The impact on emotional well-being: experiences of being a palliative care volunteer.

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Statement of word count

	Text word	Appendices (including references, tables and figures)	Total
Thesis abstract	269	-	269
Literature review	7,641	13,040	20,681
Research paper	7,997	11,767	19,764
Critical appraisal	4,041	848	4,889
Ethics section	4,371	3,522	7,893
Total	24,319	29,177	53,496

Thesis Abstract

The impact of palliative and end-of-life care volunteers' roles in relation to their emotional well-being is explored in this thesis. Firstly, a systematic review and thematic synthesis on the emotional experiences of being a palliative care volunteer provides an overview of existing research. The thematic synthesis employed an iterative three-stage synthesis of 22 included papers. Themes identified include intrinsic and extrinsic challenges, personal gain and the development of relationships. Volunteers face unique challenges; however, they also experience a number of positive impacts on their emotional well-being. It is important to monitor how volunteers cope and provide appropriate support. Few papers focus directly on the emotional experiences of volunteers and a need for research that explores these experiences is highlighted. Secondly, an interpretative phenomenological analysis study was conducted exploring the impact of hospice volunteers' roles in relation to their emotional well-being. Ten participants were recruited across three hospices and data were collected via semi-structured interviews. Data were analysed using interpretative phenomenological analysis and four themes were developed: (1) it can be challenging; (2) it's where I'm meant to be; (3) managing death; (4) the importance of connection. Although there are psychosocial benefits for volunteers in their role, considering challenges is important to ensure that support is provided to help volunteers manage these challenges. Thirdly, a critical appraisal: a reflection on the experience of conducting the thesis, focusing on ideas for future research, boundaries and other areas of concern or interest throughout. This thesis highlights the need for more research into the emotional experiences of palliative and end-of-life care volunteers and indicates value in implementing formal support for volunteers.

Declaration

This thesis records research undertaken for the Doctorate in Clinical Psychology course at the Division of Health Research at Lancaster University from June 2019-May 2020. The work presented is the author's own except where reference is made. The work has not been submitted for the award of any higher degree elsewhere.

Acknowledgements

I would like to thank the hospices and volunteers who showed an interest in this research as, without them, I would have been unable to complete the research. I thoroughly enjoyed listening to volunteers' experiences about their role within palliative care and admired their strength and care for others.

I would also like to thank my supervisors Professor Catherine Walshe who has been there throughout the process with guidance, knowledge and encouragement and to Dr Andy Thomas who first sparked my interest in palliative care and provided me with a wonderful placement. I will forever be grateful to you both.

Thank you to my mentor, Dr Hannah Wilson, who has provided me with a safe space over the last three years to grow. Thank you to my friends from the course, particularly Mimi, for providing me with humour, friendship and reassurance. Thank you to my mum, Rosemary, for being a fantastic proof-reader and always being at the end of the phone. Finally, I would like to thank my partner, Brad, whose unwavering love, patience and support got me through not only the thesis but the entire DClinPsy. With you, anything is possible.

I dedicate this thesis to my late Grandad whom I told on his deathbed that I would, one day, become a Clinical Psychologist. You always called me 'Miss Ology'. I hope you are proud – Derric David Marsh 22/03/1920 – 08/08/2011.

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Section One: Literature Review

What are the emotional experiences of being a volunteer in palliative and end-of-life care settings? A systematic review and thematic synthesis.

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Prepared in accordance with the 'instructions to authors' for Palliative Medicine

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What are the emotional experiences of being a volunteer in palliative and end-of-life care settings? A systematic review and thematic synthesis.

Abstract

Background: Previous research has focused on paid staff within palliative care, however volunteers in patient-facing roles are exposed to similar stressors. Volunteers increasingly provide emotional support to patients and families but receive little formal support for themselves. It is important to understand volunteers' emotional experiences of their role to identify strategies that could be implemented to support them effectively.

Aim: To synthesise qualitative data on the emotional experiences of being a volunteer in palliative and end-of-life care settings, including how people cope with this role and how they can be best supported.

Design: A thematic synthesis design was selected, an iterative three-stage synthesis, including line-by-line coding, organising this into descriptive themes and then developing analytical themes.

Data sources*:* Four databases (PsycInfo, CINAHL, MEDLINE and EMBASE) were searched in November 2019. The Critical Appraisal Skills Programme was used to evaluate the included papers.

Results: From the 22 studies, the results indicate four themes across the studies: (1) intrinsic challenges; (2) extrinsic challenges; (3) personal gain; and (4) developing relationships. Challenges included personal feelings related to their role for example uncertainty, not being 'good enough' and feeling drained as well as frustrations within the palliative care system.

Conclusions: Volunteers face unique challenges but also positive impacts that can affect their emotional well-being. It is important to monitor how volunteers are coping and provide appropriate support.

Keywords: qualitative research, hospices, hospice care, terminal care, palliative care, volunteers

Key statement

What is already known about the topic?

- Research has focused on the emotional experiences of paid staff in palliative care but has not explored the emotional experience of volunteers.
- Volunteers provide emotional support to patients but receive little formal support themselves.

What this paper adds

- An insight into the positive and negative emotional experience of palliative care volunteers in relation to their role. For example, the impact of intrinsic and extrinsic challenges, personal gains and the development of relationships.
- An understanding of the unique intrinsic and extrinsic challenges faced by volunteers in palliative care in relation to emotional well-being, such as feelings on uncertainty, not being 'good enough', feeling drained and frustrations with the palliative care system.

Implications for practice, theory or policy

- It is important to monitor how volunteers are managing within their role and provide appropriate support.
- It highlights the need for future research to focus on: the specific impacts of the role on volunteers' emotional well-being and explore what volunteers would find useful to support them in their role.

Introduction

Palliative care volunteers are individuals who give their time to support the running of end-of-life care in a variety of settings including hospices, hospitals and in the community. They often offer support in administration, fundraising and in patient-facing roles(1). Palliative care volunteers are needed worldwide due to the number of people requiring end-of-life care in a variety of settings. Globally, deaths due to noncommunicable diseases are currently predicted to increase: for example annual deaths due to cardiovascular diseases are estimated to rise from 17.5 million in 2012 to 22.2 million in 2030, whilst annual mortality due to cancer is likely to rise from 8.2 million to 12.6 million(2). This has implications for healthcare providers, including hospices, as many deaths are preceded by a period of progressive decline and chronic illness(3) and these individuals could benefit from end-of-life care during their period of illness(4). The rise in the ageing population and the need for palliative care indicates that volunteers will continue to be integral in supporting patients at the end of life as they offer a different and complementary service to that of paid staff. For example, they are able to spend more time with patients, focusing on psychosocial needs. There are over 125,000 volunteers in hospices throughout the UK(5) with one-point-five volunteers to every paid member of staff(1), however there are insufficient data on the number of volunteers in each role, for example administrative, fundraising, inpatient and day therapy unit volunteers(6). The value of their involvement is projected to be over £200 million annually(5). They are estimated to reduce UK hospice costs by 23% indicating a financial benefit for hospices to recruit and retain volunteers(7). For effective retainment of volunteers, and to promote a positive volunteering environment, emotional well-being needs to be considered to ensure they are content and have effective resources to manage within their role.

The emotional impact of working in palliative care settings for paid staff includes risk of burnout, stress and an impact on general emotional wellbeing(8). Although volunteers are exposed to similar stressors within palliative care, literature reviews have not focused on volunteers' emotional responses or considerations of support that could be implemented to assist in coping with their role. Recent literature reviews have focused on the contribution of volunteers' services to end-of-life care(9), personality traits(10), stressors(11), understanding the role of volunteers and exploring the distinction between paid staff and volunteers(1), the benefit of volunteers on patients and their families(12) and examining volunteers' experiences of being in inpatient hospital settings(13). However, to the author's knowledge, there have been no literature reviews focusing exclusively on the emotional experience of being a palliative care volunteer. Research on palliative care volunteers that focused on other areas mentioned the volunteers' emotional experiences. This led to an interest in exploring further and synthesising research including elements of palliative care volunteers' emotional experiences in relation to their role.

Although palliative care volunteers are present in a number of different settings, the current review focuses on those who have actively chosen to volunteer within palliative and end-of-life settings such as hospices (both inpatient and in the community) or hospital wards dedicated to such care in patient-facing roles. This population has been found to volunteer for a number of reasons including personal gain, altruism, civic responsibility and leisure(14). The volunteer role has developed over the years with more volunteers in patient-facing roles leading to an increase in hospice interest in developing these roles further(9). Volunteers are increasingly providing emotional care to patients and families, with 86% of hospices reporting that volunteers provide emotional care in inpatient settings(15). Volunteers providing emotional care is also common within community settings, with 68% of hospices

surveyed reporting that volunteers are involved in counselling(15). Irrespective of whether individuals were volunteering their professional skills, counselling can be an emotionally demanding role and, without appropriate support and supervision, could negatively impact volunteers. Volunteers may also be with patients and families at the end of life, supporting them in a challenging time.

Conducting a qualitative literature review and thematic synthesis could provide a rich and more in depth understanding on hospice volunteers' emotional experiences related to the role and more understanding of their beliefs and attitudes in relation to their role. The findings could have an impact on future research and interventions for hospice volunteers, reflecting their importance in the running of hospices. The findings of this review could also be useful for clinical psychologists working within hospices and highlight areas of development that could support hospice volunteers. The current input of clinical psychologists supporting volunteers is minimal, although they are becoming increasingly involved in supporting paid staff within hospice settings through the development of reflective practice groups and supervision. This indicates that clinical psychologists would be well placed to consider implementation of support or supervision for volunteers.

Methods

Aims

This review aims to synthesise the current qualitative data on palliative care volunteers' emotional experiences of their role and how they manage this. Therefore, the review seeks to answer the following research question, "What are the emotional experiences of hospice volunteers in relation to their role and how do they manage this?".

Design

A thematic synthesis design(16) was selected. This approach emulates thematic analysis within empirical research and includes both the author's and participants' interpretations of a particular experience. Thematic synthesis is an iterative three-stage synthesis including line-by-line coding, organising this into descriptive themes and then developing analytical themes. The researcher adopted a critical realist position, ontologically realist and epistemologically relativist(17). This indicates that the data obtained does not lead to direct access of reality, but that individuals' perceptions and beliefs affect their understanding of reality(17).

Search strategy

The research tool SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type)(18) was used to identify key parts of the research question and assisted in structuring the search strategy (see table 1)[1]. Other tools, such as PICO (Population/problem, Intervention/exposure, Comparison and Outcome)(19) are more suited to quantitative reviews. The SPIDER tool was developed to assist with qualitative and mixed method research(18) and was deemed most appropriate to use for the current review.

[1] Although standard DClinPsy theses are instructed to insert tables at the end of the paper, in accordance with advice from my supervisor and the journal guidelines, tables have been embedded within the text. This was also agreed with the DClinPsy Research Director.

Table 1. ‘SPIDER’ tool(18)

SPIDER Terms	Search Concepts
S – Sample	Volunteers
PI – Phenomenon of Interest	Hospices / end-of-life care
D – Design	Qualitative research methodology
E – Evaluation	Evaluating the experiences of the impact of volunteers’ roles of emotional well-being
R – Research Type	Qualitative Research

Inclusion and exclusion criteria

See table 2 for inclusion and exclusion criteria.

Table 2. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
▪ Peer review publications ▪ Published in English (due to lack of time and resources for translation) ▪ No date restrictions ▪ Reports primary research Participants ▪ Palliative / end-of-life volunteers in adult settings ▪ Should have experience of volunteering in palliative / end-of-life care Focus ▪ Palliative care (synonyms: end-of-life care, end-of-life care, hospice care, supportive care, terminal care) ▪ May include volunteers working with adult patients with any terminal diagnosis (not limited to cancer) ▪ Any settings (e.g. hospital, hospice, community) Data ▪ Data about the volunteers' emotional experience of interacting with patients whilst doing their role including direct reference to primary and secondary emotions, reference to cognitive appraisal and meaning-making of emotions and emotional experiences and how emotions are managed ▪ Data about the palliative care volunteer can be extracted separately from data relating to other groups such as clinicians and patients	▪ Not primary research ▪ Publication refers to mixed adult and paediatric patient populations, where data related to volunteers working in adult services cannot be extracted separately ▪ Research about those who volunteer their time to enact a role for which they are professionally qualified (e.g. complimentary therapists, qualified counsellors). ▪ Data focused on the recruitment and training of volunteers ▪ Data focused on the volunteers' interaction with paid staff

Data sources

"MEDLINE", "EMBASE", "CINAHL" and "PsycINFO" electronic databases were searched in November 2019. These databases were thought to be the most suitable for the research topic and most likely to identify relevant papers. A psychology subject librarian was consulted and agreed the final search strategy. There were no date restrictions. A hand-search of references from the selected studies was also conducted.

