process.

Chapter 4 of this thesis explored the ways in which volunteerism was or had become entwined with participants' sense of self and self-worth. Participants consistently tracked their current experiences volunteering as a BSV back to their previous paid employment or volunteer roles. This theme links clearly to Brayley et al's (2104) concept of 'continuity of work' which proposes that ageing, and particularly retirement can provoke a truncated sense of self that can be unsettling. They argue that volunteerism provides older people with an opportunity to stabilise their sense of internal and external continuity by keeping their professional skills alive. In the same way that successful ageing emerged in opposition to 'decline and loss' paradigms of ageing, continuity theory challenged the assumption that old age precipitated 'disengagement' from society, and vice versa (Utz et al, 2002). Continuity theory suggests that while paid employment is not of itself as critical to our sense of self as had previously been stated, retirement nevertheless threatens to destabilise the integrity of our self-identity. This pursuit for an equilibrious identity is then positioned as a marker of 'successful ageing' (Henning et al, 2016) that demands forward momentum as one must seek additional opportunities and resources to maintain one's internal and external characteristics. Repurposing Minkler and Holstein's (2008) concerns that the overidentification of volunteerism within successful ageing discourse imposes an ethically dubious and unidimensional script for ageing, so too does continuity theory steamroller the idiosyncratic possibilities for ageing. Again, it perpetuates moralised dichotomies that position older people as either 'good' or 'successful' if they preserve their pre-retirement identity and 'bad' or 'unsuccessful' if they disengage from productive activity.

The volunteer narratives described in Chapter 5 speak to the discourses of successful ageing in new and more nuanced ways than has typically been addressed in previous work (Cousineau & Misener, 2019; Devaney et al, 2015; Narushima, 2005; Pardasani, 2018; Same et al, 2020; Varma et al, 2015). For example, participants' preoccupation with formal referrals, their concerns about the visibility of the project and themselves, and the policing of their peers' (in)action speaks to the demands of perpetual motion underscored by successful ageing and activity theory (Katz, 2000). It is argued that for older people, particularly those living in retirement communities such as ExtraCare, volunteerism has become a shorthand to convey good ageing and good citizenship (West et al, 2017); it is a tangible indicator that one has so far resisted the 'gravitational pull' of the fourth age (Gilleard & Higgs, 2010). For many of the BSVs the informality of support provision denied them the opportunity to display this socially sanctioned, and perhaps even mandated, behaviour leaving them with a bruised sense of sense and vulnerable to the policing of their (in)action by others within their communities.

Further to this, the significance and value of ‘casual conversations’ was constantly undermined by BSVs who expected that the BSV role was an opportunity ‘do more’ than they did before. As discussed in Chapter 6 I observed a disconnection between the action-orientated age-defying choreographed conversations aligned with ‘death talk’ (exemplified through the Gold Standards Framework) and the invitation to reside in the, perhaps uncomfortable, reality of living with loss encouraged through ‘loss talk’ (West & Glynos, 2016). ExtraCare’s legacy and brand have been cultivated on its propensity for interventions seeking to modify behaviour, typically the lifestyle factors that successful ageing promises are within our control. While pivoting to more psychological and social concerns, the Bereavement Supporter Project nevertheless approached intervention from the top down and assumed that support would be accessed in an action-orientated way. Indeed, Katz (2001) points out that “these housing developments (…) potentially mask the aging process by naturalising retirement living as continuously active and problem-free” (p. 28) whilst simultaneously and somewhat ironically being the site and even catalyst for a whole slew of losses. As evidenced in Chapter 4 of this thesis and the work of others in the field (Ayalon & Green, 2012; Shaw et al, 2016) older people in ExtraCare live alongside a raft of losses that are often concealed and actively avoided perhaps as a result of the amplified expectation within these communities to lead an agentic healthy lifestyle (Katz, 2001) whose “horizon is the elimination of the very category of old” (West & Glynos, 2016, p 228) and death is indefinitely deferred or else ‘is for others’.

In sum, the narratives of older adult volunteers in this research echoed the discourse of successful ageing in new and nuanced ways. Unlike more directive and descriptive research in the field which has presented the notion of ‘giving back’ as an uncomplicated exemplar of social good, the critical gerontological lens guiding this research permitted a more layered understanding of what volunteering means for older people to be presented. For many participants volunteerism, as enacted through the BSV role, was imbued with ambivalence as they strived to reconcile their expectations of an activity-orientated pseudo-professional role with the reality of quieter more pastoral role. It is argued that the discontent and discomfort felt by BSVs stems, at least in part, from their fear that the paucity of formal referrals confers their failure in the successful ageing project.

Contributions to knowledge

In some ways, this discussion chapter has been framed to explicate the ways in which the findings of this doctoral research contribute to and enhance knowledge. Specifically, I have used the findings developed from the Bereavement Supporter Project to make a wider appeal for more theoretically driven CC interventions. Here I will summarise more localised contributions of this thesis to CC policy and practice and directions for future research.

Compassionate Communities policy and practice

Before attending to the implications of this thesis to wider practice, it is important to address the issue of generalisability within an interpretivist paradigm. Within a positivist lens, researchers are motivated to extrapolate the statistically significant findings of their research on a specific sample to another population and are therefore concerned with issues of bias and the representativeness and randomisation of their sample (Finlay, 2006). The rejection of these motivations within interpretivist paradigms means that this research did not seek nor expect to deliver a single unifying truth or answer to how Compassionate Communities can be cultivated. Instead, I was motivated to explore the situated experiences of people within the context of a specific CC intervention; a project contained within a unique organisational structure with its own particular traditions, practices, and beliefs. Such an approach is incompatible with “horizontal generalisability” and instead inspires to contribute to the “theory building work of “vertical generalisability”, i.e., an endeavour to link the particular to the abstract and to the work of others” (Yardley, 2000, p. 220). It is from this position that I propose four key learnings from this research that serve to improve future CC policy and practice.

First, to my knowledge the Bereavement Supporter Project was the first CC intervention implemented in extra care housing and is amongst a relatively small sub-set of interventions implemented and delivered by organisations outside of palliative care (see Appendix A, ‘Scoping Review’). If the CC movement is to gain traction it is critical that organisations outside of palliative care ‘take up the baton’ to foster and “build upon current initiatives and to take this forward in matters to do with death and loss” (Kellehear, 2005, p. 59). As I attest above, taking up this baton is not without complication and resistance, nevertheless it is my contention that the Bereavement Supporter Project broadly, and BSVs specifically, made a meaningful contribution to the lives of bereaved people within ExtraCare village communities and those within it’s orbit (for example, the friends and loved ones of ExtraCare staff). It is therefore my hope that the communities served by CC interventions will continue to expand and diversify going forward.

Second, I argue that future CC interventions engage and collaborate more authentically with communities to ensure programmes are designed in line with their needs. A disproportionate amount of CC interventions, including the Bereavement Supporter Project, have adopted a community development approach which typically seek to “extend or transcend current service offerings” in “ways that complement and enhance the mission of the employer agency” (Kellehear, 2005, p. 122-124). This is usually achieved through the employment of an ‘community development worker who operates on a “sliding balance between social action (by well-meaning outsider) and actual community development (escalating insider control and activity outside')" (Kellehear, 2005, p. 125). Consequently, the active components of CC interventions are devised from the top-down with community consultation "employed alongside but after the initial decisions are taken by the leadership" (Kellehear, 2020, p. 116). Contrary to expectations, residents within ExtraCare eschewed the formalised model for support provision designed by the Bereavement Supporter Project leadership team and instead sought out informal 'casual conversations' to "take the top off their pain", if they engaged with the programme at all. Again, I do not wish to unjustly critique the project from the vantage point of hindsight, but it is certainly plausible that earlier consultation with residents would have revealed this tension from the outset and provided the opportunity to develop alternate strategies that better meet their bereavement support needs. Walshe et al (2020) likewise speculated that peer mentorship may not meet the perceived needs of bereaved people and may have contributed to the low referral of clients to their programme. It is therefore suggested that future CC interventions more actively and conscientiously consult and collaborate with community members from conception to completion.

Third, and relatedly, it is argued that CC interventions would be enhanced if they actively seek to address the bereavement needs of all members of the community. Within the context of the Bereavement Supporter Project, there was a feeling among some staff members that their needs had been unacknowledged and underserved at an organisational level. This was a point of tension for the Project Manager who was acutely aware of the struggles staff were experiencing in the workplace but had limited agency or authority to implement change. For example, over the course of this research staff spoke passionately about the stress and trauma of caring for ill, dying, and bereaved residents and then being expected to 'carry on with their rounds'. They also emphasised the challenges negotiating ExtraCare's bereavement policies which often compounded their stress and occasionally complicated their grief experience. Yet, aside from notifying senior management of these challenges there were few opportunities for recourse for the Project Manager to work to improve working conditions. It is acknowledged that the findings from this research alone are insufficient to direct future efforts to redress the unmet needs of ExtraCare staff, nevertheless it illuminates the importance of engaging and responding differentially to meet the needs of disparate groups within any given community. With respect to ExtraCare staff, I tentatively argue that they sought change at a policy level which is often not within the purview of CC interventions that adopt the community development model.

Fourth, and finally, the findings of the present study identified that pervasive social norms and scripts significantly inhibited the project's success. Other CC researchers have likewise identified that social norms around offering and accepting help may be unhelpful and potentially undermine community capacity (Grindrod & Rumbold, 2018; Patel, 2015); a lack of public knowledge about or fear surrounding palliative care may inhibit engagement (Librada Flores et al, 2018); healthcare professionals and/or organisations struggling with the concept of public health end-of-life care and consequently resisting CC programmes (Hazelwood & Patterson, 2018; Horton et al, 2015; Horsfall et al, 2020); and differences in social norms, politics, and local culture and religions relating to death and dying requiring a tailored response to CC intervention (Kelley et al, 2018; Liu et al, 2022; Vijay et al, 2018). I therefore argue that future CC interventions should concentrate on unpacking the normative beliefs and practices surrounding bereavement and bereavement support which may otherwise inhibit community engagement with the programme.

