Death Studies

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/udst20

Understanding how volunteer companionship impacts those during the end of life: A realist evaluation

John Downey, Susan Cooper, Lynn Bassett, Alejandra Dubeibe Fong, Margaret Doherty & Jon Cornwall

To cite this article: John Downey, Susan Cooper, Lynn Bassett, Alejandra Dubeibe Fong, Margaret Doherty & Jon Cornwall (04 Apr 2024): Understanding how volunteer companionship impacts those during the end of life: A realist evaluation, Death Studies, DOI: 10.1080/07481187.2024.2336006

To link to this article: https://doi.org/10.1080/07481187.2024.2336006

© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.

Published online: 04 Apr 2024.

Submit your article to this journal

Article views: 468

View related articles

View Crossmark data

Full Terms & Conditions of access and use can be found at https://www.tandfonline.com/action/journalInformation?journalCode=udst20

DEATH STUDIES
https://doi.org/10.1080/07481187.2024.2336006

Taylor & Francis
Taylor & Francis Group

OPEN ACCESS Check for updates

Understanding how volunteer companionship impacts those during the end of life: A realist evaluation

John Downey[a], Susan Cooper[b], Lynn Bassett[c], Alejandra Dubeibe Fong[c], Margaret Doherty[c], and Jon Cornwall[d]

[a]Faculty of Health, University of Plymouth, Plymouth, UK; [b]Institute of Education, Plymouth Marjon University, Plymouth, UK; [c]The Centre for the Art of Dying Well, St Mary's University, London, UK; [d]St Vincent De Paul (England and Wales), Membership, UK

ABSTRACT

Volunteers are a popular unpaid support role in end of life care yet how accompaniment influences the dying is underdeveloped. This study examined how companionship works, for whom, in what circumstances and why. Initial realist ideas were developed through participant observation (14 months), document analysis, and realist interviews with companionship trainers ($n=6$). Theory testing involved volunteer interviews ($n=7$), accounts from the dying, proxy accounts for the dying, and written reflections from companionship training. Companionship helps people live well until they die, prepare for death, and experience a good death. Four areas of volunteering explain these outcomes namely a loving friend, a holistic presence, a non-judgmental intermediary, and wrap around care. The four areas activate mechanisms related to reminiscing, preserving dignity/personhood, and easing suffering, contingent on specific contexts. The findings unpack how volunteering exerts its influence and what contextual factors facilitate outcomes, advancing the knowledge in this area.

The presence of volunteers in palliative care is popular, yet, a definition of what volunteering entails is underdeveloped (Bloomer & Walshe, 2020; Payne et al., 2022). Nonetheless, it is largely accepted that volunteers complement formal services by offering holistic support that can enhance wellbeing (Knights et al., 2020; Walshe et al., 2021). Volunteers emphasize the relational aspects of care and support the practical, social, emotional, and spiritual needs of the dying (Bloomer & Walshe, 2020; Dodd et al., 2018; Sharp, 2022). Typically, volunteers occupy a unique position traversing health professional and family. This can mean they are often better placed to provide neutrality and advocacy for the dying person (Vanderstichelen et al., 2020). The importance of addressing the holistic needs of the dying is well established but research on how volunteers support the dying is lacking (Abu-Odah et al., 2022; Sévigny et al., 2010; Vanderstichelen, 2022).

Although volunteering is diverse companionship is often seen as a core function of the role. Companionship involves "being with" rather than "doing for" people and a volunteer's presence is central to the envisaged impact on a person's quality of life (Dodd et al., 2018; Fakoya et al., 2021). Companionship can offer opportunities for conversation, psychosocial support, advocacy, and sense making (Bloomer & Walshe, 2020). Nonetheless, understanding what individual outcomes are influenced through companionship in palliative care is largely unknown.

The companionship literature to date has largely explored companion's experiences through surveys or qualitative methods to categorize features of the work. Alternatively, a priori coding manuals have been used to appraise how companionship presents in interactions with the dying. Both approaches fail to unpick how actions determine outcomes or how varying circumstances produce different outcomes, which is lacking in the literature (Pino et al., 2021; Pino & Land, 2022). Conversational analysis may be a useful innovation in understanding the intricacies of companionship, but the link to explaining how the actions of companions exert their influence is only emerging.

The impact of companionship in palliative care is noted elsewhere and common outcomes include enhancing comfort, dignity, respect and wellbeing (Sévigny et al., 2010). Nonetheless, research exploring how the companions navigate their role and what contexts catalyst outcomes is largely not documented.

CONTACT Dr John Downey john.downey@plymouth.ac.uk Centre for Health Technology, School of Nursing and Midwifery, Faculty of Health, Room 202, 6 Kirkby Place, Plymouth PL4 6DT, UK.

© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

Where authors have aspired to outline the intricacies of end of life support, results have emphasized medical needs, coordination, referral pathways, leadership approaches, and the knowledge and skills of staff (Costello, 2006; Hashem et al., 2020; Stewart-Lord et al., 2022). Some exploratory research does exist but is restricted to single outcomes or cohorts (Fakoya et al., 2021; Malcolm & Knighting, 2022). At the time of writing this manuscript a chasm remains between understanding the well documented outcomes of championship and how the presence of volunteers achieves these outcomes.