Electronic search strategy

See table 3 for the full-text search and database subject terms. Papers were exported onto a bibliography manager, Endnote (Version X9), and 1029 duplicates were removed. The titles and abstracts of the remaining papers were read and, if unsure of the suitability of a paper, the full text was read. A quarter of the papers were checked by the research supervisor to confirm that papers met the inclusion criteria.

Table 3. Free search terms and database subject terms.

SPIDER Terms	Free Search Terms	Database Subject Terms
S – Sample	Volunteer* OR ((voluntary N3 (work* or care* or service* or support* or involvement or health* or hospice* or palliative or help* or counsel* or staff or personnel or provider* or group* or organi#ation* or association* or agenc* or communit* or network* or sector* or program*))) provider* or group* or organi#ation* or association* or agenc* or communit* or network* or sector* or program*)))	**PsycINFO**: DE volunteers **CINAHL:** MH “volunteer workers”, MH “volunteer experiences”, MH “voluntary health agencies” **MEDLINE**: MH "Volunteers" OR MH "Hospital Volunteers", MH "Voluntary Health Agencies" **EMBASE:** “hospital auxiliar” [MESH]

PI – Phenomenon of Interest	Palliative OR (Terminal* N3 (care or patient) OR terminal* or endstage or "end stage" or "advanced stage" or "late stage" or "last stage" or "final stage") N3 (ill* or disease* or cancer*)) OR AB ((terminal* or endstage or "end stage" or "advanced stage" or "late stage" or "last stage" or "final stage") N3 (ill* or disease* or cancer*)) OR dying OR end of life OR hospice OR bereavement OR bereaved	**PsycINFO:** DE hospice, DE terminal cancer, DE terminally ill patients, DE palliative care **CINAHL**: MH “palliative care”, MH terminal care, MH “hospice care”, MH “hospice and palliative nursing”, MH “bereavement”, MH “grief”, MH “hospices”, MH “hospice patients” **MEDLINE**: MH “palliative care”, MH “terminal care”, MH “hospice care”, MH “hospices”, MH “bereavement” **EMBASE:** “bereavement counselling” [MESH] OR “hospice nursing” [MESH] OR “hospice care” [MESH] OR terminal disease [MESH] OR “terminally ill patient” [MESH] OR “palliative nursing” [MESH] OR “palliative therpay” [MESH]

DER – Design, Evaluation, Research Type	"qualitative" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR "perceive*" OR "perspective*" OR "view*" OR "experience" or "opinion*" OR "belie* OR "attitude*" OR "feel*" OR "know*" OR "understand*" OR “qualitative analysis” OR “qualitative research”	**PsycINFO**: DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured Interview" OR DE "Thematic Analysis") AND (DE "Interviews" OR DE "Focus Group Interview" OR DE "Intake Interview" OR DE "Interview Schedules" OR DE "Job Applicant Interviews" OR DE "Psychodiagnostic Interview" OR DE "Semi-Structured Interview" OR DE "Data Collection" OR DE "Focus Group Interview" OR DE "Interview Schedules" OR DE "Semi-Structured Interview" OR DE "Interviewing")) OR (DE "Phenomenology")

CINAHL: (MH "qualitative studies") OR (MH "focus groups") OR (MH "content analysis") OR (MH "constant comparative method") OR (MH "thematic analysis") OR (MH "grounded theory") OR (MH "ethnographic research") OR (MH "phenomenological research") OR (MH "semantic analysis")

MEDLINE: MH "Qualitative Research+"

EMBASE: “perception$”[MESH] OR “satisfaction/” [MESH], or “satis$”[MESH], or “value$” [MESH], or “perceive$[MESH], or “psychological aspect/”[MESH], or “perspective$”[MESH], or “view$”[MESH], or “personal experience/”[MESH], or “experience$”[MESH], or “health care need/”[MESH], or “need$” [MESH], or

	“human needs/”[MESH], or “issue$”[MESH],. or “medical ethics/”[MESH], or “opinion$”[MESH], or “attitude/”[MESH], or “health belief/”[MESH], or “attitude$”[MESH], or “belie$”[MESH], or “feel$”[MESH], or “know$” or “understand$”

Critical appraisal

Initially, Thomas & Harden's critical appraisal(16) was considered, however a rating system was unclear from their papers so the Critical Appraisal Skills Programme (CASP)(20) was selected to assess strengths and weaknesses of the studies. This has also been used in other papers which followed Thomas & Harden's method of analysis(1). The CASP covers ten areas and the initial two questions identify papers which are unsuitable. The remaining questions cover design, sampling, data collection, the relationship between the participant and researcher, ethical issues, data analysis, findings and value of the research which generates an overall score. The rating system was a three-point system with strong evidence being given three points; moderate evidence being given two points; and weak evidence being given one point. The scores ranged from 12 to 22 (see table 4). One quarter of the papers were evaluated by the research supervisor to assess congruence with the appraisal of included papers. The ratings of papers corresponded between reviewers which enabled a final rating to be agreed. It was decided that papers would not be excluded based on their reported quality as this could exclude relevant papers based on the reporting of the research rather than the research itself(21). Quality appraisal is a contested area in qualitative synthesis as structured approaches to quality appraisal do not necessarily achieve more agreement between reviewers(22). It was still deemed important to conduct a quality appraisal as this meant more weight could be given to findings from higher quality research.

Table 4. Critical Appraisal Skills Programme

Study	Authors	Research Design	Recruitment Strategy	Data Collection	Relationship with the researcher	Ethical Issues	Data Analysis	Findings	Value of Research	Total Score
S1	Akintola	2	2	3	1	1	2	3	3	17
S2	Andersson & Öhlén	3	3	3	1	3	3	3	3	22
S3	Azuero et al.	3	3	3	1	1	3	3	3	20
S4	Beasley et al.	2	3	2	2	2	3	3	3	20
S5	Berry & Planalp	2	3	3	1	2	2	2	3	18
S6	Brown(28)	2	3	3	1	2	2	3	3	19
S7	Brown(24)	2	3	3	1	2	2	3	3	19
S8	Claxton-Oldfield & Claxton-Oldfield	2	3	3	1	1	1	2	2	15

S9	Claxton-Oldfield & Claxton-Oldfield	2	2	2	1	1	1	1	2	12
S10	Claxton-Oldfield, McCaffrey-Noviss & Claxton-Oldfield	2	2	1	1	1	1	1	3	12
S11	Dean & Willis	1	2	2	1	2	2	3	3	16
S12	Dein & Abbas	3	3	2	2	2	2	1	3	19
S13	Delaloye et al.	2	2	3	2	1	3	3	3	19
S14	Elliott & Umeh	3	2	2	2	2	3	2	3	21
S15	Foster	2	3	3	2	2	1	1	1	15
S16	Guirguis-Younger & Grafanaki	3	3	2	2	2	3	3	3	21

S17	Planalp, Trost & Berry	2	2	2	1	1	1	3	2	14
S18	Söderhamn, Flateland, Fensli & Skaar	3	3	3	1	2	3	3	3	21
S19	Supiano, Cloyes & Berry	3	2	3	1	1	3	3	3	19
S20	White & Gilstrap	2	3	3	1	2	3	3	3	20
S21	Weeks & MacQuarrie	3	3	2	1	2	3	3	3	20
S22	Wee, Coleman Hillier & Holgate	3	2	3	1	1	2	3	2	17

Data extraction

Data were extracted and inputted into a summary table which included author, year, country, research question/aim, sample, design, data collection method(s) and findings (table 5). Where a study had data from volunteers and paid staff, only data related to volunteers was extracted. NVivo, the data analysis computer software, was used to assist in data extraction and analysis.

Table 5. Summary information of the selected papers

Author, year, country	**Research question/aim**	**Design and data collection**	**Participants**	**Findings**
Akintola (2010) South Africa	To explore the perception of rewards among volunteers working in home-based care settings.	Qualitative, interviews	Sample: n=55 Gender: female n=53, male n=2 Age: 19-55 Setting: community	Participants described intrinsic and extrinsic rewards. Extrinsic rewards included appreciation and recognition from patients and others within the community.
Andersson & Öhlén (2005) Sweden	To understand what it means to be a hospice volunteer in a country without a tradition of hospice or palliative volunteer care services.	Phenomenology, narrative interviews	Sample: n=10 Gender: female n=9, male n=1 Age: 30-70 Setting: hospice	Volunteers needed to be affirmed as a caring person. Positive encounters with a hospice are closely related to personal growth.

Azuero, Harris, Allen, Williams, Kvale, & Ritchie (2014) United Kingdom	To explore the experience of volunteers on teams. Initially a grassroots movement in response to stigmatised and socially isolated people with HIV/AIDS.	Qualitative, semi-structured interviews	Sample: n=12 Age: 40-62 Sex: female n=9, male n=3 Setting: unknown	Volunteers discussed balance between positive life meaning gained from volunteering, lessons learned and negative aspects of a volunteer team approach.
Beasley, Brooker, Warren, Fletcher, Boyle, Ventura, & Burney (2015) Australia	To investigate the lived experience of volunteers involved in a biography service.	Qualitative, semi-structured interviews	Sample: n=10 Gender: females n=9, male n=1 Age: unknown Setting: biography service in private palliative care	Volunteering gave participants a deeper appreciation of existential issues and helped them to be more appreciative of their own lives.

Berry & Planalp (2009) United States	To explore ethical issues hospice volunteers confront in their work.	Qualitative, interviews	Sample: n=39 Age: average 64 Gender: 76% female Setting: hospice	Themes included dilemmas about gifts, patient care and family concerns, issues about roles and boundaries and issues about suicide and hastening death.
Brown (2011a)(28) United Kingdom	To examine the coping techniques used by hospice volunteers.	Phenomenological, a brief 1-page questionnaire and a semi-structured individual interview	Sample: n=15 Age: 27-80 Gender: male n=4, female n=11 Setting: hospice	Volunteers used problem-focused coping, emotion-focused coping, meaning-making through appraisal and physical techniques.
Brown (2011b)(24) United Kingdom	To explore the interpretation of stress, the appraisal of the	Phenomenological,	Sample: n=15 Age: 27-80	Hospice volunteers did not perceive their work as stressful but there were challenging

	stressors and the top stressors experienced by hospice volunteers.	a brief 1-page questionnaire and a semi-structured individual interview	Gender: men n=4, female n=11 Setting: hospice	experiences such as hospice-related issues and personal issues.
Claxton-Oldfield & Claxton-Oldfield (2007) Canada	To examine the impact of hospice palliative care work on volunteers' lives.	Qualitative, in-depth interviews	Sample: n=23 Age: 28-85 Gender: 78% female, 22% male Setting: Hospital and community based	Most volunteers felt they were different now or had been changed in some way since volunteering. They also discussed doing a number of things to prevent compassion fatigue or burnout.
Claxton-Oldfield & Claxton-Oldfield (2012)	To explore what volunteers consider to be the most and least	Qualitative, informal interview-style	Sample: n=41 Gender: male n=7, females n=34	Feeling appreciated gave them great satisfaction. Boundary issues/ role ambiguities were the least satisfying.

Canada	satisfying aspects of their work and identify the reasons why volunteers might decide to leave.	group discussions	Age: 30-83 Setting: community and hospital-based	
Claxton-Oldfield, McCaffrey, Noviss & Hicks (2018) Canada	To explore how to engage male volunteers in hospice palliative care.	Qualitative , Study 1: Focus groups	Study 1: n=4, Gender: male n=4, ages ranged from 63-76 Setting: hospice community based	Study 1: Men agreed a direct approach is best.
Dean & Willis (2017) United Kingdom	To explore the views of UK inpatient hospice volunteers regarding initial training for role preparation.	Qualitative, focus groups	Focus group one: n=10, Gender: female n=10 age ranged from mid-30s to 70s Focus group two: n=7	Volunteers perceived initial training as important to increase confidence and suggested several areas where additional training would be useful.