Future research

I have expounded my hopes for future research earlier in this chapter, so I will only briefly summarise here. First, while there are certainly positive outcomes elicited from CC interventions, I argue that the field would benefit from developing interventions informed by behaviour change science so the mechanics of change can be better operationalised and understood. Second, I endorse the use of non-traditional methodologies such as Participatory Action Research given that their axiological and philosophical sensibilities parallel those of the Compassionate Communities movement. Third, for the posterity of the field I implore future researchers to report their methodological strategies and findings transparently.

Strengths and limitations

Against the broader landscape of CC interventions, the Bereavement Supporter Project, and consequently the studies presented here, are unique in a number of ways. First, previous research has largely been limited to palliative care settings (see Appendix A, ‘Scoping Review’); to my knowledge, this is the first CC initiative implemented in extra care housing. Relatedly, the Bereavement Supporter Project was designed and delivered by Cruse Bereavement Care and the ExtraCare Charitable Trust, organisations outside of palliative care which is likewise relatively unique in the field. Third, the Bereavement Supporter Project’s explicit, and primary focus on addressing the unmet bereavement support needs of older people, coupled with its emphasis on peer support set it apart from other bereavement-related CC interventions which have been more concerned with providing psycheducation to enable bereaved people to better understand their loss (Hagström, 2021; Zuniga-Villanueva et al, 2021) or have not focused on older people (Ummel et al, 2021) or peer support (Bruce et al, 2021). Therefore, the phenomenon under investigation here afforded a platform to leverage unique epistemic contributions to the field in and of itself.

Further to this, it is my contention that the methodological decisions made over the course of this research likewise served to enhance our understanding of CC specifically, but also speak to wider gerontological discourse and debate. While qualitative methods have been widely employed within CC interventions and evaluations to generate and analyse data, authors have typically presented descriptive analyses often as an adjunct to support the claims of their quantitative findings. Orientating this research within hermeneutic phenomenology provided a distinctive lens through which the experiences of people participating in a CC programme were privileged, thereby generating data imbued with depth and nuance that had hitherto been obscured.

However, achieving these aims was not without complication. For pragmatic reasons, the data I generated had two functions; first, it served the development of this thesis, and second, it informed the evaluation of the Bereavement Supporter Project. As I will expand upon subsequently (‘reflections on the research process’), this dual position was a new, and at times, an uncomfortable and confusing space for me to occupy which certainly had implications for the data generated. Untangling what it meant for me to be both ‘evaluator’ and ‘doctoral researcher’ took time and as a consequence some of the data generated at the start of this PhD lacked intention. By this I mean that when I first entered the field I was overwhelmed and had not yet developed a grounded understanding of my own interest and intent for the research and crucially, how this was distinct from the aims of the evaluation. In some ways it was easier, and more immediately pressing, to focus my efforts on responding to the needs of the evaluation. Consequently, early focus groups with ExtraCare staff and BSVs were overly preoccupied with concerns pertinent to the evaluation such as the quality of the training, and only marginally attended to the cultural or organisational situatedness of participant experience that would later become so integral to the framing and contribution of this thesis. There was then, some disconnection between the phenomenological lens of this research and some of the data generated.

Additionally, despite all of my efforts there is a notable paucity of data generated with ExtraCare residents who had received bereavement support from a BSV, and instead the experiences of those who have received support through the programme is filtered through the narratives of BSVs and ExtraCare staff. Rather than make straightforward claims of ‘accuracy’, care has been taken throughout to clearly signpost from whom excerpts have been taken and to contextualise their positionality, beliefs, and ‘stakes’ in what I intend to be a compelling presentation of my arguments. A second challenge that limited the multiperspectival (Larkin et al, 2018) contribution of this research was the Covid-19 pandemic. ExtraCare responded quickly and decisively; imposing lockdown measures within all of their villages and schemes before it was mandated by government. During this period (end of February/beginning of March 2020), I had focus groups scheduled with ExtraCare staff as well as planned discussions on whether there was merit in conducting additional data generation with BSVs, which were cancelled indefinitely. Of course, this was the right decision, and I am grateful that ExtraCare (and my supervisors) advised me not to stall my progress further by 'waiting to see what happens' in the hope of resuming data generation. Nevertheless, during data analysis I was repeatedly frustrated that my understanding of what the project had come to mean, for staff in particular, was limited. Particularly, given there were indicators that ExtraCare staff had struggled with the concept of CC. I am proud of the generated data and the contributions of this thesis, even if part of me wonders, 'what if'; perhaps this is emblematic of the PhD journey.

Reflections on the research process

As others have commented (Visser, 2017; Woodthorpe, 2007), death, like birth, is an essential and inevitable human experience; whether or not we dwell in this 'truth' is inconsequential, it will be the end of us all. Additionally, for most of us, we will also witness the death(s) of loved ones and experience other losses that echo the palpable and consuming emotions of grief. This 'insider' perspective holds incredible power for compassion and connection, but as Reason and Marshall (1987) caution, "all enquirers need to explore how distress and psychological defences that they were unaware of distort their enquiry" (p. 115). As a studious reflexive practitioner, I immersed myself in writings reflecting upon "doing death" (Visser, 2017; Woodthorpe, 2007); vicarious-trauma (Coles et al, 2014; Dominey-Howes, 2015; Eriksen, 2017; Loyle & Simoni, 2017); and emotional labour (Hochschild, 1979). In hindsight, I suspect in the hope that being fore-warned would be fore-armed.

Drawing from a reflective writing exercise from the start of my PhD I reflected (somewhat dispassionately) about the very real prospect that a member of my family or participants might die during the course of my research, I wrote, *"reflecting on the emotional labour (Hochschild, 1979) required to successfully complete my research I am faced with the question: am I strong enough for this?"* I was, at the time *"confident that I am strong enough"* but when faced with the deaths of multiple family members it transpires, I was not. Or at least not in the way I previously imagined. When I originally wrote this, the prospect of academically investigating the lived experience of bereavement while simultaneously sitting with the pain of my own grief was hypothetical. Like Woodthorpe (2007), "I did not relate my research to my own experiences of death and grief, or potential ones in the future" (p. 5), and, perhaps naïvely, believed that my own grief, should it occur, could somehow afford all the 'blessings of compassion' to connect more deeply with participants without 'unduly influencing' the research process and my capacity to operate within it. This to me was strength. The reality was my strength was pushing back against the tide of my own toxic expectations of 'success' and 'ambition' within academia that had already begun to erode my sense of identity and self-worth. I took a leave of absence, and it allowed me to re-build and reassess my priorities and imbued me with different strengths that compelled me to return to complete this thesis.

As I am drawing this thesis to a close it is important to take the opportunity to circle back to my earlier commitment (see 'Methodology and Methods') to contribute to the CC field by producing good quality qualitative research (Yardley, 2000). Yardley's four suggested quality criteria - '*sensitivity to context'*, *'commitment and rigour'*, *'transparency and coherence'*, and *'impact and importance'* – were used to ground this research and were actively engaged with throughout the research process. For brevity, I will not expound on each criterion in turn, but instead I will focus on '*transparency and coherence'* as my critique of other CC interventions in the field has largely been on these grounds. For Yardley, the crux of these criteria is "the rhetorical power or persuasiveness of the description or argumentation" presented (p. 222). To achieve this, she argues the researcher must detail every aspect of her data generation and analysis, present excerpts of textual data to allow the reader to discern for themselves the patterns identified and presented in the analysis, and to disclose all relevant aspects of the research process. It is to this last feature that I will most closely attend. The idea of 'disclosure' here speaks to the ways in which the researcher's assumptions, beliefs, and actions may have shaped, and perhaps in some ways limited, the product of the research investigation. It was from this orientation, that views the researcher as an active "instrument through which the topic is revealed" (Angen, 2000), that I operated. To honour this, I have interwoven my own experiences and challenges 'participating' in the Bereavement Supporter Project alongside those of the ExtraCare staff, residents, and BSVs who participated in this research. It was my intention to tell, as far as it was practicable to do so, the story of how it came to be that this is the story I have constructed and presented. I wanted to lay bare the (often incorrect and occasionally prejudicial) assumptions that had influenced my engagement with participants and the interpretations I proffered and had got stuck in. In some ways, by committing these assumptions and beliefs to the page I was untethered from them and liberated to consider other epistemic possibilities. As I alluded above, I was deeply conflicted and ambivalent about my positionality in this research at the beginning of this 'PhD journey' and so it is remarkable, to me, that I have inserted myself so emphatically and transparently in the 'research product'. I do this in good faith, in a spirit of candour, and it is my sincere hope that it does not distract from the participants' story but enhances it.

Concluding remarks

To produce this thesis, I have travelled across and within many fields in an effort to sensitively respond to the questions it posed. I have immersed myself in, and sparked connections between the Compassionate Communities movement (Kellehear, 2005), death and bereavement studies, volunteerism, ageing discourses, and critical gerontology to enrich my understanding of participant experiences. Consequently, this research offers support to the extant literatures from which it is drawn, yet by interrogating and interweaving threads from multiple literatures new, layered understandings have flourished. Mirroring other Compassionate Communities interventions, I have demonstrated there is an appetite, and indeed a passion amongst older people to have direct conversations about death, dying, and bereavement, and that they are both willing and able to accept the 'responsibility' of caring for the bereaved within their communities. Equally, like others before it, this research exposed significant obstacles to de-professionalising bereavement care and reorientating care within the community. However, attending to the wisdom of multiple literatures has catalysed more nuanced thinking into the sources of tension at play. I argue for example, staff resistance to Compassionate Communities programmes may not simply stem from the jealous guarding of professional identity and practices, and instead may reflect the precarity of employment, their unease engaging in 'loss talk', or else entrenched social norms and beliefs about 'good death' and 'good grief'. If the Compassionate Communities movement is to gain traction, I compel programme developers and researchers to move beyond this research by unpacking, targeting, and testing the mechanisms theorised to elicit the desired social change, and to genuinely engage in more community collaboration.