Quantifying and explaining companions contribution to care is difficult (Bloomer & Walshe, 2020) as many of the benefits escape typical measurement tools and companions do not have a routine place in the healthcare system (Dodd et al., 2018; Scott et al., 2021). Yet, companionship may mitigate the medialization of death, help ease healthcare burden, and improve quality of life (Parks & Howard, 2021). To overcome the current challenges research must build and test theory about what works, for whom, in what circumstances and why (van der Steen et al., 2022). The aim of this research was therefore to advance the understanding of what works, for whom, in what circumstances and why, in relation to end of life companionship.

Methods

Design

A realist evaluation was undertaken in line with the RAMESES quality standards (Pawson, 2016; Wong et al., 2017). Realist evaluation rejects deterministic views of causality and aspires to develop and test causal configurations related to generative causality. For realists, what is real cannot be reduced to what can be known and the task is to use retroduction to try and interpret what real, but invisible, entities are leading to intended and unintended consequences within specific circumstances. Retroduction involves theorizing what must be the case for X to exist. Program theory, the ideas about causation, are the unit of analysis and mechanisms refer to the causal powers and liabilities at play. Although mechanisms can be defined in many ways, in this project mechanisms were conceptualized as individual's responses to specific resources (Dalkin et al., 2015). Middle range theorizing involves borrowing reusable conceptual and explanatory models to abstract findings so that they advance theory in practice and provide portable learning to other settings.

Realist evaluation seeks the lived experience of the phenomena of interest. Due to the challenges with accessing palliative care settings and the risk of excluding underrepresented voices, realist evaluation was combined with transformative evaluation. Transformative evaluation is a participatory methodology based on appreciative enquiry, most significant change and transformative learning (Cooper, 2014). The two approaches share similar philosophical views making them congruent. Transformative evaluation sees those working in an area as learners and shifts the focus of evaluation from proving worth to collection action. The approach involves upskilling key people on story generation, the research process, and ethics. During a workshop volunteers devise a specific question to generate "change stories" from their settings. Post training, they return to their settings and collect naturalistic data from those they work with.

The combination of approaches offered specific advantages for this setting namely, empowering volunteers, gaining access to the voice of the dying, increasing representation, decreasing evaluative burden, and increasing explanation.

Setting

The Center for the Art of Dying Well developed an introductory end of life companionship training course and on-going support through regular group meetings and an active forum. The training was principally designed for members of St Vincent de Paul Society (England and Wales). The 3-h training course aimed to equip volunteers with the skills and confidence to support the dying and sensitize them to opportunities for companionship within the English end of life system. The training covered content related to the context of death, the spiritual principles of companionship and self -care. In addition, the training helped to normalize death and recognize the skills of "being present".

The current research utilized this project by working with the training team and the pool of trained volunteers to advance the knowledge on how companionship influences the dying. Trained volunteers perused various forms of companionship upon completion of the training. Some attendees supported families, friends, or their communities whilst others supported more formal services like hospices.

Researcher standpoint

The lead author was invited to evaluate the body of work due to specific expertise in evaluation

methodology. As a white, male, Irish researcher engrained ideas will have been brought into the interpretation of the data. A Catholic upbringing, which is not practiced as an adult, and an academic interest in person centeredness and health psychology will influence how experiences witnessed during the research were analyzed. Reflexive journaling, independent co-coding, and presenting emerging ideas to the wider research team for crosschecking helped add confidence to the areas that were being unearthed from the data.

Participants

In line with realist evaluation, key informants were defined as any stakeholder who could contribute to the development of ideas on how companionship generates outcomes for the dying. The recruitment of respondents evolved over time but essentially included training developers, volunteers, and beneficiaries in receipt of companionship who could share their story. Recruitment involved a mixture of online, telephone, email, and opportunistic approaches.

Sampling

Purposeful sampling was initially used to recruit a group who had experience of training and mentoring volunteers and select key documents and places to observe in order to postulate how companionship works and why. Theory testing also adopted purposeful sampling but included those who completed companionship training and had experience of volunteering, proxy stories of the dying from companions, and stories direct from the beneficiaries themselves.

Data collection procedures

The development of program theory involved several research methods (Table 1). Participant observation took place for 14 months (March 2021–May 2022) and included consistent fieldwork with a minimum of one field visit (electronically) a month. Field visits involved meetings with the companionship training team or attending volunteer "catch ups". Document analysis of eight key artifacts including the companionship training manual, job descriptions, and funding proposals were used to understand the conceptualization of companionship and record any mechanisms of action and/or prudent contextual factors. Observation of the meetings and documents provided information about how companionship was being implemented, surfaced prudent concepts, and the interrelationships between concepts impacting outcomes for the dying (Newbury, 2013).

Six realist interviews were undertaken with the training developers (42.8 ± 15.2 mins) to glean ideas about how companionship works, how it was envisaged to impact beneficiaries, and any key factors likely to influence outcomes. Questioning was exploratory and probed interviewees to define envisaged outcomes, explain how companionship may impact the dying and compare how contexts may influence outcomes (Manzano, 2016).