			Gender: female n=3, male n=4 Age ranged from mid-30s to 80s Setting: hospice inpatient unit	
Dein & Abbas (2005) United Kingdom	To examine the stresses associated with hospice volunteering, ways of coping and perception of support.	Qualitative, focus groups	Focus group one: n=10 Gender: female n=10 Focus group two: n=7 Gender: female n=5, male n=2 Setting: hospice	Stressors included losing patients and dealing with disfigurement.

Deloloye et al., (2015) Switzerland	To describe the experience of volunteers trained in palliative care in the context of a primary care hospital.	Qualitative, semi-structured questionnaire	Sample: n=19 Age: 40-73 Gender: female n=16, male n=3 Setting: hospital	Main difficulties were related to uncertainty of the context.
Elliott & Umeh (2013) United Kingdom	To examine the psychological experiences of volunteer carers in a UK hospice.	Qualitative, interviews	Sample: n=9 Age: 21-82 Gender: female n=5, male n=4 Setting: hospice	Motivation to volunteer, volunteering skills, psychological support and holistic care, positive perceptions of the hospice and performance hinderances were important to participants.
Foster (2002) United States	To examine volunteer-patient relationships and communication at the end of life.	Narrative ethnography, two individual interviews and	Sample: n=9 Setting: hospice	It is crucial for hospice volunteers to pay close attention to the relational dimensions of communication with hospice patients and families, but they tend to do so on an instinctive level.

		small group interviews		
Guirguis-Younger & Grafanaki (2008) Canada	To explore the rewards, challenges and unique commitments that define the experience of a palliative care volunteer.	Focus group methodology, focus groups	Focus group 1: n=7 Gender: male n=2, females n=5 Setting: acute care hospital-based Focus group 2: n=6 Gender: female n=6 Setting: freestanding community-funded hospice	Volunteers identified freedom of choice and the ability to use their natural gifts as important for satisfaction. They also felt emotional resilience as important. They also felt they needed to have a balanced perspective.

			Focus group 3: n=4 Gender: female n=4 Setting: shelter-based hospice	
Planalp, Trost & Berry (2011) United States	To understand what types of conversations volunteers considered to be especially meaningful.	Qualitative, interviews	Sample: n=26 Setting: hospice	General categories of meaningful conversations were where patients shared life stories, talked about religion and life after death, discussed their families, unfinished business, loss of capacities and shared common interests with volunteers.
Soderhamn, Flateland, Fensli & Skaar (2017) Norway	To describe a group of trained and supported volunteers' lived experiences as volunteers in palliative care within	Descriptive phenomenological approach, interviews	Sample: n=9 Gender: female n=6, male n=3 Age: mid-20s – mid-70s	Volunteers among seriously ill or dying people play an independent and important role in the palliative care team.

	the community health care services.		Setting: palliative care within community healthcare settings	
Supiano, Cloyes & Berry (2014) United States	To investigate the experiences of inmate hospice volunteers with death to illuminate grief processes.	Qualitative descriptive inquiry, interviews	Sample: n=36 Gender: male n=36 Setting: prison hospice	Volunteers could make sense of previous experiences with death to become responsive to the suffering of dying inmates. Volunteers could sense-make death and articulated growth and stamina in caregiving.
White & Gilstrap (2017) United States	To understand communicative challenges experienced by home hospice volunteers when attempting to articulate their role to hospice	Qualitative, in-depth semi-structured interviews	Sample: n=38 Gender: female n=25, male n=13 Age: 21-86 Setting: home hospice	Role articulation inhibits volunteers from communicating the full scope and relevance of role experience

	outsides and how they manage this.			
Weeks (2012) Canada	To better understand how to recruit, retain and support male volunteers.	Qualitative, interviews	Sample: n=9 Gender: male n=9 Setting: inpatient and community	There were individually based and organisationally based themes.
Wee (2008) United Kingdom	Exploring the impact of hearing the death rattle on hospice staff and volunteers.	Qualitative interpretative approach, focus groups	Sample: n=41 Gender: female n=35, male n=6 Setting: inpatient palliative care services	Most participants expressed negative feelings about the death rattle. The death rattle can have a negative impact on staff and volunteers.

Data analysis

The process of deriving themes was inductive. The lead reviewer coded and analysed papers and subsequently discussed and agreed the findings with the second reviewer.

Stage one

Line-by-line coding of participants' accounts and authors' interpretations were developed through NVivo by the lead reviewer. As new studies were introduced, new codes were developed. Each sentence had at least one code although numerous codes could be used for a sentence. Initial codes were discussed with the team.

Stage two

Codes that appeared to be related were grouped together into more descriptive themes by the team. The original papers were consulted throughout to promote a close alignment with the experiences of participants in the original studies. A more hierarchical structure was introduced to coding, and similarities and differences were considered. A tree structure was developed to organise the themes.

Stage three

This stage involved making links between the descriptive themes from stage two to develop more analytical themes that encompassed hospice volunteers' emotional experiences of their role. This stage moved away from the original findings of the primary studies to develop more understanding and answer the review question.

Results

Selected studies

3732 papers were identified (CINAHL = 588, MEDLINE = 852, PsycInfo = 437, EMBASE = 1855) (see Figure 1). 22 papers were included and were conducted across a number of countries: South Africa (n=1), Sweden (n=1), United Kingdom (n=7), Australia (n=1), United States (n=5), Canada (n=5), Switzerland (n=1) and Norway (n=1). All were published between 2002 and 2018, sample sizes ranged from 4 to 55 and participants were aged between 19 and 86. Studies took place in a variety of settings. Table 4 shows the summary information of the selected studies. The PRISMA flow-chart (see figure 1) highlights the details of the search and screening process.

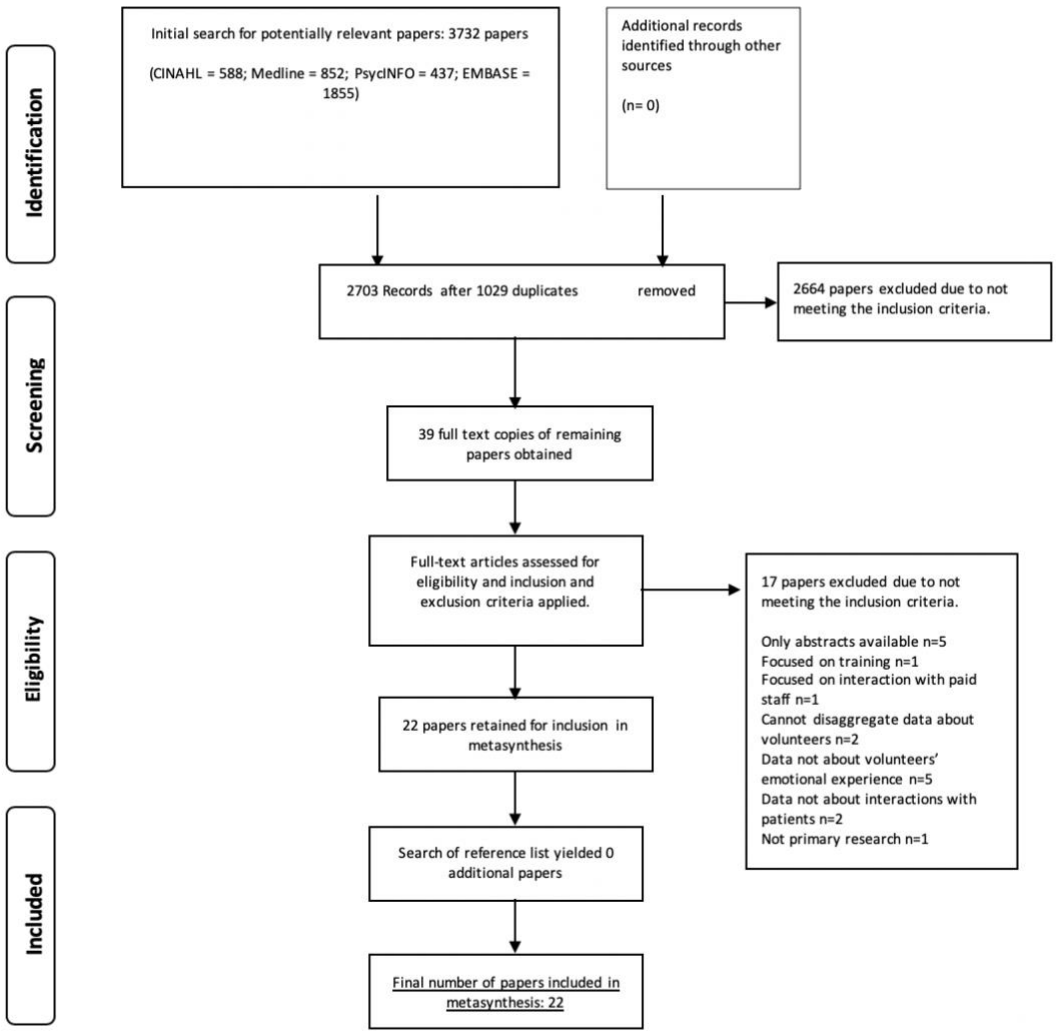

Figure 1. PRISMA Diagram

Derivation of themes

Four themes were developed: intrinsic challenges, extrinsic challenges, personal gain and developing relationships. Table 6 shows the papers relevant to each theme. The themes have more general rather emotional titles. This was appropriate based on the papers reviewed not primarily focusing on emotional experiences and this was reflected in their analysis.

Table 6. Papers relevant to each theme

Theme	Name of theme	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12	S13	S14	S15	S16	S17	S18	S19	S20	S21	S22
1	Intrinsic challenges		x	x	x	x	x	x	x	x		x	x		x	x	x	x	x	x		x	
2	Extrinsic challenges	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x
3	Personal gain	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	
4	Developing relationships		x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	

Theme one: Intrinsic challenges

This theme represents challenges that are related to the individual volunteer and how they felt within their role rather than the wider system of the hospice or challenges perceived to be caused by others. The impact of having conflicting feelings, uncertainty in the role, feelings of not being 'good enough' and feeling drained due to exposure to death will be discussed.

Participants across the studies discussed conflicting feelings in their role for example what they should be doing for patients based on their knowledge and training and how this could differ to their instincts. One participant discussed conflicting feelings in relation to dispensing medication which is something that would usually be deemed outside of a volunteers' role, however they struggled with this due to seeing a patient in pain:

> *"I'm not supposed to be dispensing medication....it was, for me, a very uncomfortable and difficult situation to be in, cause on the one hand, you don't want to watch a human being suffer. On the other hand, it was made very clear to me that, you know, ''this is something you don't do!''"(23) (p.461)*

Participants described a sense of uncertainty within their role and feeling unprepared for what they faced. Although some people felt more general training would be useful to mitigate this uncertainty, others felt it was a role that an individual would settle into with time and that increased training would not necessarily make a difference to feelings of uncertainty:

> *"Two participants suggested that it was not possible to be 'prepared for' every eventuality – some things simply had to be experienced and confidence came with*

time: From my experience I don't think…any amount of training could've prepared you for what you needed to do"(24) (p.281)

Whilst a volunteer is settling into the role, they need to be able to manage some uncertainty, nevertheless it could still be useful to provide a supportive forum once volunteers have been exposed to the realities of the role:

"''Well when I first started, not knowing what to expect was the stress. Not knowing what I was walking in to or how to deal with it, or what to say, was always stressful at the beginning.'' Four of the participants described their first experiences as 'fearful.'"(25) (p.190)

Volunteers could feel uncomfortable and unsure about what to say to patients and this could play on their minds:

"I think about knowing the right thing to say, wondering if I'm going to upset the person I'm talking to, or is this person going to like me?"(26) (p.253)

Volunteers worried about the quality of support they provided to patients and whether they were 'good enough' in their role despite training. This led to feelings of uncertainty and questioning themselves:

"Issues that tilted this balance were related to internal struggle and a sense of insecurity about the adequacy and sufficiency of their efforts, even with the receipt of formal manualized training at the commencement of the volunteer work".(27) (p.291)

As part of volunteers' roles, they have to manage seeing patients near to the end of life and/or dying. Some described feelings of grief in response to the death of patients which is a huge part of their role. If a volunteer continuously struggled with this, it would greatly affect the emotional impact of their role:

> *"The grief experienced by hospice volunteers was occasionally over-whelming. One volunteer noted: It's a part of you gone. It hurt so bad, all you can do is cry…I felt like if you cry too, it's weak. You know, men don't cry. But as I begin in this program, it makes no difference who see me cry. I feel for that person when they leave, but…I did everything I could for him, and he know I was right there".(28) (p.89)*

Experiencing grief and exposure to people at the end of life caused some to feel drained by volunteering due to intrinsic challenges and developing strong relationships with patients:

> *"One participant said she often felt physically drained following a hospice visit and would cope by going home and taking a rest".(29) (p.401)*

> *"It is very draining. The downfall with one-on-one home situations is that you get too attached (Vincent). You do develop a very close deep relationship with the patient and then there is real grief when the patient passes away (Joe)".(30) (p.347)*

Coping with intrinsic challenges

Intrinsic challenges were discussed as an inherent part of the role and volunteers touched upon how they managed these experiences.