Further to this, operating within a critical gerontological lens has alerted me to the dangers in chaining ourselves to reductive metrics for what is 'good' or 'successful' as it inevitably leads to the dichotomisation of people (as either 'successful' or 'unsuccessful') but more than this, it limits the possibilities for all. The critical discourse in response to the 'successful ageing' paradigm is well established, yet successful ageing survives and continues to impose limits upon how we *ought* to age and how we *ought* to think about older people within our societies which has very real consequences on older people's lives (Holstein, 2006). It is from this vantage point that I caution the Compassionate Communities and death positive movements to resist the pull of establishing an orthodoxy of 'good grief' that stifles idiosyncratic responses to grief, and potentially perpetuates the historical harm inflicted through stage-based models by pathologising those who do not meet its standards.

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Appendix A – Compassionate Communities Interventions: A Scoping Review (manuscript under review)

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Abstract

Background: The compassionate communities (CC) movement is an emergent health promotion approach to palliative care that views illness, dying, death, and loss as universal experiences, and challenges the notion that disease precludes one from health care attention and interest. It seeks to normalise these phenomena and reorientate care to communities by activating naturally occurring networks and mobilising community resources. A surge of interventions aligned with the ethos of CC has been observed over the last decade. This scoping review seeks to synthesise what is currently known about the design, efficacy, and impact of CC interventions.

Methods: Cochrane, PubMed, Scopus, and Web of Science were systematically searched. Hand searching was performed on three key journals, reference lists and citation lists of included articles, and relevant review articles. Two levels of analysis were conducted. First, a numerical presentation of the characteristics of CC interventions. Second, a thematically orientated narrative analysis of intervention efficacy.

Results: A total of 1882 records were screened; 62 papers were included. Most were implemented by palliative care organisations in Europe, North America, and Australia. Included studies were mapped against Clark et al's taxonomy of end-of-life interventions: educational (n = 17); service (n = 20); clinical (n = 3); cultural (n = 4); and multi-dimensional (n = 18) interventions are discussed. While preliminary findings are positive, claims of efficacy are limited due to methodological paucity in the field.

Conclusions: We argue that the field would benefit from more transparent and theoretically driven CC interventions in order to explicate the mechanism(s) for successful intervention implementation.

Keywords: compassionate communities, scoping review, intervention, palliative care.

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Introduction

The compassionate communities (CC) movement is a public health approach to palliative care that has developed against the backdrop of growing medicalisation and the perception of death as a failure or threat to public health policy (1). The CC movement advocates for death, dying, loss, and caregiving to be reclaimed as phenomena fundamental to the human condition, and to overturn the current compartmentalisation of the medical model which has taken death out of people's homes and the community (1). Influenced by the World Health Organisation's Ottawa Charter (1986) (2) which embraced a "holistic definition of health as an empowered lifestyle which is more than the mere absence of illness" (3) (p. 3), Kellehear argued that "by inadvertently omitting the idea of living with dying from health promotion discourse, it has contributed to an old medical idea that the prospect of death disqualifies one from legitimate health care attention and interest" (p. 4). He envisaged a complementary relationship between health promotion, palliative care, and community which seeks to "enhance a sense of control and support for those living with a life-threatening illness" (p. 4) through shared responsibility. In so doing, the CC movement has pivoted away from contemporary discourse, policy, and practice that reduces palliative care to the medical concerns in the weeks and days before death. Instead, it has embraced a broader conceptualisation of palliative care that includes meeting the needs of those living with chronic and life-limiting illness, caregivers, and the bereaved (4) through the combined efforts of professional specialists, the experiential expertise of social networks, and the voluntary sector (5).

Kellehear (6) has gone on to develop the Compassionate City Charter which serves to invite cultural and social sectors into palliative care and was designed to be employed over significant geo-political areas, such as cities or towns. As such, the charter requires 'buy-in' from local government or community leaders and partnerships with local services (such as palliative care, bereavement support, care for older persons). Thus, it typically operates as a top-down approach to behavioural and social change where "a community development strategy is usually employed alongside but after the initial decisions are taken by the leadership" (7) (p. 116). The charter therefore speaks to policy and programme development across a range of integral institutions (such as schools, workplaces, and prisons), community and religious groups, and hospices and care homes that are often developed and implemented in tandem. On the other hand, compassionate communities are not bound, but are often guided, by the charter to inform incremental local action which serve to showcase the social value of specific actions within their respective communities (6). Kellehear anticipated and welcomed this kind of incremental social action, arguing pragmatically that such an approach affords organisations latitude to develop relatively low-risk policies and programmes that serve their communities whilst simultaneously contributing to a growing body of evidence evaluating the efficacy and impact of CC interventions. Indeed, many communities, cities, and countries have responded to Kellehear's call to develop more compassionate communities and cities; what this looks like in practice is the focus of this scoping review.

But first, throughout this article the term 'intervention' is used to describe the projects, programmes, initiatives, and services identified. Cognisant that for many, 'intervention' has become synonymous with the randomised controlled trial we pause briefly to clarify the definition used in this paper. The holistic nature of palliative care (8), and the commitment of CC to identify, design, and deliver initiatives using participatory and emancipatory practices (1), warranted a broad and inclusive definition of 'intervention'. The definition proffered by Clark et al (9), which positions intervention as "organised responses to end of life issues" (p. 4) was embraced as it provided legitimacy to the multitude of aims, designs, and methods employed in the field that merit attention. Whilst simultaneously excluding empirical research concerned with naturally occurring networks which fell outside the remit of this review having been captured in previous reviews (10,11).

Indeed, a number of researchers in the field have produced reviews that demonstrate the advancements in the field over time and further our understanding of how CC are conceptualised and operationalised through intervention. Early systematic reviews in the field (10,11) highlighted there was a growing interest in, and discussions around developing CC and presented tentative evidence for their effectiveness. However, given that the field was in its infancy when the searches of these reviews were performed, they yielded very few interventions and therefore also incorporated conceptual papers (11) and empirical research investigating naturally occurring networks of support (10) which limited their ability to respond to their research questions. Other reviews have focused on CC interventions concerned with civic engagement (12); area-based programmes (13); and health system outcomes (14) respectively which have enriched our understanding of the field. For example, Quintiens et al (13) present a robust investigation which identified the key similarities and differences between area-based CC with regards to their contextual and developmental characteristics and called for more rigorous research to gauge intervention efficacy. While Collins et al's (14) search permitted the inclusion of any public health care intervention that measured an aspect of end-of-life experiences or care they focused their paper on five studies that specifically measured a health system outcome. Perhaps unsurprisingly then, the authors conclude that the empirical data in the field is limited and predominantly in the conceptual stage of implementation. On the other hand, D'Eer et al's (12) review yielded 34 interventions which when taken together indicated that civic engagement within the context of life-limiting illness, death and loss can elicit positive impact(s), caveated by the recommendation that more research is required to unpack the mechanisms for efficacy.

The valuable insights afforded by these reviews notwithstanding, it is contended that this review provides unique contributions in four significant ways. First, this review was born out of the first author's doctoral research which was concerned with the lived experiences of people participating in a bereavement-focused CC intervention within extra care housing. While the research aligned with the 'public health approach to palliative care'(PHAPC), there exists considerable definitional ambiguity and multiple paradigms within this broader framework (15). In response, this review was motivated by a narrower focus on interventions aligned specifically with Kellehear's CC movement as an exemplar of the PHAPC. Second, in previous reviews (10,11) there was a tension between the research questions, systematic review methodology, and the heterogeneity of studies in the field. It is argued that the scoping review methodology employed in this review is a useful way of mapping fields of study that may otherwise be difficult to visualise and is particularly suited to responding to broader topics where a range of designs is anticipated (16). Third, this review sought to present the landscape of interventions undertaken in the field of CC rather than focus on individual intervention functions (see, (12–14)). Fourth, health and social care systems have faced unprecedented challenges supporting the bereaved and those at the end of life during the Covid-19 pandemic and are looking to movements such as CC to direct future support efforts (17,18). This is therefore an opportune time to collate and synthesise what is currently known about the characteristics and efficacy of CC interventions. We present the following article in accordance with the PRISMA-ScR reporting checklist (19).

Methods

This review was conducted by the first author (CR) who followed the six-phase scoping review framework outlined in Arksey and O'Malley's (16) original paper, supplemented by the recommendations and insights that have contributed to the refinement and enhancement of scoping review methodology since its publication (20–23). The integration of these sources, adapted from The Joanna Briggs Institute Manual for Evidence Synthesis (22) is summarised in Supplementary File 1. There is no published protocol for this scoping review.

Stage One: Identifying the research question

This review aims to address two key questions: (1) What is known from the existing literature about the design of CC interventions (e.g., the population, setting, scale, methods); and (2) What are the core components of CC interventions and which are most effective and therefore valuable to include in future interventions?

Stages Two and Three: Identification and selection of studies

Electronic databases

The first author searched for English language publications in the following electronic bibliographic databases: Cochrane, PubMed, Scopus, and Web of Science. Grey literature was searched from ProQuest Dissertations and Theses. The search term *"compassionate community/communities"* within the fields of *"article title, abstract, keywords"* was executed on all databases. No limits (e.g., date of publication, document type) were applied to the search.

Inclusion criteria

The 'Participants, Concept, Context' framework (22) served to operationalise the active components of the research questions in the search strategy. The *'concept'* of "compassionate communities" was the primary indicator driving inclusion in this review, specifically, interventions that had been informed by, or inform the CC movement. Papers which framed CC as a public health approach to death, dying, bereavement, palliative care, or end-of-life care and reported an intervention aligned with this approach, were included. In an effort to map the landscape of interventions in the field, no limits were imposed regarding the core component(s) of the intervention (e.g., education, volunteer mobilisation, area-based interventions), nor was it a requirement for the intervention to have been developed in consultation with the Compassionate Cities Charter (6). Neither *'participants'* nor *'context'* per se determined inclusion for this review. However, those data were gathered to describe the characteristics of CC interventions.