In realist evaluation program theory must be subjected to empirical testing to refine ideas and move closer to the real entities causing outcomes (Pawson, 2013). Therefore, empirical data that captured the voice of the dying was fundamental. Volunteers who completed the companionship training were invited to a transformative evaluation workshop. During the workshop volunteers were equipped to collect most significant change stories from those who they accompany. The workshop co-developed acceptable data collection procedures and agreed a set of ethical principles to guide the story generation (Cooper, 2014). The group then undertook a period of story generation, opportunistically seeking written consent to collect stories with beneficiaries on salient aspects of companionship. This was captured in brief prose with the dying by asking "what do you think is the most

Table 1. An overview of the methods used and initial program theory of companionship.

Methods used	Initial rough program theory	Theory areas
Participant observation Realist interviews Document analysis	If the volunteer possesses the right attributes, and offers an attentive presence, it inspires hope and human connection that helps people die well.	A holistic presence
	If the volunteer possesses the right attributes, and is a loving friend, people feel valued, and they live well until they die.	A loving friend
	If the volunteer acts as a middleman they can be a platform for the voice of the dying and help give them agency and resolve concerns, leading to a better preparation for death.	A non-judgmental intermediary
	If support is not constrained to dying, and wrap around care is given, people gain a greater peace of mind through advocacy and relief.	Wrap around care

important thing to you about our time together?". Five volunteers were trained in transformative evaluation and had a 2-month period to generate most significant change stories with the dying, resulting in four accounts from beneficiaries.

Volunteers were also invited, through online and email recruitment, to share their experiences of companionship through semi-structured interviews. Seven brief interviews (25.4 ± 12 mins) were undertaken to explore the experiences of volunteers since completing their training. The interviews were pragmatic and were recorded to inform dissemination materials as opposed to specifically testing program theory. The structure of the interviews invited volunteers to describe their companionship experience and give an example of how people were impacted by volunteering which provided empirical data to test program theory. It was deemed unnecessary to replicate interviews which would increase undue burden on the volunteers.

Furthermore, accounts were collected from volunteers, who had experience of accompanying someone near the end of life, since their training. Volunteers were invited by email to reflect on their experiences. Five volunteers responded and used the words of the dying to describe their scenario as proxies for the beneficiaries. Volunteer forum contributions, from those who attended the training, were also examined and five additional statements were extracted specific to the research aim. Lastly, immediate reflections from training were gathered from the attendees and the tutor for 12 of the training courses. These data streams were examined to adjudicate between the envisaged and actual workings of companionship either refining, refuting, or corroborating elements introduced in the initial program theory development phase.

Ethics

Ethical approval granted by Plymouth Marjon University (EP157, 1/4/22), who made a recommendation to develop an advisory group to ensure procedural, ethical, and humanistic agendas were recognized and respected. The research team collaboratively worked with other academics, care providers, St Vincent De Paul Society England and Walas (a Catholic volunteer organization supporting families in hardship), and volunteers throughout the project. The advisory group helped to crosscheck, with invested parties, the acceptability and appropriateness of the evaluation. All data collection was overt and written informed consent was explicitly gained before participants took part in data collection.

Data analysis

The interviews and journal entries were transcribed verbatim into word documents. These documents were read and a realist qualitative approach was adopted (Maxwell, 2012). Any large passages of text which were indicative of necessary conditions, active ingredients, or successful program outcomes were coded and issued an inductive label. The context, mechanism, outcome (CMO) heuristic was used within these segments as an analysis aid (Dalkin et al., 2015), yet segments were initially arranged using the "if then" or "if then because" formula to undertake theory building in a more flexible manner. A word document was used which contained a table with columns for label, "if then" statement, quotes, and memos. As the transcripts, journal entries, and archived documents were read, the analysis consolidated textual data into causal configurations. These configurations were not always complete but data often added to a conceptual understanding of companionship and Cs, Ms, or CM or MO dyads, were tracked in the analysis (Jackson et al., 2012). Once all the initial data had been analyzed the "label" column was examined to see if inductive labels could be grouped under higher level concepts consolidating the results. Where it was unclear if aspects of companionship could be grouped by one theme, the direct quotes were crosschecked to consider if CMOs added novel elements to a theory, refined it, or required a new label (Pearson et al., 2015).

The initial analysis provided conceptual bins which guided theory testing. Each subsequent data stream underwent the same analysis procedure. Each data source was examined across themes to assess if it could reside within labels or required a new domain. Once all data had been scrutinized across the themes, mechanisms were examined against formal theories to abstract results to a middle range (Pawson, 2000). Inductive labels and key elements of configurations were used as keywords in a rapid search of the end of life literature. Constructs from theoretical frameworks that resonated with the data were adopted to provide overarching explanatory concepts to help abstract data and consolidate findings. The reorientation of data was necessary to pinpoint how outcomes were occurring (Jagosh, 2020).

Results

The findings show that end of life companionship supported diverse features of wellbeing through four theory areas identified during the theory building phase namely: accompaniment as a loving friend, a

holistic presence, a non-judgmental intermediary, and wrap around care (Table 1).

The initial tentative ideas were tested and eight realist propositions emerged from scrutinizing the data refining the initial program theory (Table 2).