> *"Taking time off from volunteering was a strategy mentioned by three volunteers (14%) (e.g., "I stopped for a couple of months because I felt I needed time to regroup.")".(31) (p.261)*

Some felt that these challenges decreased over time, some would temporarily cease volunteering and others would use different coping styles such as praying. It is important that the palliative care setting supports the volunteer in their coping styles.

Theme two: Extrinsic challenges

This theme represents challenges faced by volunteers related to external factors such as resources, what the volunteers see and frustrations within palliative care settings. Many participants described situations that had made them feel uncomfortable, for example patients and families having differing expectations of the volunteer role:

> *"Other care team members struggled with discordance between their understanding of their purpose and the care recipient or family member's perceptions of the volunteer's motives".(27) (p.289)*

Others commented on frustrations with the way the palliative care setting was run, for example not having enough information about patients and a delay in receiving referrals:

"We used to know more about the patients, but it was intruding on their privacy…it's a question of need-to-know, and we don't always know what we need to know"(32) (p.381)

''I got a referral recently and she died the next day''(33) (p.527)

Some volunteers discussed feeling uncomfortable and helpless when family members had conversations in front of patients that could be distressing for the patients:

"…they were fighting, and I could hear them fine, so I knew she (the patient) could hear them fine and that was, that was very upsetting for me. I was sick to my stomach because I had to do something, I mean I was just sitting there, and I was kind of helpless".(25) (p.190)

Others spoke more about feelings of frustration or disappointment at being pushed away by patients:

"I went in there and she started to speak then she just shut her eyes and wouldn't communicate… ..so you walk out thinking 'well I wish I'd known what to do'". (24) (p.281)

Participants in the studies discussed feeling shocked when they saw some patients and how this could negatively affect them as a volunteer. Some felt that they had not been prepared enough by the hospice for what they might see in their role and others identified preparation in this area as very important, indicating the need for more training in this area:

> *"When I went to visit her there, not having seen her for some time I was ever so shocked at how she looked. She was unconscious, but her husband was there and I had to pretend that this wasn't bothering me too much. When I came out, I was absolutely shaking from head to foot".(34) (p.60)*

Other extrinsic challenges discussed by participants were seeing patients suffering. This seemed to really affect some participants and strong emotive language was used to communicate this:

> *"I am traumatised having seen how my patients suffer"(35) (p.6)*

> *"Volunteers in 2 programs said that the thing they liked least about their volunteer work is seeing patients suffering (e.g., ''The suffering .. . some of these people suffer something terrible…you wonder where these people get the strength'')". (33)(p.527)*

Coping with extrinsic challenges

Participants discussed how they managed extrinsic challenges related to their role. There appeared to be a variety of coping mechanisms including talking with volunteer coordinators and other volunteers, leaving the challenging situation, religion and taking time off from volunteering:

> *"That is my main coping skill is to talk without my volunteer coordinator". (29) (p.399)*

> *"Two volunteers said that they prayed or studied the bible to prevent burnout." (31)(p.261)*

Although they identified a number of challenges and stressors within their roles and could discuss how they had managed this, volunteers did not seem to want to categorise these as negative experiences:

> *"Their voluntary work could be difficult at times, as they faced several tough situations, such as seeing a person suffer or watching a young person die. It was painful to experience the reactions that the terminally ill persons and/or their relatives could exhibit at the end of life. However, none of the volunteers characterized such experiences as negative"(36) (p.5)*

It is unclear from the data provided why some volunteers did not categorise some of their experiences as negative. It may be that they also experienced a number of positive aspects to volunteering which could have overshadowed the negative aspects of the experience.

Theme three: Personal gain

This theme focuses on the positive outcomes of volunteering and what this adds to participants' lives. Most participants discussed what they had gained from their role for example feeling useful and appreciated by patients, feeling inspired and rewarded, giving back to others, learning from patients and self-growth. These gains seemed to be motivating factors for continuing to volunteer as well as making the challenges more manageable. Feeling useful to and appreciated by patients and families seemed to be very important to

participants across the studies and was evidenced through receiving positive feedback, the reactions of patients and patients sharing personal information with them:

> *"…they felt joy and satisfaction after performing their duties well and receiving positive responses from patients, relatives and personnel".(37) (p.605)*

> *"Volunteers articulated to others the value of their physical presence with patients by underscoring the immediate and discernible results of their service as evidenced by "see[ing] the look on their [patients'] faces or see[ing] them smile." Thus, self-satisfaction was indelibly linked to their ability to discern impact and appreciation in real-time".(38) (p.575)*

Many spoke of finding their role rewarding thus making their role a positive experience and bringing them satisfaction:

> *"The biggest reward is in the heart…we get as much, or more, out of helping them as they get from us .." (39) (p.1534)*

> *"The volunteers…expressed personal satisfaction and reported that volunteering with the service had given them a sense of purpose and had been very rewarding".(40) (p.1423)*

As participants felt appreciated, useful and rewarded, it makes sense that this brought enjoyment to their time volunteering in palliative care:

"Some participants mentioned psychological gains, such as feeling good about helping others in need or from gaining a different perspective on their own life: 'I know it sounds very prudish, but I do enjoy helping people who need help'"(32) (p.379)

"They took great satisfaction from their work and described it as challenging, rewarding, and useful. These results are consistent with the literature on volunteering in hospice and palliative care".(41) (p.605)

They also spoke about learning from patients and how this could also help to build relationships:

"I think she sees me as a friend, also someone to maybe pass on some of her wisdom, because she has these little pearls she drops occasionally".(26) (p.250)

"Five volunteers noted how much they had learned from patients' life experiences"(42) (p.485)

Overall, it seemed that participants experienced self-growth and general personal development through their role as a volunteer:

"Many of the volunteers indicated that volunteering enabled them to achieve self-growth and personal emotional and psychological development".(35) (p.5)

> *"At every encounter, I have the feeling of gaining insight into human universes, always fascinating and never the same".(41) (p.603)*

Some spoke of gaining more perspective on their own lives and becoming more grateful for what they had:

> *"One participant explained that she would often think about how lucky she was when she found herself in a stressful situation".(29) (p.400)*

Others felt their role had enabled them to become stronger in themselves and cope with more, indicating that they would get better and more comfortable with their role over time:

> *"Emotional resilience was the product of direct personal experience of pain and loss, as well as exposure to death and dying in the volunteer settings".(43) (p.19)*

Many discussed how they had been changed as a person through volunteering:

> *"Nearly all of the volunteers acknowledged that they were different now or had changed in some way as a result of their volunteer experience". (31)(p.262)*

Being changed could be linked to the challenges faced by volunteers but also the personal gains and self-development that comes with the role such as feeling useful, learning from patients and feeling inspired.

Theme four: Developing relationships

Relationships with patients and families were important to participants across the studies and this was discussed in relation to forming close relationships, having appropriate boundaries, understanding the patient's experience and having curiosity and flexibility when working with patients. Although volunteers were not directly involved in patients' medical care, they offered holistic care through spending time with patients, which can support deep connection:

> *"Volunteers come to care deeply about patients and want what is best for them without being able to openly make suggestions".(23) (p.460)*

This could be challenging if volunteers felt as though they had good ideas for things that could enhance a patient's well-being. It seemed that closer relationships would form if the patient and volunteer were alike or held similar values:

> *"We instantly connected because we left out all the bullshit and just connected on a human level…We connect as two women…So, she, I realized, shares the dreams and desires and aspirations that I have. We're sisters under the skin"(26) (p.250)*

Some held clarity about their role in the volunteer-patient relationship and were aware that this would soon end as they were working in palliative care and the patient would die:

> *"There was certainly an agreement that volunteers valued the closeness with dying patients and cherished the experience. This closeness appeared less like an emotional attachment and more like accompanying another on a journey at the end of which parting was inevitable. Volunteers understood that they had to "let go" and that the investment was a unique one. This delicate balance of connections and distance was*

well understood...they acknowledged that the ability to maintain this balance was an essential quality in a volunteer"(43) (p.22)

This enabled the volunteers to protect themselves emotionally from an overwhelming sense of grief when their patient died. However, other volunteers took a different position and felt the connections made would inevitably lead to grief:

"You do develop a very close deep relationship with the patient and then there is real grief when the patient passes away". (30)(p.347)

Although it seems that volunteers had differing views on their role within the patient's life and the level to which they should become emotionally involved, another participant described their views as somewhere in the middle:

"I'm happy and I'm sad. Because I know that the patient, from my belief system, that the patient is on to a better life, a better existence. And it's sad, because the human part of me and the connection that we've made, to see that person go". (28)(p.88)

Due to strong relationships forming, some questioned whether they had become too attached to their patients and that others had also commented on this:

"Karen consequently questioned whether she had become too attached to the patients and their families: "I suppose you do get attached even though you try not to. I know my husband worries about it. He worries about me getting too involved.""(40) (p.1422)

Sometimes this awareness could lead to the development of stronger boundaries with patients, whether that meant being somewhat emotionally removed or spending less time with them. This is important as the role of a volunteer is not always clear to patients with regards to expectations of what they 'should' give:

> *"Issues might be as simple as being asked to stay for longer hours as one might ask of a friend but not of a professional"(23) (p.461)*

Some participants deliberately put up internal barriers as a way of managing the emotional burden of losing a patient:

> *"I don't allow her to climb completely into my heart, and I don't climb completely into hers. There's a certain boundary that I reserve for my own sanity, because I know that she will die eventually"(26). (p.254)*

Close relationships that form between volunteers and patients, can spark a curiosity within volunteers about the patients' health conditions but they do not necessarily need this information:

> *"All the time those questions are there…I wonder what is wrong with him or her. It may be someone you see a lot, others you never see. I haven't felt OK to ask either, since somehow we have got to know that we don't need to know what's up with people'".(37) (p.605)*

A friend or professional would often know what is wrong with someone, however volunteers appear to be in a limbo and do not receive much information which can be challenging. This could be a barrier in developing a close relationship and also requires an understanding that patients will share this information if they wish. Boundaries are important to consider due to maintaining the role of 'volunteer' rather than 'friend'.

Discussion

Main findings

This systematic review focused on the emotional experiences of being a palliative care volunteer and has identified a number of intrinsic challenges such as how the volunteer felt within their role including feelings of uncertainty, not being 'good enough' and feeling drained. Extrinsic challenges were also recognised, including challenges related to external factors such as resources, what the volunteer sees within their role and frustrations with the setting. More positive emotional experiences were also highlighted such as the process of developing relationships with patients and families and the personal gains of volunteering. Personal gains include what volunteering adds to the volunteers' lives, positive feelings initiated by the role (for example, feelings useful, appreciated and inspired) and general self-growth. It is clear that the role of a volunteer is different to that of paid staff. Although challenges faced by volunteers sometimes overlap with paid staff, they have unique traits that need to be considered.

What this study adds

Volunteers experienced a number of intrinsic and extrinsic challenges related to their roles thus impacting on their emotional experience of the role. This is concurrent with a review focusing on challenges in volunteering in patient-facing roles within palliative care; it was

found that stressors can include limited emotional support (extrinsic), the need for more training (extrinsic), dealing with the patient's family (extrinsic), dealing with death and dying (intrinsic) and not being able to do more for patients linking to one of the intrinsic challenges of not feeling 'good enough'(9). There were overlaps in the papers included in the current review. Intrinsic challenges faced by volunteers included feeling drained due to death exposure and other experiences within the hospice. Research in other complex settings outside of palliative care has also found this, with the emotional burden being highlighted and a suggestion that appropriate boundaries can support a volunteer with not getting too involved with a patient living with dementia(44). This was also discussed in the current review with regards to the development of good relationships with the implementation of boundaries to protect both the patient's expectations and the volunteer. Other challenges included not feeling 'good enough' or that they were not doing enough for their patient. Similar challenges are also highlighted in the befriending literature where volunteers felt a sense of guilt or anxiety that they were not doing enough(44). They also reported not always knowing what to say to patients which could result in them feeling uncomfortable(45).