The types of evidence sources permitted for inclusion included primary research articles, review studies (e.g., systematic, scoping, narrative reviews), evaluation reports, and book chapters. Documents were included irrespective of design (e.g., randomised controlled trial, before and after studies, prospective and retrospective cohort studies, cross-sectional studies) or methods employed to evaluate the intervention (e.g., quantitative, qualitative, or mixed methods).

Exclusion criteria

Papers were excluded based on the following: (1) reference to *"compassionate communities"* in a context outside of the area of interest; (2) full text not available (including presentation, conference, or meeting abstracts); and (3) not available in English.

Hand-searching

Three journals (*'Annals of Palliative Medicine'*, *'BMC Palliative Care'*, and *'Progress in Palliative Care'*) were identified as key because of the volume of included studies published in them and were screened. Citation chaining of the included studies was also performed.

Quality assessment

Not performing a formal quality appraisal of the evidence included in a scoping review has been identified as one of its defining (16,22,24), and most contentious (25), features. Nevertheless, it is argued that eschewing prescriptive and restrictive notions of evidence hierarchies and quality concerns liberates the scoping review, permitting the inclusion and dissemination of evidence from a range of different methods and study designs (16). While individual paper quality assessments were not performed as part of this review, Yardley's (26) four principles of good quality research, *'sensitivity to context'*, *'commitment and rigour'*, *‘transparency and coherence’*, and ‘impact’, were used to inform more generic critical evaluations of the state of the evidence overall.

Stage Four: Data charting

A summary of each of the included papers recorded: the author(s), year of publication, country of study, organisation(s) implementing the intervention; study setting; study population(s); core component(s) of intervention; intervention comparator (if any); duration of intervention; method(s) of data collection; method(s) of data analysis; sample size and demographic details; and key findings. In alignment with the iterative sensibility of the scoping review methodology (16), we later added level of community involvement to the data charting form.

Stage Five: Collating, summarising, and reporting the results

As recommended by Arskey and O’Malley (16), two levels of analysis were performed. First, to establish the nature of the evidence base, a basic numerical analysis of the key features of included studies (e.g., country of study, setting, population) was performed with a view to identify trends, and potentially isolate gaps in the literature. The second, a thematically orientated (organised by intervention type) narrative synthesis of the findings identified the efficacy and value of CC interventions.

Stage Six (optional): Consultation exercise

Time and resource constraints prohibited consultation with stakeholders.

Results

The search, last performed in May 2022, yielded 310 titles and abstracts (see ‘Identification of studies via databases and registers’, Figure 1); duplicates (n = 110) were immediately removed leaving 200 records. Through screening, 168 records were excluded as: irrelevant (n = 138); full text unavailable (n = 27); duplication (n = 2); and not available in English (n = 1). Consequently, 32 records were retained for inclusion. As summarised in Figure 1 (‘Identification of studies via other methods), a further 1572 records were identified through a combination of reference (n = 982) and citation searching (n = 180) the 32 records retained for inclusion, journal hand searching (n = 271), hand searching Kellehear’s book (27) (n = 14), and reviewing the studies included in review papers (n = 125). Of these 335 were duplicate records and 106 were obviously irrelevant (e.g., bibliography, back matter etc.) and were immediately removed, leaving 1131 records. Screening excluded 1101 records as: irrelevant (n = 1045), full text not available (n = 24), and not available in English (n = 32). Consequently, 30 additional records were retained for inclusion bringing the total to 62 included studies.

FIGURE 1. PRISMA FLOW DIAGRAM

Key characteristics of Compassionate Community interventions

A total of 62 empirical studies were included in this review (see Table 1); it is noted that some CC interventions yielded multiple studies. For example, the Healthy End-of-Life Project (28,29); End-of-Life Social Action Study (30,31); All With You (32,33); Caring Community in Living and Dying (Landeck) Project (34–36); Cheshire Living Well Dying Well (37,38); End-of-Life Care in First Nations Communities (39,40); Good Neighbour Partnership (41,42); Heidi’s Have a Go Project (43,44); Last Aid Courses (45–48); Nav-CARE (49–52); and the Pallium Project (53,54).

Since 2013 there has been a rapid rise in publications about CC interventions, particularly in Europe (n = 35) (30,31,33–38,41,42,45–47,55–75), Canada (n = 12) (28,39,40,49–54,76–78), and Australia (n = 9) (29,43,44,79–84), but also in Taiwan (n = 1) (85), India (n = 1) (86), Hong Kong (n = 1) (87), Mexico (n = 1) (88), and through cross continent collaboration (n = 3) (32,89,90).

The vast majority (n = 28) (30,31,33,37,38,41,43–45,49–52,54,56–58,62,63,67,69,70,72,73,76,79,84,89) of the included interventions were designed and implemented by palliative care teams/organisations or through multi-agency (often including palliative care) collaboration (n = 21) (28,32,34,35,42,53,59,61,64,65,71,74,75,77,78,82,83,85–88). Single interventions were implemented by primary care (55); a children's charity (60); community group (68); and a dementia care centre (81). Nine studies (29,36,39,40,46,47,66,80,90) did not specify who had deigned and/or implemented the intervention.

The level of community involvement in the intervention differed across studies. The majority of interventions were designed, delivered, and evaluated at an organisational level and partnered with community organisations to support interventions in their communities (n = 16) (32,34–36,38,41,53,54,59,62,64,65,71,73,82,85); involved community members in a consultancy capacity to provide feedback on the programme (n = 8) (37,45–47,57,67,69,80); or recruited them as community volunteers (n = 16) (30,31,33,42,49–52,55,56,74–77,79,87). Interventions were also developed in response to needs identified from within the community (n = 11) (28,29,39,40,58,61,63,68,70,72,86); activities were co-constructed (n = 6) (43,44,66,78,81,89); or emerged from communities themselves (n = 3) (83,88,90); and in two studies community involvement was not an explicit goal (60,84). The language used to describe community involvement was applied inconsistently across studies.

The population under study predominantly fell under one of three categories: residents or organisations within a particular community or region (n = 23) (28,32,34–41,45,54,59,61,65–68,70,73,83,85,87); specific patient group(s) (e.g., those living with a terminal illness) (n = 27) (30,31,33,42–44,49–52,55,56,58,60,63,71,72,74–81,86,88); and the general public (n = 9) (46,47,57,62,69,82,84,89,90). The three remaining studies (29,53,64) did not state the study population.

The majority (n = 46) of included studies stated no intervention comparators, however, more robustly designed interventions including pre- and post- intervention comparisons (n = 9) (37,51,55,58,67,69,81,84,87), and (non-)randomised controlled studies (n = 7) (30,31,33,42,74,76,79) were included.

To generate data the included studies employed mixed methods (n = 20) (30,39–47,51,53,57,59,63,66,69,73,74,79,81); qualitative method(s) (n = 21) (28,29,34–36,49,50,52,60,61,70–72,75,77,78,80,82,83,86,90); and quantitative method(s) (n = 12) (31,33,37,54,55,58,67,76,84,87–89). Of these, a small number of included studies (n = 5) (30,31,33,76,87) employed psychometric scales to evaluate intervention efficacy. However, most had not yet completed data collection prohibiting direct comparison. Finally, a sizeable number of the included studies do not name their methods for data collection (n = 8) (32,38,56,62,64) and/or data analysis (n =22) (29,32,38,41,53,56,58,59,61–65,68,69,76,81,85).

TABLE 1. MAIN FINDINGS OF INCLUDED STUDIES

What do evaluation findings contribute to our understanding of the efficacy and value of Compassionate Community interventions?

In order to present the findings of the included studies in a cohesive narrative they were mapped onto the taxonomy of interventions at the end of life developed by Clark et al (9) (see Supplementary File 2) based on the overarching aim(s) and the core components of the intervention. Clark et al themselves acknowledge that these categories are not to be viewed as discrete or exhaustive but rather intend them to serve as a "road map" (p. 5) to organise, strengthen, and deepen our understanding of end-of-life interventions. In summary, the included studies were identified as educational (n = 17); service (n = 20); clinical (n = 3); cultural (n = 4); and multi-dimensional (n = 18). The subsequent sections will expand on the implementation, findings, and learnings of each of these categories, respectively. See Table 1 for a summary of the main findings of the included studies.

Educational interventions

17 education-based interventions were included. The majority aimed to provide information and raise awareness about end-of-life care (37,45–47,54,57,65,66,69,70,84), and to provide attendees with skills and tools to encourage further conversations (and other actions) about death, dying, loss, and care (37,46,47,54,57,69). A smaller number of studies had more specific aims: to support and empower couples to navigate the changes and challenges of dementia (81); to provide workshop discussions for pharmacists to better understand the needs of people with dementia and their carer (71); to scale-up learning and development in rural, remote, and other resource-constrained settings (53); to assess the educational needs of First Nation communities in Canada (39); and to provide psychoeducation on topics related to grief and loss in combination with discussion-focused sessions (60,88). The majority were one-off educational events that could be completed within a couple of hours (37,45–47,57), a single day (54,66,71), or a flexible delivery over the course of a few days or sessions (54,60,69,81,84); five were delivered online (46,54,57,69,84), the others were delivered in-person. Half of the included studies report on small-scale pilot study/studies (60,65,66,69–71,81,84), with the remainder (37,45–47,53,54,57,88) reporting on ongoing educational events.

Findings from cross-sectional studies (45–47,54,57,69) evaluated course content favourably, and the majority (99-100%) of respondents recommended the course to others (47,57). While educational interventions have shown to be effective at 'continuing the conversation' (84) they have had limited success in encouraging participants to 'take action', such as making a will (37), with only two participants having done so at follow-up. Overall, attendees welcomed the opportunity to discuss their experiences of death, dying, and loss and to connect with others through shared experience (37,60,66,81). Most studies reported on the evaluation of developed and implemented programmes, however, Paul et al (70) and Prince et al (39) focused on the educational needs of specific communities, primary school children and First Nations communities, respectively. Both emphasised the importance of holistic but tailored educational initiatives that connect with, and serve, all members of the community and health care systems. Implementation and evaluation of these initiatives was forthcoming at the time of publication.