In line with reporting standards for realist evaluation abstraction to established theories was undertaken (Wong et al., 2017). The current findings show how aspects of humanism, reminiscing, personhood, suffering, and dignity were manifested through companionship and how this impacts the dying. The following subheadings use the theoretical label of the mechanism as a focal point and describe what contexts facilitate the activation of the mechanism, what elements of the four theory areas interact with the mechanism, and what outcomes are supported. Context, mechanism, and outcomes are represented in brackets by their respective initial.

Storytelling and reminiscing

Living well until death was principally enhanced through the presence of a loving friend represented by humanistic caring, a well-established concept in palliative care (Pereira et al., 2018). The current data indicated that the dying could increase the fullness of their life through storytelling and reminiscing (M). The analysis showed that where humanistic support allowed trust and bonding (C), the sharing of stories inspired hope, distraction, and filled beneficiaries with life (O).

> "And it's that retelling with somebody who's a fresh pair of ears and I think most of us; there are some things in our lives that we do like to talk about and retell." (Volunteer ID001).

In addition, a non-judgmental intermediary who was not family or a healthcare professional helped individuals prepare for death. This occurred where conversations about death were difficult with others (C). Humanistic care again provided the catalyst for the dying to benefit from reminiscing (M), but through a different lens, namely seeking closure by resolving past tensions they harbored (O).

> "But as someone who's not a relative you provide a different space. And very often those things that have been troubling the person who's dying they don't want to worry or concern that their relatives with, they will talk to you about it" (Volunteer ID002).

Maintaining dignity and personhood

Personhood is a useful concept (Davies, 2020) to represent various features of the findings as it encapsulates prudent activities covering the preservation of identity, normalcy, spiritual needs and advocacy. Where the person had limited capacity (C), being present with a good awareness of their needs enhanced the dignity of the person by respecting their human rights (M), aiding the preparation for death (O).

> "I think it's more a feeling thing you can experience and maybe because she was bedridden and wasn't able to move or say very much that the maybe, the spiritual experience, is what she felt was she needed at the time" (Volunteer ID001).

When the dying were isolated and had the choice to engage with a companion (C), loving friendship helped the dying live a full life through stimulation giving purpose and a sense of normalcy (M). Offering a consistent presence and range of activities eased boredom and supported engagement enhancing the quality of life until death (O).

> "Since I am on my own, I am grateful for your friendship which is one of the things that kept me going during the worst times. You have been arranging loads of activities which stimulate the mind. I would be lost without you." (Proxy Beneficiary ID011).

Where the family were experiencing grief (C) it was found that the companion could provide wrap around care and advocate for the dying person. This gave the beneficiary a sense that their wishes would be

Table 2. An overview of the theory testing phase and refined CMOs.

Theory areas	Context	Mechanism	Outcome
A holistic presence	C-The dying have limited capacity	M-Sensitivity to needs preserves dignity	O- Preparation for death
	C-Appropriate volunteer attributes	M-Spiritual presence ensures forgiveness	O- Good death
A loving friend	C-Trust and bonding	M-Reminiscing gives a full life	O- Living well until death
	C-Isolation and choice for a companion	M-Stimulation gives purpose and normalcy	
A non-judgmental intermediary	C-Difficult conversations	M-Reminiscing gives closure	O- Preparation for death
	C-Worry about their family left behind	M-Reassurance and comfort	O- Good death
Wrap around care	C-Family are in grief	M-Practical support	O- Good death
	C-Family are overwhelmed by the process	M-Advocacy and knowing their family will be supported	

tended to (M) increasing the experience of a good death (O).

> "And when the family couldn't support her anymore: it was exhausting, there was too much to handle for them during the day…So I was sitting with her for 5 or 6 hours… that was challenging for me because her need was not managed, I felt in my heart that I had to intervene, to communicate. The patient is in pain you cannot ignore it …. So I had to diplomatically communicate that and become the link before the palliative care was properly involved. And the family was not assertive enough." (Volunteer ID003).

Easing suffering and distress

The concept of suffering (Castro et al., 2021) was evident in the data primarily showing how spiritual support can enrich the dying experience. Suffering covered physical, psychological, emotional, existential, spiritual, and social dimensions. When the individual was worried about their family (C) and the companion provided a non-judgmental listening ear, it led to a good death and people could "let go" (O). This worked as people could gain reassurance (M).

> "It was with a young mother. She had two teenage sons and she was anxious how they would be after she had died. So that was a lovely opportunity for me to talk through with her, to share with her about the boys' strengths and characters and to assure her that they will be able to cope" (Volunteer ID006).

Where the companion had the appropriate characteristics to offer a holistic presence, individuals can better prepare for death. When the person has limited capacity (C) a spiritual presence may help people seek forgiveness (M) and can help beneficiaries with acceptance and give a good death (O).

> "Maybe there were things in her past that she hadn't said to me, or to her family, that she just needed that forgiveness at the end of her life. And that's what happened… (family feedback) after you left, she seemed so much calmer…she knew it was all ok that we understood she was leaving and seemed to accept it" (Volunteer ID001).