Coping with intrinsic and extrinsic challenges within the volunteers' role was central. Coping is an individual's attempt to manage or reduce external and internal demands(46). The volunteers had a number of different coping strategies to draw upon including talking with volunteer coordinators, leaving the situation they found challenging, religion and taking time away from volunteering. These findings are supported in other reviews which present coping strategies as either problem-focused, emotion-focused or meaning-making through appraisal(9). The development of coping strategies through the palliative care volunteer role can impact the volunteer's wider life as they have experienced personal growth through managing their experiences.

Increased training for palliative care volunteers has been widely discussed throughout the literature(47)(9). This supports the findings in the current review which indicates that more training on ethical issues, death and preparing for patient's dying, managing disfigurement and feelings that might arise could be useful for volunteers. Other reviews have indicated the importance of organisational support in helping people to manage challenges from their workplace(48). Volunteers require a good level of self-care to manage their role(49) therefore training could also be implemented to support volunteers to develop and maintain self-care strategies. Previous research indicates that it is rare for palliative care volunteers to experience burnout or compassion fatigue related to their role, in comparison to paid staff(50). However, there has been little research on compassion satisfaction which is defined as the fulfilment individuals feel when caring for others(51) and is a factor that could offset the risks of burnout(52).

The current review indicates that, although there are a number of challenges for palliative care volunteers, the positive aspects of their role can outweigh the negative: overall the role contributes positively to volunteers' emotional well-being. Resilience in palliative healthcare professionals has been discussed with some indicating that it is where healthcare professionals overcome difficulties(53) whilst others indicate it is more about adapting to these challenging situations(54). Volunteers, similarly to paid staff, manage exposure to death and dying as well as boundary ethical issues regularly within their role, therefore resilience is a key factor that can help volunteers to manage their experiences(55). It is important that volunteers are given the time and space to reflect on their experiences to reduce the likelihood of them coping through emotional detachment, a less adaptive way of coping. This has been shown in palliative care nurses who did not have time to reflect on

their experiences(56). This could support volunteers in fostering resilience. Other strategies that have been shown to be useful for informal caregivers in promoting resilience and effective coping include: developing active coping skills, focusing on positive aspects of caring for others and encouraging the development of personal meaning from their experiences(57). These findings could be useful to consider when setting up further support for volunteers.

Positive aspects of volunteering were also reflected in the wider literature. Personal gain can be viewed as a motivation for continuing to volunteer as this indicates that the volunteers also benefit from giving time to patients as they feel a sense of connection to those that they are spending time with. A number of different motivations have been highlighted throughout the literature and, in support of the current review, appear to be similar across countries and settings(9). Research into volunteering in mental health settings also supports the current findings of volunteers experiencing personal gain from their role, for example, feeling useful, learning from patients and self-growth(58). This is also indicative of feelings of competence within their role. Similarly, peer support volunteers for people with limb loss also experienced positive benefits of volunteering such as feeling a sense of pride, purpose and usefulness(59). These positive aspects of volunteering can be seen as representative of intrinsic motivation from the self-determination theory (SDT) where the individual is inherently interested in their role and enjoys it; competence and relatedness have been highlighted above and volunteers also have a sense of autonomy as they are choosing to engage in their role and have freedom over their behaviour(60). These findings also contribute to the indication that volunteers experience compassion satisfaction(51). This level of personal satisfaction can contribute to reduced stress in the workplace, being a protective factor against stress and burnout(61).

A key finding from this review was the importance for volunteers of developing a good relationship with patients. Building close relationships, considering boundaries and understanding the patient experience with flexibility and curiosity has also been found in other reviews. The social nature of the role has previously been discussed with the role being characterised in social terms rather than the tasks they do and this has been found across different palliative care settings(1). This is also supported within the befriending literature where a core element of volunteers as befrienders for those with cancer, depression and other mental health difficulties was developing social relationships(62). Other research supports the findings of strong relationships forming between the volunteer and patient, also classed as a personal gain(58). It has been identified that volunteers struggle if a strong connection has not been made with a patient which highlights the importance of this development(45).

The befriending literature separates types of befriending into a 'friendship' style befriending and a 'professional' style of befriending which raises different questions regarding boundaries(63). Volunteers in the current review appeared to choose where they naturally fell on that continuum and, whilst close relationships developed between volunteers and patients, some volunteers highlighted situations where boundaries needed to be implemented. How a volunteer implemented boundaries was personal to the volunteer but it was recognised that a lack of boundaries could result in a bigger emotional impact when the patient died. This indicates that there are higher emotional risks of 'true friendship' in comparison to a 'professional' befriending relationship which supports the current findings (63).

The findings of the current review support the job-demands resources (JD-R) model(64) as psychological processes influence the development of job strain and motivation. However,

this model does not specify how demands and resources interact. (SDT)(65) indicates that demands lead to burnout if the individual has low resources. This highlights the importance of individuals developing a range of resources to support them. It describes autonomous motivation, including intrinsic and extrinsic motivations and controlled motivation(66). Autonomous motivation describes feelings of choice, interest and value, either doing something because it is interesting (intrinsic motivation) or because it leads to a consequence (extrinsic motivation)(67). The current review highlights personal gain in the selected papers which encompasses both intrinsic and extrinsic motivation as the papers described volunteers feeling useful, appreciated, inspired and rewarded (intrinsic) but also provided them with learning from patients and self-growth (extrinsic). Controlled motivation, where an individual does something in order to get a reward or avoid punishment(68), was not highlighted in the current review. This is positive as individuals are usually more engaged and have greater levels of emotional well-being when they are autonomously motivated(69).

The SDT also encompasses the three basic human psychological needs from the cognitive evaluation theory: competence, relatedness and autonomy(70). The current review highlights these basic needs. For example, some of the intrinsic challenges highlighted were not always feeling ‘good enough’. This is linked to the basic need of competence hence why volunteers may find it challenging to feel this way. Relatedness is also present through the development of relationships between volunteers, patients and families. This gives them the chance to both care for others and have others care about and value them. It seems that this psychological need is largely met in the current review, but it can be challenging when patients push volunteers away and this may be because it contradicts the volunteers’ need for relatedness. Autonomy was not explicitly highlighted in the current review; however, volunteers had some level of choice and control over their coping strategies used to manage challenges

within palliative care. They also had autonomy over whether or not they continued to volunteer as they were not financially tied to their role.

Strengths and limitations

This systematic review and thematic synthesis is the first to directly examine the emotional experiences of being a palliative care volunteer and provides evidence that volunteers face specific challenges within their role and could benefit from more structured support. ENTREQ(71) reporting guidelines were adhered to. The search was comprehensive and used a range of databases to obtain papers. No date or study design restrictions were implemented in an attempt to capture all relevant research that was published in English. Research in other languages was excluded due to limited time and money for translation and interpretation, therefore some relevant papers in other languages could have been missed. Papers were critically appraised; however, none were excluded based on this score. This is due to a limited number of papers that met the inclusion criteria and it being a contested area in qualitative synthesis(72).

Recommendations for future research, practice and policy

The impact of volunteers' roles on their emotional well-being, was not a focus of most included papers. It would be useful for research to consider the specific impacts of the role on volunteers' emotional well-being and explore what volunteers would find useful to support them. Initially, it would be helpful to gather qualitative data to explore volunteers' experiences and subsequently develop quantitative research from this to gather a wider range of data. It is important that when reporting research, authors focus on outlining clear and detailed methodology as this was missing from some papers included in the review thus impacting on their quality.

It would also be useful for palliative care services to consider the importance of stress-reducing techniques training for volunteers. It is understood that volunteering in palliative care can present a number of challenges and that prolonged stress can negatively impact an individual both physically and psychologically(73). Therefore, providing sessions for volunteers that focus on stress reducing techniques such as imagery, mindfulness and breathing techniques could support volunteers(52). A focus on stress reduction, particularly through practicing mindfulness has been shown to increase health outcomes for both clinical and nonclinical populations(74). This could be written and/or delivered by a clinical psychologist. The importance of including techniques to enhance psychological well-being for healthcare professionals working in palliative care has previously been indicated(75), therefore it would be useful for this to also translate to the volunteer population.

The intrinsic challenges faced by volunteers indicate that they would benefit from a space to reflect on the impact of their role on their sense of self and general emotional well-being. This could be implemented in the form of a reflective practice group run by a clinical psychologist, similar to the provision available for nursing staff in some hospices. The extrinsic challenges may also be addressed in a reflective space and it could be useful to focus these discussions on how volunteers make sense of extrinsic challenges and their feelings related to this. Clinical supervision groups have been found to reduce the risk of burnout in palliative care professionals(76), reduce anxiety, increase confidence and commitment to the role(77). Some extrinsic challenges could be considered on a more organisational level, some of which could be addressed through additional training. This may include knowing what to say to patients when volunteers are pushed away and preparation for seeing suffering and physical disfigurements. Both formal and informal support can promote

coping and resilience in palliative care nurses(48), thus would be useful to consider for volunteers.

To gain more understanding of people who struggle with the role, it may be useful to conduct research on previous volunteers who no longer felt able to continue in their role. This could give more insight into the stressors they encountered and support considerations of what the palliative care setting could have done to support them.

Conclusion

Palliative care volunteers are less likely to experience stress and burnout than paid staff. However, this does not mean that the emotional impact of their role should not be considered. Understanding volunteers' experiences has previously been emphasised as important as this can assist settings in recognising suitable support which can influence overall well-being(44) (78). Volunteers face unique challenges which can impact on their emotional well-being but also experience a number of positive impacts on their emotional well-being. It is important to monitor how volunteers are coping with their role and provide support where appropriate.

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Appendices

Appendix A - Guidelines for publication

***Palliative Medicine* Instructions to authors**

At *Palliative Medicine* we want to publish the highest possible quality of papers. Our instructions to authors therefore focus on what we want you to do to enhance the quality of your research reporting. We only have space for around 20% of papers submitted to us, so paying attention to high quality research reporting will enhance the chance of us being interested in your paper.

There are TWO mandatory uploads together with your paper: the reporting checklist for your study type and the authors' checklist to acknowledge that you have followed the instructions below.

These instructions to authors fall into four main sections.
First, an explanation of the type of papers we are interested in so you know you are writing for the right journal. **Second**, a clear description of what we want to see in your writing which you will need to take account of when you are drafting your paper, to promote the highest possible quality of reporting.
Third, specific instructions on formatting etc., as well as more detail on reporting specifications to meet journal and publisher style requirements.
Fourth, information on how to submit your article and what happens after you have submitted it, including information on Open Access options and publicising your published paper.

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1. What type of papers do we want to publish?

a) *Palliative Medicine* is a highly ranked, peer-reviewed scholarly journal dedicated to improving knowledge and clinical practice in palliative care. It reflects the multi-disciplinary and multi-professional approach that is the hallmark of effective palliative care. Papers are selected for publication based on their scientific excellence, contribution to knowledge, and their importance to contemporary palliative care. We welcome papers relating to palliative care clinical practice, policy, theory and methodological knowledge.

b) *Palliative Medicine* is an international journal with authors, reviewers and readers from around the world. You must make sure that your work is contextualised for such a readership, and where research is conducted within a single country, how the results contribute to an international knowledge base.

c) *Palliative Medicine* is a research journal, and primarily publishes papers which report original research and systematically constructed reviews. We also publish short reports, service evaluations/audits, research letters and case reports occasionally, but if you are

considering submitting these types of papers please take time to read our specific guidance on them below.

d) *Palliative Medicine* is the official research journal of the European Association for Palliative Care and a journal of the Association of Palliative Medicine. This Journal is a member of the Committee on Publication Ethics. This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

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2. How do we want papers to be written?