Evidence from the included interventions suggest educational interventions effectively provide attendees with an opportunity to gain information and provide space to discuss topics pertaining to illness, dying, and bereavement. However, given that evaluation of the included studies (excepting (37,60)) took place on the day of the intervention, the impact of these interventions beyond the classroom is unknown. Furthermore, it is suggested that the included studies were influenced by participation bias; with attendees being disproportionately retired, educated women from the least deprived areas (37,84) who were demonstrably 'death-positive' prior to the intervention (37,81,84). It is unfortunate that studies drawing from broader populations, such as Martins Pereira et al (66) and Plunger (71), provided limited insight of the perspectives, attitudes, and experiences of attendees despite employing potentially data-rich methods such as semi-structured interviews, focus groups, and participatory observation. In future education-based interventions, a more concerted effort is required to recruit participants beyond healthcare professionals and those with a vested interest in death, dying, and bereavement.

Cultural interventions

In an effort to facilitate a death-positive discourse among the general public, a small number of included studies (n = 4) focused on cultural events, namely Café Conversations (67), Death Cafés (90), Twitter discussions (89), and combining arts-based activities with "weaving conversations" to cultivate a community garden (83). In one study, the #PallANZ hashtag was used to create a safe space for discussion and information provision during the

Covid-19 pandemic (89). Analysis of these Twitter discussions elicited conversations between 25 participants and generated almost 750,000 impressions, with a second discussion a month later generating greater engagement indicative of ongoing, and perhaps growing, engagement.

Furthermore, through Death Cafés McLoughlin et al (67) reported significant post-intervention improvements in understanding the importance of talking about the topics under consideration, although respondents' perceived difficulty talking about death, dying, loss, and care did not reach significance. Richards et al (90) had a wider orientation, conducting an international exploration of Death Café organisers' experiences which challenged UK-centric findings. For example, globally, organisers and attendees were more diverse than had previously been reported. Nevertheless, they contend that both organisers and attendees were predominantly women, and in the case of organisers, the majority were healthcare, mental health, or death industry professions. Notwithstanding geographical, cultural, political, and religious differences, participants spoke of the prevalence of death avoidance and the outsourcing of death to professionals within their respective countries. Against this backdrop, participants were emphatic that people needed a 'safe space' to talk about death and believed this was "a good thing in and of itself" (p. 23). Marsh et al (83) likewise reported that 'death talk' was seldom permitted as part of the everyday and so participating in the community garden was a "cathartic emotional experience" (p. 113) as it provided a much-needed opportunity to deliberately discuss death and dying. Moreover, while some organisers suggested that conversations could extend to other spheres, such as making practical plans or carrying on the conversation with their loved ones, others cautioned against the over-emphasis on tangible evaluative outcomes as this ran counter to the central ethos of the Death Café movement (90).

In summary, findings suggest there is a growing counter-cultural appetite to engage in death-positive discourse (67,83,89,90), and that cultural events can elicit significant changes in attitudes (67) and encourage continued action in other aspects of life (90). Given the paucity of research focused on end-of-life cultural interventions conclusions are tentative, more research in this field would be welcome.

Service interventions

Within the context of CC, service interventions (n = 20) adopted a broadly equivalent approach; community volunteers were trained and matched with vulnerable older people (and/or their carer) with the aim of providing ongoing support and advice, and mobilising community networks to provide appropriate support (30,31,33,42,49–52,55,56,58,74–77,79,87). While these were often implemented by palliative care organisations, or allied professionals, there was an emphasis on redirecting care away from clinicians and into the capable hands of the community. Notable exceptions developed services to rehabilitate prisoners through hospice volunteerism (63); provide online bereavement support for people during the Covid-19 pandemic (78); and provide peer-led bereavement support group for carers of someone at the end of life (72). Five of the included interventions (30,33,42,76,79) had not yet concluded, therefore these papers report no findings.

Findings indicate that being supported by a volunteer reduced total visits to GP practice, total phone calls to family doctor, total accident and emergency (A&E or emergency room) admissions, total unplanned hospital admission, and total calls to/visits by out-of-hours palliative care services (55,58). With an increase only in planned hospital visits (58). However, randomised controlled studies that compared 'volunteer intervention' to 'usual care' on a battery of measures, including quality of life, loneliness, social support, and coping strategies reported no statistically significant differences between comparator groups at any time points (31,74). Although the authors cautiously assert there was a positive trend in favour of the intervention group. Given that the effect size of these interventions was small, both suffered from being insufficiently powered.

Qualitative research with clients has reported high levels of satisfaction. Benefits included increased confidence asking for help, having access to someone knowledgeable, provision of resources, and knowing there was back up when needed (50), particularly when clients had previously felt “invisible” (77). Clients also shared humorous and uplifting anecdotes with the volunteer; such experiences “altered the qualitative nature of their experience, even if it did not change the medical trajectory” (51) (p. 9). Additionally, stakeholders argued that writing personal health goals “empowered [clients] to improve their social connections and personal wellbeing through intentional connections to community activities” (77) (p. 5). The authors claim clients echoed these benefits but provided no direct excerpts from clients to support this. Volunteer experience however was marked by ambivalence, with volunteers asserting their lives had been equally enriched through the programme, yet role ambiguity challenged their ability to gauge their performance and contribution (51). This was ameliorated somewhat over time as volunteers refined their understanding of the role to include the significance of emotional as well as instrumental support.

Furthermore, three of the included studies focused on supporting people bereaved by, or during the Covid-19 pandemic (49,75,78). Bruce et al (49) and West et al (75) both emphasised the unique challenges endured by bereaved people during the Covid-19 pandemic, including being denied the opportunity to be with their loved one at the end of their life (49); the loss of the usual rhythms of life (49), and the absence of forward momentum (75); the acute pain of grieving alone (75), and thwarted efforts to hold remembrance events for their loved one(s) (75). For those at the end of life, forced isolation led to sadness and regret as opportunities to connect with others was lost (49). Nevertheless, participants identified affordances nurtured through pandemic grief, such as developing new activities and hobbies (49); dwelling more deeply in life (49); the re-collectivising of bereavement through collective mourning and memorialisation (49,75); and welcome respite from “mandatory happiness” (75).

Moreover, a number of the included studies reflected on their experience implementing the intervention which offers critical insights for future programmes and research. First, the single best predictor of successful implementation was having trusted community leaders (58) with the right characteristics, beliefs, and attitudes to take ownership of and carry forward the intervention (50). However, organisational capacity, disruption, and resistance of the respective partners often undermined the efforts of community leaders and volunteers and threatened programme success and sustainability (50). Specifically, authors reflected on the unanticipated challenge of instilling the ideals and practice of community-volunteer end-of-life services within clinical teams (56), which led to a disappointing number of professional referrals that inhibited the recruitment of clients to the respective studies (50,74). Walshe et al (74), for example, hypothesised clinics may not be the most suitable recruitment location for non-clinical interventions and argued that alternative recruitment strategies, such as social and traditional media advertising, could be utilised in the future as it is more “congruent with the mutuality of a peer mentor intervention” (p. 11). Abel and Townsend (56) likewise acknowledged a tension operating within a risk-averse corporate understanding of volunteering and the principles of community participation and engagement which, perhaps unduly, influenced intervention implementation. Furthermore, they pointed out that referrals often occurred late in the patient’s illness which limited the possibilities for emotional support and network development and therefore the efficacy of the intervention.

Clinical interventions

A small number of the included studies delivered clinical interventions (n = 3), in many ways these were similar to ‘services’ but were more overtly orientated within, and delivered by, professional or clinical teams. For example, Aoun et al (91) described a pilot study testing the acceptability of an adapted version of the Carer Support Needs Assessment Tool (CSNAT) - which seeks to identify unmet carer needs - to be administered in a paediatric context. Through qualitative interviews, parents commended the comprehensiveness of the

CSNAT in that it “highlighted issues that might otherwise have been forgotten, especially in a stressful situation” (p. 5) and provided validation of their needs. Furthermore, parents reported it had improved communication with clinical teams, and empowered them to seek additional sources of support in response to their needs.

The other two included studies (43,44) report on the programme “Heidi’s Have a Go” which facilitated palliative care patients to “have a go” at something they had longed to do. It is a model of care that features no predetermined programme activities, rather, it is a collaborative approach that responds to the unique wishes of each individual and their family. Activities included, but are not limited to, learning how to make cheese (the eponymous Heidi’s elected activity), cuddling a koala, and shooting a gun. These two papers report on qualitative semi-structured interviews with staff and volunteers engaged with the programme. Participants reflected the informality of the programme “created a personalised space within the clinical world where humanity was shared” (43) (p. 536) which in turn provided welcome respite from the typically medicalised focus of care (44) and redistributed the balance of power in care relationships that “empowers a sense of control for patients who may have relinquished a lot of choice to those guiding their care and treatment” (p. 539). Furthermore, activities had the power to “nurture intimate moments” (44) (p. 8) within families that “witnessed and supported an experience of emotional processing, nurturing the foundation of a deeper, connected relationship between this family and staff” (p. 8).

Multi-dimensional interventions

There were 18 interventions that are perhaps better understood as Compassionate Cities. They describe multi-phase protocols and, in some cases, preliminary findings, that apply the Compassionate Cities Charter (6) into practice in their respective city or region (28,29,32,34–36,38,40,41,59,61,62,64,68,73,82,85,86). Their aims were ambitious, striving to shift cultural attitudes to normalise death, dying, and bereavement, and to enrich society by bridging community, social, spiritual, psychological, and medical resources for (amongst others) those with advanced illness, caregivers, and the bereaved. Consequently, these interventions were multi-faceted, multi-phased, multi-agency initiatives that embraced a multi-dimensional approach by incorporating three or more intervention categories from Clarke et al’s (9) taxonomy.