These explanations can be explained through a comforting mechanism. The realization of this outcome also relied on the family being unfamiliar or overwhelmed by the dying process (C). Wrap around care supported the dying as it reduced isolation, practical matters were supported, and individuals knew their family will be cared for when they went (M), decreasing fright and increasing peace (O).

> "And then we called the on-call GP back. A different one came and verified the death and then we got a friend to come and stay with her. And I stayed there until the friend arrived. We waited until the undertaker was there and took his body. But I made sure that she had plenty of time with him because I didn't want her to feel rushed and be taken away before she had a chance to say goodbye" (Volunteer ID003).

Discussion

The purpose of this study was to understand how volunteer companionship works, from whom, in what settings, and why. Three mechanisms encapsulated how companionship influenced the wellbeing of the dying namely reminiscing, preserving dignity, and easing suffering. These mechanisms operated in a variety of ways and four unique aspects of companionship were detailed-accompaniment as a loving friend, a holistic presence, a non-judgmental intermediary, and wrap around care.

Accompaniment as a loving friend advances the concept of humanism by showing that it activated a reminiscing mechanism. Humanistic care is the most widely utilized theory in palliative care (Pereira et al., 2018) which has been shown to improve wellbeing (Taghinezhad et al., 2022). The opportunity for reminiscing also has widespread avocation (Hesse et al., 2019; Laskow et al., 2019; Synnes, 2015). Nevertheless, how these concepts correspond to each other has not been detailed previously. The diversity of how reminiscing unfolds (Macleod et al., 2021) and the importance of the unique position of volunteers were verified in the findings which is, however, noted elsewhere (Vanderstichelen et al., 2020).

As suggested in the findings, and supported by others, the relationship between the care giver and the person impacts outcomes (Hunter et al., 2022; Synnes, 2015; Taghinezhad et al., 2022). The challenges in the literature spanning both humanistic practice and storytelling pertain to heterogeneous delivery, poor measurement, weak theoretical underpinning, poor understanding of antecedents, and an unclear conceptualization of wellbeing (Hesse et al., 2019; Hunter et al., 2022; Laskow et al., 2019; Macleod et al., 2021; Taghinezhad et al., 2022). The current data addresses some of the challenges by explaining how humanistic practice interlinks with reminiscing and how it can improve wellbeing through a greater preparation for death and enhancing living well until death.

Personhood resonates with many elements of the current findings as it recognizes the need to maintain the person's identity but also wider notions of spiritual embodiment (Davies, 2020; Edwards et al., 2010). Being present was a central theme in the current data

which is an accepted feature of volunteering (Bassett et al., 2018; Bloomer & Walshe, 2020; Dodd et al., 2018; Vanderstichelen et al., 2020). Volunteering is often undertaken in times when people lack the capacity to interact, creating a challenge to capturing the impact of companionship. The current findings showed that in these circumstances "being with" the person can contribute to a basic preservation of dignity and aid the preparation for death. Practical support from a place of unconditional compassion may allow the person to experience respect and be nurtured which involves the use of silence, music, or prayer which requires companion intuition. The area of spiritual care has been described in other settings (Edwards et al., 2010; Söderman et al., 2020) supporting the current findings specific to end of life companions.

Dignity therapy is also discussed elsewhere to preserve the basic right to feel human (Bylund-Grenklo et al., 2019; Östlund et al., 2019; Zheng et al., 2021). Where people were isolated humanistic care, coupled with providing a range of activities, helped people live well until they die. The role of facilitated activities to ease boredom and support belonging has been described by those nearing the end of life (Shiells et al., 2020). Specifically in this study, these provisions were stimulating which may be explained through preserving dignity. Others have highlighted how the preservation of dignity should attempt to maintain normalcy, support living in the moment, and give life purpose (Östlund et al., 2019).

In addition, the current data verified the importance of being the person's voice when they are unable to communicate their wishes. Others have highlighted the role of advocacy to support dignity in palliative care, especially in situations where difficult conversations are needed (Bylund-Grenklo et al., 2019; Östlund et al., 2019; Söderman et al., 2020). This scenario was a context deemed important in the current study where the process of death may be overwhelming for family which can stifle their ability to act as the person's voice, which a companion can bolster.

Although easing holistic suffering is central to palliative care often physical outcomes are prioritized (Castro et al., 2021). Interestingly, the current findings the relief of physical discomfort contributed only a small part of the data. Comfort was a mechanism in the data which covered sub themes of reassurance, closure, letting go, and transcendence. Once again, the role of a loving stranger, who felt privileged to journey with people, was an important element to ease suffering. Those near the end of life have verified the importance of love, compassion, altruism, and empathy (Sinclair et al., 2017, 2021) supporting the current findings.

Suffering exists when valued elements to the person are endangered (Hartogh, 2017). In the current findings this notion was relevant in circumstances when people were worried about their family and companions provided a reflective space to increase reassurance and work through practical matters. In settings where communication was not possible it is purported that companionship eases anguish and increases acceptance through a companion's presence. Others support the use of prayer, silence, and music as it facilities inner communication with a personal entity (Edwards et al., 2010).