All papers submitted to *Palliative Medicine* are scrutinised carefully by a number of members of the editorial team before being sent for external peer review. A substantial number are declined at this point, before peer review. Common reasons are that the papers report work which does not appear to be novel or does not add to knowledge explicitly, or that the design or methods of the study are not appropriate to the question posed or poorly reported. We strongly suggest therefore that this information on writing and reporting is followed whilst drafting your paper, well before you consider submission to the journal, as there is evidence that this will enhance the clarity of your writing and message to readers. The SAGE Author Gateway has some general advice on how to get published, plus links to further resources.

a) ***Reporting guidelines***. All papers must be written following appropriate reporting guidelines, and a reporting guideline checklist indicating where required elements are found in the manuscript must be uploaded at the time of paper submission as a mandatory file (excluding research letters). A full list of reporting guidelines is found on the EQUATOR network website. Guidelines are known to improve the quality and comprehensiveness of research reporting, and we expect all relevant aspects of the guideline to be followed. Common guidelines include CONSORT (with any relevant extension) for trials, COREQ for qualitative research, PRISMA or ENTREQ for reviews. Interventional studies must also describe the intervention according to the TIDieR guidelines.

b) The ***key messages*** of the paper must be easy to see and interpret for readers. For this reason we ask you to pay close attention to the title, structured abstract and key statements. For some readers this may be all they look at to decide if they are interested in your paper, so they have to be informative, accurate, and meaningful to clinicians, researchers and policymakers. We have recommendations on titles, abstracts and key statements which are designed to improve the discoverability and usability of your papers and it is important that you read these and incorporate them into your manuscript.

c) Full details of ***ethics/research governance/data protection approvals*** must be given, with reference numbers, full names of the committee giving approval, and the dates of

approvals. If research ethics committee/IRB approvals were not required for your work please reference the law or regulation granting exemption, and/or submit a letter from the relevant authorities granting this study exemption. This must be clear within the body of the paper. We expect in all circumstances that the highest possible standards of research ethics and governance are followed and demonstrated throughout the paper.

d) The ***discussion section*** of your paper must be structured, to enhance readers' ability to find the information about your work and its applicability. We ask that you provide clear subheadings which address:

i) ***Main findings/results of the study***: A short statement of the principal findings of the study should be presented.

ii) ***Strengths and weaknesses/limitations of the study***: A discussion of the strengths and weaknesses/limitations of the study with reference to other studies or reviews in this area.

iii) ***What this study adds:*** A discussion of what is already known about this topic area and what this research/review adds, and a clear discussion of the implications of the research/review for clinical practice, theory or methods in this area. We suggest that you raise further research or review questions.

Specific instructions on titles, abstracts, keywords and key statements for all papers

a) **Titles**. A significant proportion of readers come to the *Palliative Medicine* site by running simple searches. It is important therefore that an article's title, keywords and abstract are written to be optimally "discoverable" by search engines. You must ensure that the main key phrase for the topic is in the article title. Make sure the title is clear, descriptive, unambiguous, and accurate, and reads well. Titles must include details of the methods used within the paper. We do not recommend the use of country names in titles as there is evidence this can restrict readership, countries can be mentioned in the abstract. There is evidence that putting the findings of the paper in the title can attract readership. An example of such a title would be: *Intervention A leads to a greater reduction in (primary) outcome x for people in their last year of life, compared to intervention B: A pragmatic randomised controlled trial*; or *The experience of X is challenging for family carers of people with advanced cancer: An ethnographic study*.

b) **Abstract**. Key tips for discoverability include repeating key phrases within the abstract and between the abstract and keywords – think about the key phrases you would type into a search engine if you were searching for the article. Repetition of a particular key phrase may strengthen the ranking of the article. Please read and follow these guidelines: http://www.uk.sagepub.com/authors/journal/readership.sp. Abstracts should not contain abbreviations or references. All our abstracts are structured, and should follow the formats below. There is some flexibility for audit/service evaluation as it is important that these are not presented as research:

i) ***Research Paper/Short Report/Audit/Service Evaluation abstract (250 words):***

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.

Aim: A clear statement of the main research aim(s), research question(s) or hypotheses to be tested. *Design*: A statement about the research strategy adopted. For intervention studies, a clear statement of the intervention is required. For clinical trials, the trial number should be given. Give brief details of data collection methods. For interventional studies please add a sentence about the intervention tested.

Setting/participants: Indicate the type of setting(s) the research was conducted in (e.g. primary/secondary care), the number of centres, and who participated, including a brief indication of inclusion/exclusion criteria, numbers of participants and any relevant characteristics.

Results: Report the main outcomes(s) or findings of the study. If appropriate, report levels of statistical significance and/or confidence intervals.

Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology. Give suggestions for further research.

ii) Systematically constructed review abstract (250 words)

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.

Aim: A clear statement of the review aim(s).

Design: A statement about the review strategy/methods adopted (e.g. meta-ethnography, realist synthesis, systematic review, meta-analysis). If prospectively registered (e.g. on PROSPERO), this information should be given here.

Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal.

Results: Report the main outcomes(s) /findings of the review.

Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

iii) **Case Report and Case Series abstracts (200 words)**

Both abstract and full submission should follow the same structured format of:

Background (including existing evidence, literature and related cases in the public domain)

Actual case including details of the practice challenge and details of ethical review

Possible courses of *action*

Formulation of a *plan*

Outcome with timescales and how success /failure was judged

Lessons from the case

View on research problems, *objectives or questions* generated by the case

c) **Keywords.** Please give at least four key words, and up to eight. At least one should be subject-related, and at least one relate to your chosen research design. All keywords should be MeSH headings and should be checked against this list http://www.nlm.nih.gov/mesh/. Please provide a justification for any keywords which are not MeSH headings.

d) **Key statements**

Palliative Medicine has a system where all research and review papers (not letters) are required to state clearly what is already known about the topic, what the paper adds, and implications for practice, theory, or policy. You are required to give these at the start of the manuscript, as part of your manuscript text. Please use these three specific headings (see below), with 1-3 separate bullet points for each heading. Please use clear, succinct, single sentences for each bullet point rather than complex or multiple sentences.

What is already known about the topic?

Short statement(s) about state of knowledge in this area.
You may highlight both what is known and what is not known.
Be specific rather than making broad or sweeping statements. Avoid statements such as 'little is known about ... x or y' in favour of statements specifying exactly what is known.

What this paper adds

Short specific statement(s) about what this paper adds.
These should be styled in terms of outcomes where possible (This study demonstrates that x intervention has a (specific) impact on y outcome) rather than study aims or process, (This study considers whether x intervention has an impact of y outcome).
Be as specific as possible. Avoid broad statements such as 'New Knowledge is added about ... ', rather be specific about exactly what this knowledge is. For example, rather than 'We add to the knowledge base on x' we would prefer the more specific statement 'x variable was found to increase the experience of y outcome (by z amount)'.
Ensure that these statements clearly relate to the findings of the study.

Implications for practice, theory or policy

Short specific statement(s) on the implications of this paper for practice, theory or policy. These should clearly draw from the findings of the study, without over stating their importance. to an international readership.

Specific guidance on paper types and word limits

a) ***Review Articles*** – 5,000 words. The reviews we publish are usually systematically constructed reviews, clearly following the relevant publication guidelines (such as PRISMA, RAMESES or ENTREQ) for the particular review style chosen. We are happy to consider a range of review types (systematic reviews, meta-analysis, metaethnography, realist review for example) for publication, but they must be methodologically clear and rigorously conducted. If reviews are registered (e.g. on PROSPERO https://www.crd.york.ac.uk/PROSPERO/) this should be stated and a link given within the paper. Please ensure that you include a PRISMA type flowchart for all reviews to enable readers to understand your search processes. All reviews should include sufficient detail on review question, inclusion and exclusion criteria, search strategies, data extraction and synthesis methods (as appropriate to the review design) for the study to be replicated. Please include a table of included studies. If some of these are large, you can consider

adding them a supplementary online only files, but these must be referred to within the text of the review. Please note our specific requirements on review abstracts above.

b) ***Original Articles*** – 3,000 words with up to six tables or figures. Original articles must report robust, ethically conducted research. We publish research using a range of designs, as appropriate to the question posed. Please see general advice above for information on the relevant reporting guidelines which must be followed, and our title and abstract requirements. Please also look at instructions for short reports and research letters which may be a better 'fit' for papers reporting smaller pilot, exploratory or feasibility studies.

For trials and interventional studies, we expect that the intervention is fully described using accepted guidelines (e.g. TIDieR) as well as being reported according to the appropriate guidelines (e.g. CONSORT or one of its extensions). *Palliative Medicine* endorses the ICMJE requirement that clinical trials are registered in a WHOapproved public trials registry at or before the time of first patient enrolment. However, consistent with the AllTrials campaign, retrospectively registered trials will be considered if the justification for late registration is acceptable. The trial registry name and URL, and registration number must be included at the end of the abstract. If the protocol has been published this should be referenced within the paper.

For papers reporting qualitative methods we prefer papers which state their particular qualitative approach (e.g. grounded theory, phenomenology, ethnography etc.) and articulate their methodological (epistemological and ontological) position, how this relates to their question and design, and which present a so called 'thick' description and interpretation of their findings clearly. Participants' quotations may be excluded from the word count, and we prefer that they are integrated into the text rather than presented separately. We still prefer, however, that these quotations are succinct and carefully chosen – it is rare that more than one quote is required to illustrate the point being made.

Papers which report primarily the development or testing of scales/measures or questionnaires must include a copy of the relevant instrument as a supplementary file (with translation into English if appropriate, as well as in the original language), and such papers will not be accepted without such a file. Authors are expected to obtain any copyright permissions required for such reproduction.

For research articles, authors are required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Full details of all research ethics committee (e.g. IRB) and/or organisational governance approvals must be given within the body of the text with reference number and date of approval. If such approvals were not required, information about the exemption from this (and on what authority) must be given within the text of the paper.

The date(s) of data collection must be given within the paper. If your data were collected more than five years before submission we expect a strong justification for why reporting these results is still relevant to the *Palliative Medicine* readership.

c) ***Short reports*** – 1,000-1,400 words. These should report research, but are usually small scale survey/pilot/feasibility studies etc., which would not warrant a full original research paper. Please see the original article section above for general instructions.

d) ***Case & Case Series Reports*** **-** A good case report, or preferably a case series, can inform an important part of healthcare development and improvement through the creation of links from practice to research and back to practice. To do so it must provide close analysis of practice-based examples, giving insights into what happens in clinical and other practices when empirical evidence-based options have been exhausted, and identify potential 'golden nuggets' to signpost for further research exploration.

Palliative Medicine is a research journal. As such we are interested in case and case series reports which achieve these goals. We publish case reports to highlight issues of practical interest and identify research questions for further study. Research focused learning points must be explicit within the report.

We understand a case series can legitimately be identified and analysed retrospectively, particularly in areas of evolving and challenging practice. However, prospective planning of data collection will usually strengthen the findings and implications and if so if you are planning a case study series using prospective research methods please review this methodological paper http://journals.sagepub.com/doi/pdf/10.1177/0269216311419883 and consider whether to submit your work as a case series report or an original research article, with appropriate justification of your choice in your covering submission letter.

Essential elements of a case or case series report in *Palliative Medicine:*

- There must be a clear practice-based challenge that the report seeks to address: the challenge may be related to physical (e.g. medications and symptom control), social, psychological, spiritual or ethical issues but it must be a challenge faced in frontline palliative care practice.
- Evidence of reasonable international literature review, including other case reports or series on the same / similar subject matters must be included as must evidence of seeking to identify consensus of practice internationally regarding comparable cases.
- When similar cases or case series have been previously published then submitting authors are required to create a referenced case series from the previous cases as background to their own and to highlight how this informed actions in their own cases. In addition, submitting authors must justify how a further publication will take the field forward.
- The actual cases should be presented briefly (150 words or less is recommended) at the start of the submission, followed by up to four

possible courses of action posed in response to the question ‘What would you do next?’

- A clear explanation of how a plan was prospectively formulated to assess the options and manage the case must be given. This should include the theoretical basis of any interventions and the underpinning reasoning behind decision making.

- Explicit details of critical elements of the case should be given, while seeking to preserve anonymity of individual patients / other persons not included in the authorship of the submission. We expect the majority of cases to be anonymised to the extent that someone who knew the patient could still not positively identify them. If this is not possible, for example because specific details or photographs are required to present the case, then

  there must be inclusion of a statement within the submission confirming that all individuals and organisations potentially identifiable from the case have agreed to its publication. Further to this, copies of written informed consent from patients and other non-professional members of the team as well as any professionals should be submitted as supplementary files. This must include the provisional title of the submission, consent for all material (including photos, images, text or other material) to appear in the Sage publication *Palliative Medicine* and related forms of publication such as, but not limited, social media associated with the journal, blogs and press releases. The person consenting must confirm they have seen the material, read the submission and that they are legally entitled to give their consent. They should confirm that they understand publishing of the material without their name attached does not guarantee complete anonymity as it is possible someone may recognise them or their case. They should confirm that they understand potential distribution is worldwide and access is not controlled by the journal or Sage, and also that they will not receive any financial benefit from publication. They must confirm that they understand consent cannot be revoked post publication and that their consent form will be retained securely by Sage.