While the complexity of these interventions is acknowledged, there are nevertheless taxonomical trends observed across the included studies, which include a combination of: *‘research’* into the current needs of the communities under study (29,35,38,59,61,64,68), or surveying pertinent literature and theory to inform policy and practice (29,32,41); *‘education’* through the development and dissemination of pertinent resources and information activities (29,32,34,35,38,41,59,61,62,68,82,85); driving changes in *‘policy’* (32,34,41,62,82); *‘clinical’* programmes such as Advanced Care Planning (34,64,85); *‘services’* such as community volunteer programmes to supplement and mobilise existing support networks for people at the end of life or bereaved people (29,32,35,38,41,59,61,82,85); *‘cultural’* events, such as art exhibitions, Death Cafés, and remembrance festivals (34,41,59,61,62,64,68,82,85); and *‘advocacy’* efforts including, community and organisational outreach, engagement, and partnership (28,32,34,35,38,41,59,61,62,68,82,85,86). A small proportion of included studies focused on the development of palliative care to communities that had previously had little to no access and/or provision (40,86). These studies employed equivalent implementation techniques, but focused on establishing palliative care systems, cultivating trust between healthcare professionals and community members, and attending to issues pertaining to cultural competency and security.

While overall there is a paucity of methodological and analytical detail related to evaluation strategies, the preliminary findings indicate that positive outcomes had been achieved. The level of community and organisational engagement with events and training, and commitment to establishing and maintaining partnerships demonstrates an appetite to engage with a Compassionate Cities approach to death, dying, and bereavement (32,38,41,59,61,68,85,86). Hasson et al (61) for example have reached over 7400 people through workshops, conferences, Death Cafés, and training courses over a four-year period. There is also evidence (38) that public education sessions can produce change in perceptions about death and dying. In particular, attendees reported recognition of the individual and social aspects of death and dying, in addition to the medical, although others have reported discussion to be too difficult and painful (68).

Furthermore, a small number of studies reflected upon the learning and challenges they have experienced implementing CC interventions. These include but are not limited to: social norms around offering and accepting help which may be unhelpful and potentially undermine community capacity (29,68); a lack of public knowledge about palliative care (32); healthcare professionals and/or organisations struggling with the concept of public health end-of-life care and consequently resisting CC programmes (38,62,82); social norms, politics, and local culture and religions relating to death and dying (40,85,86); limited funding opportunities and poorly linked resources creating significant barriers to sustainability (32,38,68); and the breadth of the CC agenda and concerns over efficacy (62,68,73,82). Reflecting on their experience, Wegleitner and Schuchter (34) eschew the conceptualisation of CC as something that can be 'implemented' using standardised techniques and measurements. Instead, they propose CC to be "a type of framing, mutual care philosophy, which has to be translated into concrete, localised practices in collaboration with the community" (p. 7).

Discussion

The magnification of the experiences and support needs of the bereaved and those at the end of life during the Covid-19 pandemic is likely to have amplified (17,18) an already growing interest in and development of CC interventions (1). This review sought to map the core characteristics of CC interventions and synthesise what is currently known about their efficacy and value. Given the heterogeneity of fields in their infancy, a scoping review methodology was employed as it permitted greater latitude for inclusion than traditional systematic review procedures (16).

By mapping out the core characteristics of the field this review has identified distinct trends, as well as notable absences within the current literature. Most notably, the vast majority (n = 39) of the included studies were designed and implemented by and within palliative care organisations. Given the CC movement is rooted in palliative care practices and traditions, it follows that this emerging field of work would initially be driven by palliative care priorities and/or settings. However, several of the included studies discuss the challenges inherent in developing community-centred programmes within medically orientated environments (50,56,74). Specifically, authors noted that a lack of public knowledge about palliative care (32); tensions operating within risk averse institutions (56); and healthcare professionals' resistance to the de-professionalisation of palliative care (38,62,82) limited the efficacy of intervention implementation.

The professional and medical dominance in palliative care was identified by Kellehear (1) to be the single greatest challenge to any public health approach, warning that, "anger and pique is the usual reaction towards new ideas by those who are the guardians of the old ones" (p. 105). Unfortunately, while Kellehear aptly identified these potentially significant cultural and organisational barriers to the implementation of CC interventions, he offers few strategies or solutions to overcome them. It is then imperative that future publications in the field continue to reflect upon, and where possible, share their experiences and strategies to overcome, or mitigate these obstacles, as well as developing community-led initiatives outside of palliative care.

As Kellehear anticipated (6), this review identified interventions that implemented the Compassionate Cities Charter (n = 17) in addition to interventions with a narrower focus (educational (n = 17); service (n = 20); clinical (n = 3); cultural (n = 4)). Irrespective of intervention function, the vast majority of interventions articulated a commitment to community development to “enable as much resource as possible to exist within the community, without always involving health and social care services” (55) (p. e808), often through participatory action research approaches (28,29,34–36,39,40,72,78,83). That being said, most of the interventions were designed to “extend or transcend current service offerings” (1) (p. 122) through formal direct services as opposed to bottom-up grassroots initiatives. While the ‘healthy cities model’ employed by multi-dimensional interventions and the 'community development model’ adopted by service and educational interventions are certainly legitimate approaches, we welcome and encourage future programmes to use the ‘community activist model’ in an effort to move beyond organisationally orientated services.

The second aim of this review was to synthesise the most efficacious intervention functions to cultivate CC. Preliminary findings indicate there is public appetite to attend cultural and educational events (37,38,41,45–47,54,57,59,60,65–69,84,88), and that attendance can precipitate further conversation and action (37,60,68). Additionally, there is accumulating evidence that being supported by a community volunteer can contribute to reduced emergency hospital admissions of those identified at risk (55,58), as well as positively influence quality of life, social connectedness and cohesion, and illness experience for those at the end of life (43,44,50,51,72,83) and during bereavement (49,75,78). However, the two randomised controlled trials included in the review (31,74) reported no statistically significant benefits to receiving volunteer support than ‘usual care’. At this stage, the mechanisms contributing to the observed effects of CC interventions remains unclear, in part because interventions appear to be “based on implicit common-sense models of behaviour” with “no formal analysis of either the target behaviour or the theoretically predicted mechanisms for action” (92) (p. 2). Further to this, interventions were largely cross-sectional meaning there was no mechanism to assess whether the intended behaviour change has occurred. Consequently, the most efficacious approach(es) for implementing CC remains elusive, and more theoretically driven research is needed to be able to identify the most efficacious components for change.

There were limitations to the literature included in the review. Methodological detail was missing in a sizeable proportion (n = 22) of the included studies. It is acknowledged that the inclusion of varied sources of evidence (such as book chapters where there is potentially less emphasis placed on describing intervention protocols and methods rigorously) is likely to have contributed to this. It may also be expected that interventions initiated by communities are conducted without reference to theoretical or methodological background and so these features cannot be reported, at least in the ways we have come to expect in scientific journals. Nevertheless, Yardley’s (26) *‘transparency’* criterion speaks to the expectation that research (of any kind) is reported thoroughly. It is a fundamental requirement in research to describe what work has been done and how, and this has not been met in a sizeable proportion of the included interventions. Consequently, the trustworthiness of their claims is significantly undermined, a critique echoed in other reviews (10,11).

In addition, there are limitations in the conduct of the review. First, limited resources precluded engagement with the (optional) consultation exercise advocated within the scoping review methodology (16,20,21), and restricted eligibility to literature written in English. Second, while the search terms employed (*‘compassionate community/communities’*) yielded a greater volume of eligible studies than other reviews that employed more comprehensive search terms (11) it is possible that some literature was missed. Third, although this review was conducted systematically and meticulously, it is acknowledged that reviews conducted by a single researcher are open to criticism (21,93).

Conclusion

In conclusion, this review identified 62 articles that describe CC intervention(s), the majority of which were published within the last five years, indicative of a movement gaining traction. The CC movement seeks to radically reorient how we think about, talk about, and act towards death, dying, and bereavement. Interventions aim to change cultural and societal attitudes about death, dying, and bereavement; to facilitate fruitful partnerships between, and within public, private, and third sectors to better serve individuals at the end of life; and finally, to raise social capital through the mobilisation of community volunteers. Success against such ambitious objectives is perhaps to some extent an impossible standard to meet, and yet, the emergent findings of this review do demonstrate an appetite at both organisational and individual levels for a shift in how we conceptualise, discuss, and support those at the end of life and their families. Further to this, marrying the philosophy of community development to improve the quality of life of people with life limiting illness with the medical dominance within palliative care remains a challenge. Nevertheless, the clinical interventions included in this review demonstrate that these two philosophies can work together to elicit meaningful (80) and memorable (43,44) experiences when facing life limiting illnesses. There is emerging evidence that interventions informed by the CC movement can elicit change in attitudes and behaviour, as well as improve the quality of life of those living with advanced illness. Finally, the surge in (non)randomised controlled trial protocols published (33,42,76,79) is promising as evidence from robustly designed and evaluated studies will soon be forthcoming. It is imperative going forward that published works demonstrate greater methodological transparency and rigour to engender greater trust in the efficacy and value of their findings.