Strengths and limitations

The current work adopted an approach which supported learning about complex settings, increased the access to volunteers and voice of the dying, collected data in a naturalistic manner, and accumulated a holistic understanding of how volunteering practices unfold. In addition, as the approach was theory led, it consulted with established theory advancing knowledge on how known concepts operate in practice which strengthens the claims about how wellbeing can be enhanced.

The limitations of the work related to the challenges of gaining a representative voice of the dying and navigating the unpredictable nature of volunteering. Ideally, triangulation would have been possible by combining diverse datasets and not relying solely on narrative stories. As per the realist evaluation seminal work, mixed methods research could strengthen the claims about the emerging theory areas which was not undertaken in the present study.

Conclusion

Volunteer companionship creates the opportunity for people to live well until they die, prepare for death, and experience a good death. Benefits to wellbeing are achieved through mechanisms including reminiscing, preserving dignity, and easing suffering. As noted in the nascent literature, companions do not deliver standardized care and most benefits are achieved by "being with" rather than "doing for" people. Although, the literature laments for more consistent practice, it was shown in this research that contextual factors demand the tailoring of care to maximize the best care for the dying. It was noted that several of the outcomes were contingent on factors including the

challenge of speaking about death, gaining the human bond, and settings where the dying cannot communicate. Instead of critiquing the current diversity of volunteer work, the current authors encourage a greater variety of research methods which can learn about the impact of contextual factors and strengthen the evidence on what outcomes are achieved, for whom, and how.

Acknowledgments

All volunteers, the training team, and wider advisory board.

Disclosure statement

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This work was supported by the Center for the Art of Dying Well.

Data availability statement

Qualitative data and realist configuration analysis is available upon request from john.downey@plymouth.ac.uk

References

Abu-Odah, H., Molassiotis, A., & Liu, J. Y. W. (2022). Global palliative care research (2002–2020): Bibliometric review and mapping analysis. *BMJ Supportive & Palliative Care*, *12*(4), 376–387. https://doi.org/10.1136/bmjspcare-2021-002982

Bassett, L., Bingley, A. F., & Brearley, S. G. (2018). The contribution of silence to spiritual care at the end of life: A phenomenological exploration from the experience of palliative care chaplains. *Journal for the Study of Spirituality*, *8*(1), 34–48. https://doi.org/10.1080/20440243.2018.1431034

Bloomer, M. J., & Walshe, C. (2020). 'It's not what they were expecting': A systematic review and narrative synthesis of the role and experience of the hospital palliative care volunteer. *Palliative Medicine*, *34*(5), 589–604. https://doi.org/10.1177/0269216319899025

Bylund-Grenklo, T., Werkander-Harstäde, C., Sandgren, A., Benzein, E., & Östlund, U. (2019). Dignity in life and care: The perspectives of Swedish patients in a palliative care context. *International Journal of Palliative Nursing*, *25*(4), 193–201. https://doi.org/10.12968/ijpn.2019.25.4.193

Castro, M. C. F. D., Fuly, P., dos, S. C., Santos, M. L. S. C., dos., & Chagas, M. C. (2021). Total pain and comfort theory: implications in the care to patients in oncology palliative care. *Revista Gaúcha de Enfermagem*, *42*, 1–8. https://doi.org/10.1590/1983-1447.2021.20200311

Cooper, S. (2014). Putting collective reflective dialogue at the heart of the evaluation process. *Reflective Practice*, *15*(5), 563–578. https://doi.org/10.1080/14623943.2014.900019

Costello, J. (2006). Dying well: Nurses' experiences of "good and bad" deaths in hospital. *Journal of Advanced Nursing*, *54*(5), 594–601. https://doi.org/10.1111/j.1365-2648.2006.03867.x

Dalkin, S. M., Greenhalgh, J., Jones, D., Cunningham, B., & Lhussier, M. (2015). What's in a mechanism? Development of a key concept in realist evaluation. *Implementation Science: IS*, *10*(1), 49. https://doi.org/10.1186/s13012-015-0237-x

Davies, D. J. (2020). Dividual identity in grief theories, palliative and bereavement care. *Palliative Care & Social Practice*, *14*, 2632352420921867. https://doi.org/10.1177/2632352420921867

Dodd, S., Hill, M., Ockenden, N., Algorta, G. P., Payne, S., Preston, N., & Walshe, C. (2018). 'Being with' or 'doing for'? How the role of an end-of-life volunteer befriender can impact patient wellbeing: interviews from a multiple qualitative case study (ELSA). *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *26*(9), 3163–3172. https://doi.org/10.1007/s00520-018-4169-2

Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). Review: The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research. *Palliative Medicine*, *24*(8), 753–770. https://doi.org/10.1177/0269216310375860

Fakoya, O. A., McCorry, N. K., & Donnelly, M. (2021). How do befriending interventions alleviate loneliness and social isolation among older people? A realist evaluation study. *PloS One*, *16*(9), e0256900. https://doi.org/10.1371/journal.pone.0256900

Hartogh, G. D. (2017). Suffering and dying well: on the proper aim of palliative care. *Medicine, Health Care, and Philosophy*, *20*(3), 413–424. https://doi.org/10.1007/s11019-017-9764-3