- If the patient has died, we would expect the authors to request permission from a person with Lasting Power of Attorney or in the absence of LPA, a relative, and to make this clear on the consent form and in the submission. If no written consent is possible from either the patient or relative, we will consider the utility of the case carefully against the likelihood of identification or potential distress. It is likely that in this position more information will have to be removed from the case to reduce the possibility of identification, and this will have to be made clear in the submission.

- Details of any relevant ethical approval processes for interventions should be included. In the event of a submission describing an intervention not subject to formal governance or ethical review then authors should provide justification of the reasons for this e.g. not required in the local jurisdiction for this type of research, clinical cases were shared decision making took place for a novel management with a specific patient and set of clinicians in the absence of no other options and in response to an urgent need. It would still be expected that such cases would have been discussed, including potential ethical issues, among the clinical multidisciplinary team and an explanation of this and how the work/practice was conducted ethically and with integrity must included in the submission. Authors should include explanation of how any novel treatment was discussed with patients prior to use.

- We are particularly interested in how case / case series submissions might direct and instigate further research and ultimately lead to better evidenced practices:

    - The outcome of the case / case series with details of any outcome measures used should be given.

    - The case must conclude with a view on research problems, objectives or questions generated through the challenge of the case and how these might be addressed. In simpler terms this might be posed as answering a 'so what?' question.

- While not specifically excluded extremely rare cases are likely to be of less interest to our wider readership and so priority will be given to publishing cases that build a picture of contemporary practice and collective consensus on managing issues at the frontline of practice while awaiting further research evidence.

- Appropriate case / case series EQUATOR reporting guidelines should be used. See:
  https://www.equator-network.org/

- The submission must not exceed 1500 words plus 2 tables or figures, acknowledgements, 10 references, and a 200-word structured abstract plus separately three key learning points (written as 1-2 sentence bullet points) for practice / research.

Further requirements:

- Case reports / case series should include the words 'case report' or 'case series' as appropriate in the title and keywords. Please do not use 'case study' as this leads to confusion with the research strategy of the same name.

- Drug names should be generic not proprietary.
- Details of management should be specific and described to be understandable by those who may follow different protocols in different contexts.
- Both abstract and full submission should follow the same structured format of: ○ Background (including existing evidence, literature and related cases in the public domain)
    - Actual case including details of the practice challenge and details of ethical review ○ Possible courses of action ○ Formulation of a plan
    - Outcome with timescales and how success /failure was judged ○ Lessons from the case
    - View on research problems, objectives or questions generated by the case

e) **Practice Reviews** - can either be commissioned by the Editor in Chief or agreed by submission. For the latter an initial outline pitch of a practice review proposal should be submitted for consideration by the Editor in Chief by emailing Debbie.Ashby@bristol.ac.uk in the first instance rather than a submission being made directly through Manuscript Central. This should include a brief summary of the anticipated extent and quality of literature supporting the proposed review.

Not all submitted proposals will be accepted, and for those that are, there may be an informal work-up process required to reach agreement prior to the pitch being accepted. **The review must have its own novel research question that the authors seek to answer** (or if an update of a previous review, justification for why an update is needed e.g. significant time has elapsed and there is a significant body of new empirical evidence).

Once accepted pitched proposals will proceed in the same way as commissioned reviews. Commissioned reviews will occur a few times a year and may be related to themed issues, virtual issues or stand-alone. All reviews will be subject to peer-review, when possible by a member of the journal's Editorial Board in addition to external review.

The purpose of practice reviews is to provide a 'stock take' or overview of the current 'state of the science' in an area of practice with a supporting evidence-based summary of guidance and recommendations which can be drawn from evidence about what is known to be beneficial or not. Reviews might cover newly emergent 'hot topics' but equally might be the basis of establishing the need for further research in a long-established topic area by considering the evidence base on which current practices are based and what would take the field forward.

Practice review subjects can be clinical, ethical or relate to another aspect of palliative care such as spiritual, social or psychological care or professional development. Review subjects which are relevant to the shared practices of multidisciplinary teams are particularly welcome.

Reviews should both orientated to recommendations for frontline practice and identification of scientific equipoise, i.e. absence of studies, with suggestions for further research. The implications of the review findings must be considered from the perspective of policy-makers, researchers, clinicians, ethicists and funders of research or quality improvement interventions. Review authors should aim to give a clear steer on what might be the most important gaps to be addressed through further research.

Purely descriptive summaries of evidence will not be accepted.

We ask that these aims are achieved by following the structure below in order to generate learning for both our practitioner and researcher audience. We are very grateful to Erik Driessen, Editor-inChief, and Robert McKinley, Section Editor, *Perspectives on Medical Education* for letting us adapt the format (McKinley, R. & Scheele, F. Perspect Med Educ (2015) 4: 275. https://doi.org/10.1007/s40037-015-0230-8; https://www.springer.com/education+%26+language/journal/40037?detailsPage=editorialBoard
).

Review presentation and structure - submitting authors should provide an overview of "Dos, Don'ts and Don't Knows" on a specific subject in clinical practice. Following a brief introduction, including the context, scope and methods used to conduct the review the remainder of the submission should be divided into a tabulated digest summarising each aspect of the evidence item by item and a review article providing the relevant supporting evidence, and indicating the strength of the evidence for each particular item.

- Dos – should be recommendations for practice that can be made with a supporting body of evidence for effectiveness or efficiency.
- Don'ts – should be recommendations against activities for which there is a supporting body of evidence to show inefficiency, ineffectiveness, or indeed harm.
- Don't knows – should be identified areas for further research as there is either an absence of evidence or the current evidence is unclear or not of convincing quality or rigour. Don't knows should be expressed as questions which if answered through further research would have an impact on clinical practice.

The digest table should be provided using this format:

Table 1. Summary of guidelines/recommendations for XXX

	Aspect A	Strength of recommendation
Do's		
Don'ts		
Don't knows		
	Aspect B	
Do's		
Don'ts		
Don't knows		

The choice of subject for the review should be guided by identification of the subject as an area of importance to clinical practice, in which there is some evidence for aspects of practice. The scope of the review will vary from subject to subject but should be broad enough to take into account different settings, both in terms of considering an international audience and across different areas of palliative care, i.e. hospice, hospital and community. Within the subject the dos, don'ts and don't knows should be items of importance to practitioners and will usually relate to common choices and decisions required in providing clinical care for patients with particular symptoms or diseases. All items should be made as specific as possible. Authors are likely to find it helpful to collaborate as a team and to pull together a provisional list of do's, don'ts and don't knows prior to conducting their review of the evidence which can then be revised in the light of the review findings.

Authors are free to choose their own methodology and methods for the review process, but this must be justified and appropriate to the subject and review question chosen. Practice reviews should be consistent with relevant publication guidelines (such as PRISMA, RAMESES or ENTREQ) for the particular review style chosen. We are happy to consider a range of review types (systematic reviews, meta-analysis, meta-ethnography, realist review for example) for publication, but they must be methodologically clear and rigorously conducted. If reviews are registered (e.g. on PROSPERO https://www.crd.york.ac.uk/PROSPERO/) this should be stated and a link given within the paper.

Judgements about the strength of evidence should allow for multiple types of evidence to be considered so that readers are provided with an overview of what exists. Authors can choose their own framework for assessing the strength of evidence but the review should not be limited to particular types of studies. A useful guide to rating strength is below:

Strength of recommendation:
Strong: A large and consistent body of evidence such as a systematic review

Moderate: Solid empiric evidence from one or more papers plus the consensus of the authors Tentative: Limited empiric evidence plus the consensus of the authors

Review formatting and additional requirements

- In addition to the tabulated digest of recommendations and further research requirements, the main content of the review must not exceed 2000 words
- A PRISMA type flowchart should be included as a supplementary online file
- Included studies must all feature within the reference list and a further table detailing these should also be provided as a supplementary online file.
- Any limits on the timeframe of the review must be clearly justified.
- A structured abstract of 250 words or less must be provided. The structure should be:

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.
Aim: A clear statement of the review aim(s) and / or research question it seeks to answer. Purely descriptive summaries of evidence not synthesised into do's, don'ts and don't knows will not be accepted.
*Desig*n: A statement about the review strategy/methods adopted (e.g. meta-ethnography, realist synthesis, systematic review, meta-analysis). If prospectively registered (e.g. on PROSPERO), this information should be given here. Use of appropriate quality framework / guidelines to conduct the review should be included.
Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal. As a minimum a scoping review using recognised methods must be conducted.

Results: Report the main outcomes(s) /findings of the review. This should include key statements on answering the review question/aims, and the meaning of the findings.
Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

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(iii) Approved the version to be published,

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Acknowledgements. All contributors who do not meet the criteria for authorship should be listed in an acknowledgements section as described above. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

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Section Two: Research Paper

The impact on emotional well-being: experiences of being a palliative care volunteer.

An interpretative phenomenological analysis.

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Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Prepared in accordance with the 'instructions to authors' for Palliative Medicine

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The impact on emotional well-being: experiences of being a palliative care volunteer. An interpretative phenomenological analysis.

Abstract

Background*:* There is a huge reliance on volunteers in palliative care, particularly in hospices. They can provide psychosocial care to patients and families but do not receive formal supervision. Thus, it is important to understand the impact their role has on emotional well-being. Evidence shows that being a paid healthcare professional in palliative care can risk stress and burnout, but little research has been conducted with volunteers.

Aim: To explore the experiences of palliative care volunteers and how the role impacted on their emotional well-being.

Design: An interpretative phenomenological analysis design.

Setting/participants: Volunteers in a patient-facing role within palliative and end-of-life care settings in North West England who had been volunteering for over one month were included. A semi-structured interview schedule was used, and interviews were audio recorded.

Results: 10 participants were interviewed across three hospices. Four themes were developed: (1) it can be challenging; (2) it's where I'm meant to be; (3) managing death; (4) the importance of connection. Challenges included frustrations and questioning themselves. Although difficult at times, volunteers expressed the importance of the role, doing well and that they benefitted too. They also had to manage death and discussed beliefs about life and death, acceptance and managing patients' fears. Connection with the hospice, patients, staff and other volunteers was important, with a need for everyone to feel valued.

Conclusions: The study suggests that although there are psychosocial benefits for volunteers in their role, it is important to understand the challenges faced and consider ongoing support

to help volunteers manage these challenges. This could be addressed through the consideration of coping mechanisms and clinical psychologists providing training and reflective practice.

Keywords: palliative care, terminal care, hospice care, hospices, volunteers, qualitative research

Key statement

What is already known about the topic?

- Paid staff in palliative care can experience stress and burnout but little research has explored the emotional experience on volunteers.
- Volunteers provide emotional support to patients but receive little formal support.

What this paper adds

- An insight into the emotional experience of volunteers in relation to their role for example the impact of the challenges faced, feelings of belonging and benefitting from the role, managing death and the importance of connection with the hospice, other volunteers and patients.

Implications for practice, theory or policy

- Highlights the benefit of reflective practice groups to better understand how volunteers are managing within their role.
- Highlights the need for future research to focus on: gender differences and people who ceased volunteering.

Introduction

Volunteers are an integral part of the palliative care system, particularly in hospice settings. In countries such as Germany, Switzerland and Poland, volunteers run some hospices and organisations(1). Many countries cannot provide an accurate representation of the number of volunteers in palliative care; however, several European countries estimate over 1000 volunteers(1). In the UK, there are more than 125,000 volunteers; these services are reliant on the support of volunteers for delivery of current provision(2). Palliative care aims to improve the quality of life of individuals living with an incurable illness(3). There is an increasing demand on hospice and palliative care services due to the ageing population(4). Therefore, an increasing role for volunteers providing support in these settings. Volunteers in adult settings can be involved in many areas, including bereavement services, providing emotional support to patients and being with patients at the end of their life. This indicates that volunteers in patient-facing roles can be involved in providing psychosocial care(5).