Footnotes

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Appendix B: Focus group with Bereavement Support Volunteers discussion guide

Question	Rationale for asking question	Prompt
Can you tell us why you decided to volunteer with the bereavement supporter project?	To establish background and expectations of participants	What were you experiencing at the time? (i.e. life context) What were your expectations? Are you involved in any other volunteer work either inside or external to EC?
What do you think about the training you received?	To get a feel for what the training was like for participants as an experience	Was there a particular aspect you enjoyed/found useful? Was there a particular aspect you didn't enjoy/find useful? Was there anything missing from training? - Provide an example/elaborate
Did you feel prepared to provide support following the training?	Opportunity to discuss how the skills/learning of the training translated into 'real life' applications – did they feel suitably prepared?	In what way? Can you provide an example/elaborate?
Using specific examples, can you tell me about the bereavement support you have given since becoming a Cruse Bereavement Supporter?	Explore what kind of support (informal/informal, resident/family) is being given Identify differences between villages/individuals	Who have you supported? (e.g., resident, family) How did you provide support? (e.g., one-off conversation, face-to-face, telephone) How long did the support last? - Participants encouraged to provide specific examples How did you feel about it?
Are there any benefits you have experienced personally since volunteering?	Examines wider implications of being a bereavement supporter	In other words, what do you feel like you get out of the bereavement supporter role? Examples may include, feeling useful, engaging in meaningful activity, being part of community
Can you think of any challenges you have experienced personally since volunteering?	Examines wider implications of being a bereavement supporter	Have you found anything difficult/unexpected to deal with? Has it met with your expectations? Has it raised any personal issues for you? (e.g., about bereavement, losses you have

Question	Rationale for asking question	Prompt
		experienced and/or your own mortality)
What do you think that you bring to the role of Cruse Bereavement Supporter? Why do you think that is important?	Opportunity to showcase their own skills, experience, and expertise	What skills, qualities, experience do you have that enable you to fulfil this role? What do you think makes a good Bereavement Supporter?
Is there anything you would like to add? Or thought we would ask and didn't?	Provides final way for participants to voice what is important to them with no direction.	

Appendix C: Interview with Bereavement Support Volunteers discussion guide

Question	Rationale for asking question	Prompt
As you know, I'm evaluating the Cruse Bereavement project. Today, I'm interested in your experiences as a BSV Although I have got some questions prepared, I'd like to start by giving you the chance to tell the story of your experiences in your own words and in your own way. So, when you're ready, please can you tell me about your experiences of being a BSV?	Open dialogue – allow participants to tell their own story.	
Can you tell us why you decided to volunteer with the BSP?	To establish background and expectations of participants	What were you experiencing at the time? (i.e., life context) What were your expectations? Are you involved in any other volunteer work either inside or external to EC?
Using specific examples, can you tell me about the bereavement support you have given since becoming a CBS?	Explore what kind of support (informal/formal, resident/family) is being given Identify differences between villages/individuals	Who have you supported? (e.g., resident, family) How did you provide support (e.g., one-off conversation, face-to-face, telephone etc?) How long did support last? How did you feel about it - Use specific examples
Did you feel prepared to provide support following the training?	Opportunity to discuss how the skills/learning of the training translated into 'real life' applications – did they feel suitably prepared?	In what way? Can you provide examples/elaborate?
Are there any benefits you have experienced personally since volunteering?	Examines wider implications of being a BSV	In other words, what do you feel like you get out of the BSV role?
Can you think of any personal challenges you	Examines wider implications of being a BSV	

Question	Rationale for asking question	Prompt
have experienced personally since volunteering?		Have you found anything difficult/unexpected to deal with? Has it met with your expectations? Has it raised any personal issues for you? (e.g., about bereavement, losses you have experienced and/or your own mortality)
What do you think that you bring to the role of BSV? Why do you think that is important?	Opportunity to showcase their own skills, experience, and expertise	What skills, qualities, experience do you have that enable you to fulfil this role? What do you think makes a good BSV?
Is there anything you would like to add? Or thought I would ask but didn't?	Provides a final way for participants to voice what is important to them with no direction.	

Appendix D: Participants

Name*	Village*	Position
Dawn	Sycamore Grove	Bereavement Support Volunteer
Mary	Sycamore Grove	Bereavement Support Volunteer
Nancy	Sycamore Grove	Bereavement Support Volunteer
Lydia	Sycamore Grove	Sales
Marnie	Sycamore Grove	Receptionist
Martha	Sycamore Grove	Dementia and Wellbeing Advisor
Samantha	Sycamore Grove	Care Manager
Bernie	Sycamore Grove	Resident
Iris	Sycamore Grove	Resident
Rahul	Sycamore Grove	Resident
Rosa	Sycamore Grove	Resident
Charles	Oaks Bluff	Bereavement Support Volunteer
Cynthia	Oaks Bluff	Bereavement Support Volunteer
Dorothy	Oaks Bluff	Bereavement Support Volunteer
Lois	Oaks luff	Bereavement Support Volunteer
Richard	Oaks Bluff	Bereavement Support Volunteer
Alice	Oaks Bluff	Volunteer Organiser
Dan	Oaks Bluff	Village Manager
Joyce	Oaks Bluff	Care Manager
Francis	Oaks Bluff	Wellbeing Advisor
Melissa	Oaks Bluff	Receptionist
Patrick	Oaks Bluff	Volunteer Organiser
Mrs Carter	Oaks Bluff	Support Recipient
Mrs Law	Oaks Bluff	Support Recipient
Cathleen	Cedar Court	Bereavement Support Volunteer
Elizabeth	Cedar Court	Bereavement Support Volunteer
Hyacinth	Cedar Court	Bereavement Support Volunteer
Rupert	Cedar Court	Bereavement Support Volunteer
Daisy	Cedar Court	Personal Support Assistant

Name*	Village*	Position
Debbie	Cedar Court	Dementia and Wellbeing Enabler
Karen	Cedar Court	Care Manager
Dolores	Cedar Court	Resident
Jerry	Cedar Court	Resident
Lucille	Cedar Court	Resident
Veronica	Cedar Court	Resident
Walter	Cedar Court	Resident
Lil	Elmwood Forest	Bereavement Support Volunteer
Marcus	Elmwood Forest	Bereavement Support Volunteer
Meredith	Elmwood Forest	Bereavement Support Volunteer
Steph	Elmwood Forest	Bereavement Support Volunteer
Anika	Elmwood Forest	Housing Assistant
Cassandra	Elmwood Forest	Volunteer Organiser & Housing Support Assistant
Clara	Elmwood Forest	Apprentice Healthcare Assistant
Jordan	Elmwood Forest	Personal Support Assistant
Kimberly	Elmwood Forest	Dementia and Wellbeing Enabler
Nicole	Elmwood Forest	Receptionist
Sharon	Elmwood Forest	Wellbeing Advisor
Sophie	Elmwood Forest	Dementia and Wellbeing Enabler
Tasnim**	Elmwood Forest	Personal Support Assistant
Mrs Laverty	Elmwood Forest	Support Recipient
Matthew	N/A	ExtraCare Senior Management
Grace	N/A	Cruse Senior Management
Lisa	Not one of the four evaluation sites	Dementia and Wellbeing Advisor

*Names and places have been replaced with pseudonyms

**Participant did not consent for their words to be used verbatim in research outputs

Appendix E: Focus group with Bereavement Support Volunteers (full information and consent form)

STUDY TITLE – **Evaluation of Cruse Bereavement Supporter Project**

WHAT IS THE STUDY?

We will be spending the next 4 years talking with volunteers, residents, and staff within your village about their experiences of the Bereavement Supporter Project as part of our evaluation.

We are interested in your experiences as a Cruse Bereavement Supporter. We would like to discuss: training and support, examples of bereavement support you have given, and challenges you may have faced. You will also be able to talk about aspects of your experience as a Cruse Bereavement Supporter that are important to you.

WHAT EXACTLY WILL I DO?

We are inviting all Cruse Bereavement Supporters at [name] and [name] villages to participate in a focus group. You will be asked to discuss your experiences in small groups (approximately 5-7 people). It is expected to last approximately two hours in total. The focus group will be audio recorded. Identifying features (such as names, places etc.) will be changed so it will not be possible to identify you. Reimbursements for travel costs (where appropriate) and refreshments will be provided. We will also invite you to a follow-up session in six months' time (you do not have to participate in both if you don't want to).

DO I HAVE TO TALK TO YOU?

No. You do not have to talk to the research team, and you can withdraw from the study at any time. However, we will assume that you are happy for us to include information you gave us on earlier occasions unless you specifically let us know.

WHAT WILL YOU DO WITH MY INFORMATION?

Our analysis of the focus group data will explore; what it means to be a Cruse Bereavement Supporter (for example, what are the benefits and challenges), what kinds of bereavement support are being offered and under what circumstances, and how can bereavement services be improved. Our findings will be shared with; Cruse Bereavement Care, ExtraCare Charitable Trust residents and staff (including you), and the scientific community (for example, through journal articles and conferences).

WHAT ARE THE RISKS AND BENEFITS OF TAKING PART?

We hope that you will enjoy taking part in this focus group. However, it is possible that the memories you recall as part of the discussion will be upsetting for you. You are free to take a break at any time, or skip questions that you do not want to answer.

All of the researchers who carry out the focus group will be required to have Enhanced Disclosure of any criminal record from the Government's Disclosure and Barring Service (DBS).

One of the aims of this evaluation is to understand what works best in supporting people experiencing a bereavement as people get older. We plan to share this information with organisations such as ExtraCare, and policy makers and so improve care for people in the future.

WHAT IF THERE IS A PROBLEM, AND WHO DO I CONTACT IF THERE IS?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If there are still any aspects of the research that has been carried out that you are unhappy about, you are free to contact the Director of Governance on email j.g.walter@aston.ac.uk or telephone 0121 204 4869.

WHO HAS REVIEWED THE STUDY?

All research in the University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity.

Thank you for taking time to read about this study.

Karen West

Prof Karen West School for Policy Studies, University of Bristol. (karen.west@bristol.ac.uk)

THE CONSENT FORM (Research with Resident Bereavement Supporters: Activity C)

Name of ExtraCare location…………………………………………………
and Participant ID Number: ______________

Name of Principal Investigator: Dr Karen West email: k.west@aston.ac.uk

Name of Researcher conducting assessments today: _________________

Please initial, rather than tick boxes

☐ 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ 2. I understand that if I withdraw or can no longer continue, the researchers will assume I am happy for them to use data already recorded unless I specifically ask for it all to be withdrawn retrospectively.

☐ 3. However, I also understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected.

☐ 4. I give permission for the researchers to keep my contact details so that should there be opportunity to follow up further, they may contact me.

☐ 5. I give permission for my data to be made available to other people for research purposes, providing my identity is never revealed (optional).

☐ 6. I give my consent to allow for direct quotes from the audio-recording of our conversation to be used in any written reports or publications and that these will be completely anonymous.