Hashem, F., Brigden, C., Wilson, P., & Butler, C. (2020). Understanding what works, why and in what circumstances in hospice at home services for end-of-life care: Applying a realist logic of analysis to a systematically searched literature review. *Palliative Medicine*, *34*(1), 16–31. https://doi.org/10.1177/0269216319867424

Hesse, M., Forstmeier, S., Ates, G., & Radbruch, L. (2019). Patients' priorities in a reminiscence and legacy intervention in palliative care. *Palliative Care & Social Practice*, *13*, 2632352419892629. https://doi.org/10.1177/2632352419892629

Hunter, P. V., McCleary, L., Qiao, T., Sussman, T., Venturato, L., Thompson, G., Wickson-Griffiths, A., & Kaasalainen, S. (2022). Delivering person-centred palliative care in long-term care settings: Is humanism a quality of health-care employees or their organisations? *Ageing & Society*, 1–18. https://doi.org/10.1017/S0144686X22000459

Jackson, S. F., Kolla, G., Sager, F., Munkvold, B. E., & Fritzsche, E. (2012). A new realistic evaluation analysis method: Linked coding of context, mechanism, and outcome relationships. *American Journal of Evaluation*, *33*(3), 339–349. https://doi.org/10.1177/1098214012440030

Jagosh, J. (2020). Retroductive theorizing in Pawson and Tilley's applied scientific realism. *Journal of Critical*

Realism, *19*(2), 121–130. https://doi.org/10.1080/14767430.2020.1723301

Knights, D., Knights, F., & Lawrie, I. (2020). Upside down solutions: Palliative care and COVID-19. *BMJ Supportive & Palliative Care*. https://doi.org/10.1136/bmjspcare-2020-002385

Laskow, T., Small, L., & Wu, D. S. (2019). Narrative interventions in the palliative care setting: A scoping review. *Journal of Pain & Symptom Management*, *58*(4), 696–706. https://doi.org/10.1016/j.jpainsymman.2019.06.009

Macleod, F., Storey, L., Rushe, T., & McLaughlin, K. (2021). Towards an increased understanding of reminiscence therapy for people with dementia: A narrative analysis. *Dementia (London, England)*, *20*(4), 1375–1407. https://doi.org/10.1177/1471301220941275

Malcolm, C., & Knighting, K. (2022). A realist evaluation of a home-based end of life care service for children and families: What works, for whom, how, in what circumstances and why? *BMC Palliative Care*, *21*(1), 31. https://doi.org/10.1186/s12904-022-00921-8

Manzano, A. (2016). The craft of interviewing in realist evaluation. *Evaluation*, *22*(3), 342–360. https://doi.org/10.1177/1356389016638615

Maxwell, J. (2012). *A realist approach for qualitative research*. Sage.

Newbury, D. (2013). Diaries and fieldnotes in the research process. *Research Issues in Art Design & Media*, *1*, 1–17. papers://b384f54c-36dc-4b6d-90b9-f041a965aefc/Paper/p137

Östlund, U., Blomberg, K., Söderman, A., & Werkander Harstäde, C. (2019). How to conserve dignity in palliative care: Suggestions from older patients, significant others, and healthcare professionals in Swedish municipal care. *BMC Palliative Care*, *18*(1), 10. https://doi.org/10.1186/s12904-019-0393-x

Parks, J. A., & Howard, M. (2021). Dying well in nursing homes during COVID-19 and beyond: The need for a relational and familial ethic. *Bioethics*, *35*(6), 589–595. https://doi.org/10.1111/bioe.12881

Pawson, R. (2000). Middle-range realism. *European Journal of Sociology*, *41*(2), 283–325. https://doi.org/10.1017/S0003975600007050

Pawson, R. (2013). *The Science of evaluation*. Sage. https://uk.sagepub.com/en-gb/eur/the-science-of-evaluation/book238842

Pawson, R. (2016). The ersatz realism of critical realism: A reply to Porter. *Evaluation*, *22*(1), 49–57. https://doi.org/10.1177/1356389015605206

Payne, S., Harding, A., Williams, T., Ling, J., & Ostgathe, C. (2022). Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): A Delphi study. *Palliative Medicine*, *36*(4), 680–697. https://doi.org/10.1177/02692163221074547

Pearson, M., Brand, S. L., Quinn, C., Shaw, J., Maguire, M., Michie, S., Briscoe, S., Lennox, C., Stirzaker, A., Kirkpatrick, T., & Byng, R. (2015). Using realist review to inform intervention development: Methodological illustration and conceptual platform for collaborative care in offender mental health. *Implementation Science*, *10*, 134. https://doi.org/10.1186/s13012-015-0321-2

Pereira, A., Ferreira, A., Martins, J., & Barbieri-Figueiredo, M., C. (2018). Nursing theories in palliative care investigation: A review. *Hospice & Palliative Medicine International Journal*, *2*(4), 231–234. https://doi.org/10.15406/hpmij.2018.02.00097

Pino, M., Doehring, A., & Parry, R. (2021). Practitioners' dilemmas and strategies in decision-making conversations where patients and companions take divergent positions on a healthcare measure: An observational study using conversation analysis. *Health Communication*, *36*(14), 2010–2021. https://doi.org/10.1080/10410236.2020.1813952

Pino, M., & Land, V. (2022). How companions speak on patients' behalf without undermining their autonomy: Findings from a conversation analytic study of palliative care consultations. *Sociology of Health & Illness*, *44*(2), 395–415. https://doi.org/10.1111/1467-9566.13427

Scott, R., Goossensen, A., Payne, S., & Pelttari, L. (2021). What it means to be a palliative care volunteer in eight European countries: a qualitative analysis of accounts of volunteering. *Scandinavian Journal of Caring Sciences*, *35*(1), 170–177. https://doi.org/10.1111/scs.12832

Sévigny, A., Dumont, S., Cohen, S. R., & Frappier, A. (2010). Helping them live until they die: Volunteer practices in palliative home care. *Nonprofit & Voluntary Sector Quarterly*, *39*(4), 734–752. https://doi.org/10.1177/0899764009339074

Sharp, L. A. (2022). Death and dying in carceral America: The prison hospice as an inverted space of exception. *Medical Anthropology Quarterly*, *36*(2), 177–197. https://doi.org/10.1111/maq.12688

Shiells, K., Pivodic, L., Holmerová, I., & Van den Block, L. (2020). Self-reported needs and experiences of people with dementia living in nursing homes: A scoping review. *Aging & Mental Health*, *24*(10), 1553–1568. https://doi.org/10.1080/13607863.2019.1625303

Sinclair, S., Beamer, K., Hack, T. F., McClement, S., Raffin Bouchal, S., Chochinov, H. M., & Hagen, N. A. (2017). Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. *Palliative Medicine*, *31*(5), 437–447. https://doi.org/10.1177/0269216316663499

Sinclair, S., Kondejewski, J., Jaggi, P., Roze Des Ordons, A. L., Kassam, A., Hayden, K. A., Harris, D., & Hack, T. F. (2021). What works for whom in compassion training programs offered to practicing healthcare providers: A realist review. *BMC Medical Education*, *21*(1), 455. https://doi.org/10.1186/s12909-021-02863-w

Söderman, A., Östlund, U., Werkander Harstäde, C., & Blomberg, K. (2020). Dignity-conserving care for persons with palliative care needs – Identifying outcomes studied in research: An integrative review. *Palliative & Supportive Care*, *18*(6), 722–740. https://doi.org/10.1017/S1478951520000139

Stewart-Lord, A., Baillie, L., Green, L., Murphy, F., & Leary, A. (2022). Implementation and perceived impact of the SWAN model of end-of-life and bereavement care: A realist evaluation. *BMJ Open*, *12*(12), e066832. https://doi.org/10.1136/bmjopen-2022-066832

Synnes, O. (2015). Narratives of nostalgia in the face of death: The importance of lighter stories of the past in palliative care. *Journal of Aging Studies*, *34*, 169–176. https://doi.org/10.1016/j.jaging.2015.02.007

Taghinezhad, F., Mohammadi, E., Khademi, M., & Kazemnejad, A. (2022). Humanistic care in nursing:

Concept analysis using Rodgers' evolutionary approach. *Iranian Journal of Nursing & Midwifery Research*, *27*(2), 83–91. https://doi.org/10.4103/ijnmr.ijnmr_156_21

van der Steen, J. T., Bloomer, M. J., & Martins Pereira, S. (2022). The importance of methodology to palliative care research: A new article type for Palliative Medicine. *Palliative Medicine*, *36*(1), 4–6. https://doi.org/10.1177/02692163211069566

Vanderstichelen, S. (2022). Palliative care volunteering: Pressing challenges in research. *Palliative Medicine,36*(4), 564–566. https://doi.org/10.1177/02692163221089483

Vanderstichelen, S., Cohen, J., Van Wesemael, Y., Deliens, L., & Chambaere, K. (2020). The liminal space palliative care volunteers occupy and their roles within it: A qualitative study. *BMJ Supportive & Palliative Care*, *10*(3), e28–e28. https://doi.org/10.1136/bmjspcare-2018-001632

Walshe, C., Garner, I., Dunleavy, L., Preston, N., Bradshaw, A., Cripps, R. L., Bajwah, S., Sleeman, K. E., Hocaoglu, M., Maddocks, M., Murtagh, F. E., Oluyase, A. O., Fraser, L. K., & Higginson, I. J. (2021). Prohibit, protect, or adapt? The changing role of volunteers in palliative and hospice care services during the COVID-19 pandemic: A multinational survey (Covpall). *International Journal of Health Policy & Management*, *11*(10), 2146–2154. https://doi.org/10.34172/ijhpm.2021.128

Wong, G., Westhorp, G., Greenhalgh, J., Manzano, A., Jagosh, J., & Greenhalgh, T. (2017). Quality and reporting standards, resources, training materials and information for realist evaluation: The RAMESES II project. *Health Services & Delivery Research*, *5*(28), 1–108. https://doi.org/10.3310/hsdr05280

Zheng, R., Guo, Q., Chen, Z., & Zeng, Y. (2021). Dignity therapy, psycho-spiritual well-being and quality of life in the terminally ill: Systematic review and meta-analysis. *BMJ Supportive & Palliative Care*, *13*(3), 263–273. https://doi.org/10.1136/bmjspcare-2021-003180