☐ 7. I agree to not disclose anything discussed during this study focus group to anyone outside of the study.

☐ 8. I agree to take part in the above study.

_________________ Name of Participant	__________________ Signature	Date ____________________
________________ Name of Person taking consent	_________________ Signature	____________________ Date

Appendix F: Focus group with Bereavement Support Volunteer (revised consent form for recruitment)

WHAT IS THE STUDY?

As part of our on-going evaluation of the Bereavement Supporter Project we are inviting all Cruse Bereavement Supporters at [name] [name] Villages to participate in a focus group to discuss their experiences.

The focus group will take place on:

[Time, date, location]

You will be asked to share and discuss your experiences in a small group (approximately 5-7 people). What we talk about will be guided by you, but we may discuss: examples of support that you have provided; any changes that have occurred since the last focus group that have impacted your experience; any challenges that you are currently experiencing etc.

It is expected to last approximately an hour and a half in total. The focus group will be audio recorded. Identifying features (such as names, places etc.) will be changed so it will not be possible to identify you.

Reimbursements for travel costs (where appropriate) and refreshments will be provided.

Note: ALL volunteers from [name] and [name] villages are invited, irrespective of whether or not you attended the last focus group.

DO I HAVE TO TALK TO YOU?

No. You do not have to talk to the research team, and you can withdraw from the study at any time.

WHO HAS REVIEWED THE STUDY?

All research in the University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity.

WHAT HAPPENS NEXT?

If you would like to take part, please let Eve Wilson (Bereavement Supporter Project Manager; eve.wilson@cruse.org.uk or 07496 922 385), or Caity Roleston (rolestce@aston.ac.uk or 0798 041 6061) know as soon as possible.

Thank you for taking time to read about this study.

Appendix G: ExtraCare Resident focus group recruitment poster

Death and bereavement touches everyone at some stage in their life.

We are interested in hearing your views and experience about the support available in the village following a bereavement or loss.

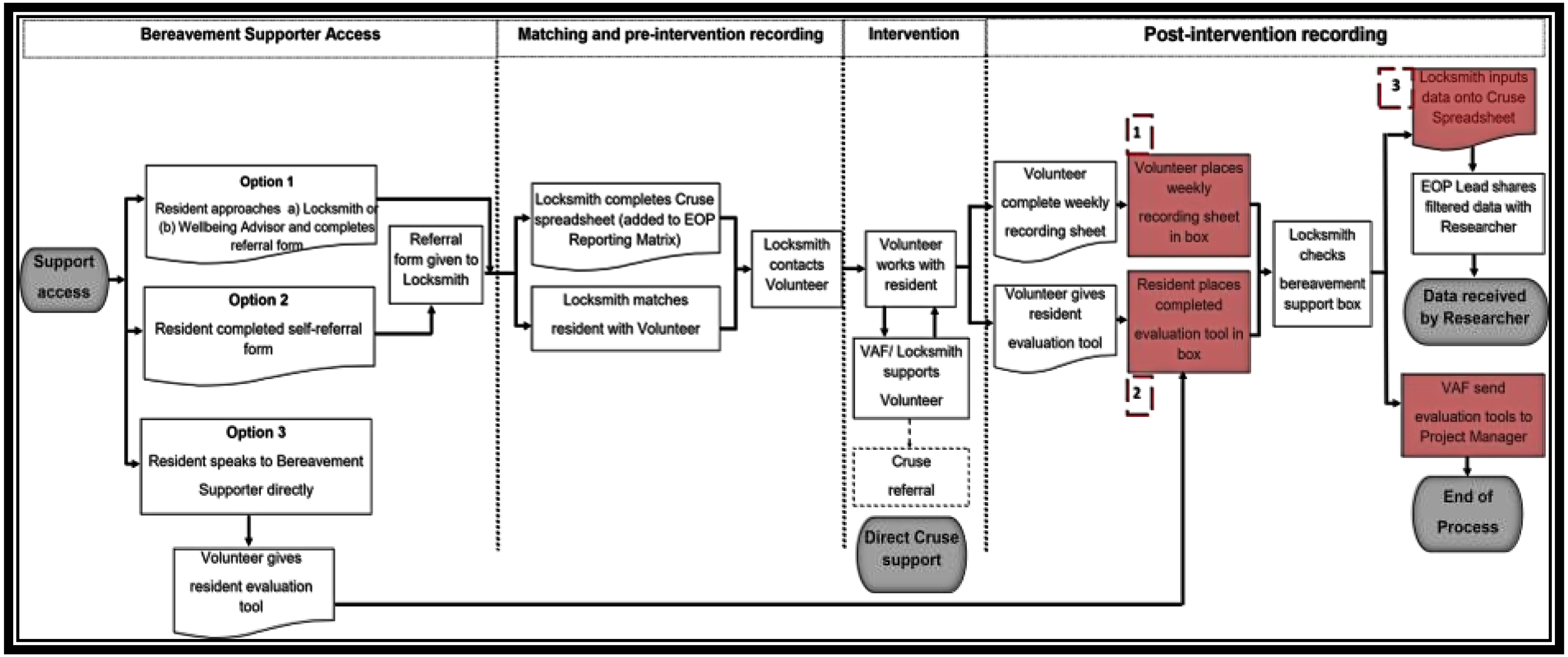
We are inviting all residents of [name] village, who are <u>not</u> Resident Bereavement Supporter volunteers, to participate in a small focus group (5—7 people).

<u>If you wish to attend, please complete the sign-up sheet held on Reception.</u>

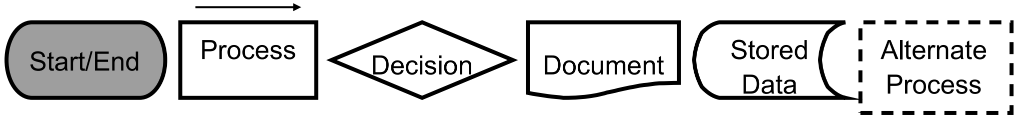
The focus group will be audio recorded. Identifying features (such as names, places etc.) will be changed so it will not be possible to identify you.

Appendix H: Bereavement Supporter Project staff-referral process map

Process A: Locksmith as lead person

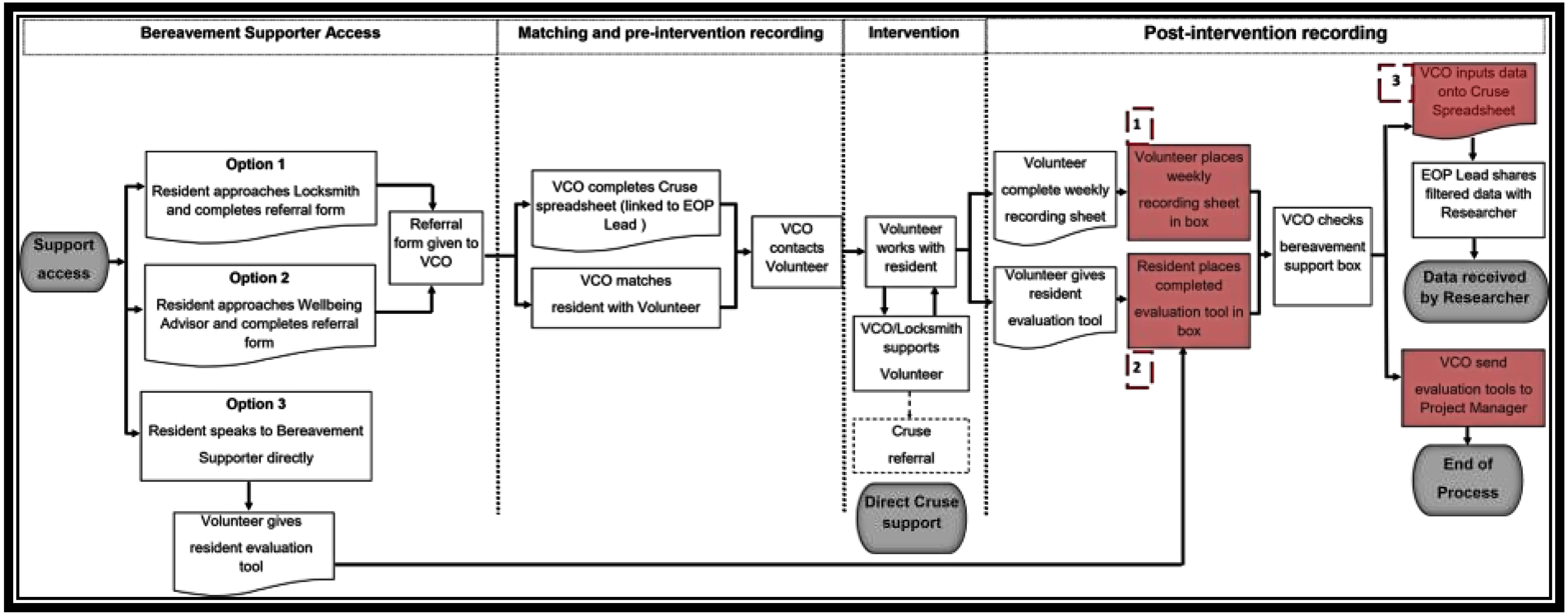


KEY:



Data risks: 1. Inconsistent; 2. Resident may not complete evaluation tool or include their name; 3. Locksmith not reporting.

Process B: Volunteer Coordinator as lead person



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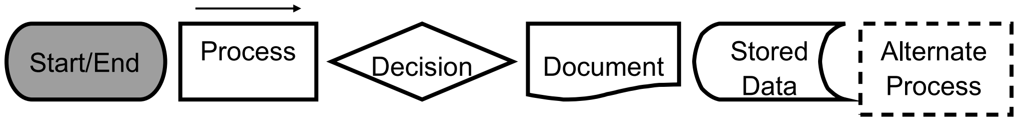

Data risks: 1. Inconsistent; 2. Resident may not complete evaluation tool or include their name; 3. Volunteer Coordinator not reporting.