Psychosocial care involves supporting an individual with their psychological, social and spiritual care(6) and good psychosocial care has been reported to increase patients' quality of life and impact positively on physical symptoms(7). Professionals in palliative care often provide psychosocial care to patients and those in paid roles manage numerous emotional demands that can lead to personal psychological distress(8). Working within palliative care provides unique experiences for staff and the emotional risks include stress, burnout and mental health difficulties(9). Burnout is defined as "emotional exhaustion, depersonalisation and reduced personal accomplishment"(10) (p.1) and is a pertinent issue within the wider healthcare system. Research has considered the prevalence of burnout, the association with burnout and other factors (for example, marital status, gender and years of experience within palliative care) and protective factors(11)(12)(13) in paid staff within palliative care.

The impact of stress and burnout can be far-reaching: for example physical and mental health difficulties (anxiety, depression, substance abuse)(14)(15), decreased job satisfaction and leaving the profession(16)(17). The more exposure to death and dying someone experiences, the higher their risk of burnout(18). These outcomes are also reflected in the literature surrounding compassion fatigue(19)(20) which is a secondary traumatic response experienced by those in 'helping' positions that are involved in the care of patients who are suffering(21); it is the 'caregiver's cost of caring'(22). There have been suggestions to support paid staff in palliative care settings, such as training and support in developing individualised coping strategies to encourage self-care and resilience(23)(24). However, burnout has not been considered for volunteers in palliative care despite their regular exposure to death and dying. This indicates a need to consider the impact of death on volunteers' emotional well-being and how they are coping within their role.

Volunteering across a number of settings has positive impacts for the volunteer on areas such as mental health, life satisfaction and social interaction(25). This is emphasised in older adults transitioning into a new stage of life as it can support individuals to connect with communities and build social relationships(26). However, volunteering within palliative care can result in stressors related to their role including poor communication, lack of emotional support, feeling undervalued and the need for training(27). There has been little research into the emotional impact of the role on volunteers within hospice settings. Research has focused on personality characteristics of palliative care volunteers(28), the reasons for becoming a volunteer(29)(30) and consideration of improving and developing volunteers' roles(31). This appears to be largely based on maximising the benefit of having volunteers in contrast to exploring the impact this role has on volunteers' emotional well-being.

Palliative care volunteers have a positive impact on patients, their families and carers; the more volunteer involvement a patient and family receive, the more satisfied they are with their care(31). Due to the reliance on volunteers' support, research is needed to understand the experiences of volunteering in a hospice setting. Volunteers report that they have been changed in some way by their experience of being a hospice volunteer(32) indicating that their role impacts on life outside of the hospice. If volunteers' experiences were communicated, this could help to retain and recruit into these roles, whilst creating more positive experiences for volunteers.

Understanding the experiences of being a volunteer is relevant to clinical psychology. Based on the results of the current study, clinical psychologists could be involved in providing consultancy in how to address psychological needs of volunteers. Clinical psychologists are required to provide such support, supervision and consultation to paid members of the multi-disciplinary team in hospices(33)(34), so would be well placed to provide this support to volunteers. Clinical psychologists are expected to provide consultation to support others in practicing effectively thus contributing to good quality service delivery(35). Guidelines do not state that this is confined to paid professionals (34). Volunteers may have effective coping strategies to manage their emotional well-being and the feasibility of these strategies with paid staff could be considered. Therefore, the results may also support paid staff(36).

This study aims to build upon what is already known about volunteers in hospices. The findings from the literature review in chapter one indicated that it would be helpful to have a more in-depth examination of volunteers' experiences of how their role may impact their emotional well-being. In doing this, findings may be applied within palliative care settings to support volunteers in their roles, ultimately improving care for patients. The following

research question was developed: ‘What are palliative care volunteers’ experiences of the impact on their emotional well-being from working in adult hospice care?’.

Method

Design

A qualitative methodology was selected due to the exploratory nature of the study which was appropriate due to the lack of research on this topic. A qualitative approach allows the in-depth study of experiences about a particular topic. Quantitative research would not have permitted the exploration of participants’ experiences nor answered the research question(37).

An Interpretative Phenomenological Analysis (IPA) design was selected(38) because its epistemology suggests that, through interpretative methodology, it is possible to access someone’s ‘inner world’, gain a deeper understanding of a particular aspect of human experience and how individuals make meaning out of their experiences(39)(40). This reflects the research aims: to explore hospice volunteers’ experiences of the impact of their role on their emotional well-being, focusing on this meaning for the individual. The researcher adopted a critical realist position, typical in IPA(41). Therefore, the researcher believes that individuals make sense of a reality, which occurs separately to their thoughts, influenced by social experiences(37). IPA is a double hermeneutic (the researcher is making sense of the interviewee’s sense-making)(42). This means that the researcher and participant co-construct an understanding of the topic(43). In contrast to other phenomenological approaches, IPA is also able to highlight differences through identifying both convergent and divergent themes. This helps the researcher to represent each participant’s experience, congruent with IPA’s idiographic approach(41).

Grounded Theory(44) was considered, however this aims to develop wider theoretical explanations and usually has a larger sample size. IPA (with a smaller sample size) enables a more detailed account of individuals' experiences which are more in line with the research aims. Similarly to IPA, narrative analysis(45) focuses on meaning-making of experiences. However, narrative analysis focuses on stories as a whole including how that story is narrated by the individual. In contrast, IPA separates individuals' accounts into themes and is concerned with the analysis of a particular phenomenon. It was decided that IPA could include the way in which participants construct and communicate their story but could also incorporate a number of other elements through the analysis(46).

Setting

Data were collected from three hospices in the North West of England. There are a wide variety of settings in which volunteers provide support for people at the end of life (for example, in the community and in hospitals). However, one type of setting was selected for this research as experiences could vary greatly across settings, including the level of contact a volunteer might have with the hospice and the support they would be able to access. The researcher wanted to ensure that the sample was homogenous(45), therefore wanted to focus on one setting, looking at experiences of hospice volunteers in patient-facing roles.

Participants

IPA is idiographic and aims to understand how something has been experienced and understood by certain people(46). Therefore, IPA research tends to have a small, homogenous sample, purposively selected(47). See table 1 for inclusion and exclusion criteria.

Table 1. Inclusion and exclusion criteria for participants

Inclusion criteria	Exclusion criteria
▪ English speaking due to limited funding for research (thus translation/interpretation costs) and limited time for collecting and analysing data in other languages. ▪ Aged 18 or over ▪ Those who have the capacity to consent ▪ People volunteering within palliative and end-of-life care settings with adults ▪ Volunteers in patient-facing roles	▪ Those who have been volunteering for less than one month.

Sampling

Purposive sampling was used, consistent with IPA, to gain insight into an individual's specific experience(46). The researcher was interested in individual's intrinsic experiences. It was thought that there could be some site-specific factors, therefore the preference was to recruit approximately three participants from each hospice to mitigate this. IPA is most suitable for small homogenous samples meaning a group of individuals who are similar according to a particular experience(47). The small homogeneous sample is hospice volunteers in patient-facing roles as they share a similarity of role and setting.

Recruitment

Volunteer coordinators at each hospice circulated information about the study to eligible volunteers by post, email or on collection. If interested, volunteers were asked to contact the researcher (by telephone, email or posted reply slip). For all volunteers who made contact, the lead researcher explained the study and arranged interviews if they wanted to participate. The first 10 participants identified were included in the study. If there was a lack of participation, further hospices would have been approached however this was not needed. Recruitment closed in October 2019 due to sufficient data collection. IPA is concerned with

an in-depth examination of participants' experiences of a particular phenomenon; therefore, smaller sample sizes are sufficient to enable careful consideration of participants' experiences(48). Sufficient data were collected due to the quality of the data. Although quality not quantity is advocated within IPA(49), the length of the interviews provided a rich and detailed account of participants' experiences.

Data collection

Data collection was conducted through semi-structured interviews. On the day of the interview, participants could re-read the participant information sheet and ask questions. They were asked to sign a consent form. It was explained that participants could withdraw during the interview and up to two weeks post-interview. Participants were made aware that if they requested their data to be withdrawn after it was pooled for analysis, it may not have been possible to withdraw their data. However, every effort would have been made.

Face-to-face semi-structured interviews were conducted, commonly used within IPA. The interview schedule was generated based on previous literature and in accordance with the recommendations for IPA. Semi-structured interviews were chosen as IPA aims to elicit rich, detailed data(50) and semi-structured interviews allow an opportunity for this. Specific topics could be covered with flexibility so participants could also discuss their own ideas. The interviews were audio-recorded and transcribed verbatim by the researcher. After the first interview, data were discussed with the research supervisor and the interview schedule reviewed. No additional questions or prompts were incorporated. The topic guide included questions around motivations to become a volunteer, personal experiences of death and dying, 'good' and 'not so good' parts of their role, support received, strong thoughts and

feelings in their role, what the organisation could do differently and advice for new volunteers.

Analysis

The data were analysed using IPA(38). As IPA is a double hermeneutic, the analysis was an account of both the individuals' meaning-making of their experience and the researcher's interpretation of this. First, the transcripts were read with the audio-recording then re-read numerous times. Initial thoughts were recorded. Line-by-line analysis of each transcript highlighted descriptive, linguistic and conceptual comments. Descriptive comments recorded the context of the participants' lived experiences. Linguistic comments focused on the language and conceptual comments encouraged a more interpretative focus to begin, considering more abstract concepts. Emergent themes were developed using more of the initial notes rather than the transcripts themselves. This process was repeated for each transcript. Patterns across cases were then documented. Participants' individualism was maintained whilst also developing higher order concepts(46). Analysis was managed using NVivo12 software(51).

Quality

As the researcher can influence the data through their individual experiences, supervision was helpful to examine emerging themes and agree the current themes. An individual transcript, summary notes and theme descriptions were reviewed by the supervisor to ensure credibility of the analysis. However, this would not necessarily be the only credible or 'true' account(46). This is in line with Yardley's(52) criteria for assessing the quality of qualitative research.

Two volunteers reviewed the interview schedule prior to the data collection. They also read the consent form, participant information sheet and participant debrief sheet and suggested some amendments which were incorporated.

Ethical approval

Ethical approval was obtained from the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University (see section 4). FHMREC reference: FHMREC18072. The hospice sites also provided governance approval. Ethical considerations included the disclosure of risk from participants and participant discomfort due to the topics.

Results

Ten hospice volunteers in patient-facing roles participated. See table 2 for demographic details. Though not intentionally recruited in this way, all participants identified as 'white British' therefore they shared a similar demographic. The interviews lasted a mean of 84 minutes (range 63-129 minutes). Four themes were developed: (1) it can be challenging; (2) it's where I'm meant to be; (3) managing death; (4) the importance of connection. Eight out of ten participants contributed to at least three of the four themes. See table 3 for a graphic representation of how the themes emerged. See table 4 for an example transcript.

Table 2. Demographic details of participants

Age	36-84 years old (mean 66.9 years old)
Gender	F = 6, M=4
Ethnicity	White British n=10
Marital Status	Single n=3 Widow n=2 Co-habiting n=1 Married n=3 Widowed and remarried n=1
Employment Status	Employed full-time n=1 Employed part-time n=1 Retired n=8
Length of time volunteering in current patient-facing role	9 months – 17 years (mean 6.2 years, SD 6.6)
Volunteer role	Community (e.g. hospice at home, hospice neighbour) n= 1 (P1) Day therapy n= 2 (P8, P10) Inpatient unit n= 2 (P5, P6) Driver n= 2 (P2, P9) Day therapy & inpatient unit n= 2 (P3, P4) Inpatient unit & community n=1 (P7)
Has a close friend or relative had EOL care in a hospice?	Yes n=8 No n=2
Participants from each hospice	Hospice 1 n=5, Hospice 2 n=2, Hospice 3 n=3
Location of interviews	Hospice = 9 University = 1
Hospice induction and training	Hospice 1 = comprehensive induction programme including on-to-job training tailored to each role Hospice 2 = half day induction, on-the-job training and a series of training days for specific roles e.g. inpatient, befrienders and advisors Hospice 3 = induction programme, training for specific roles

Table 3. Graphic representation of themes

It can be challenging	**It's where I'm meant to be**	**Managing death**	**The importance of connection**
It can frustrating/tough	Huge part of my life	Death doesn't frighten me	Relationships with patients
Questioning self – am I good enough? Am I giving enough?	I benefit too	Beliefs about life and death	Everyone should be valued
How I manage the challenge e.g. faith, knowing my limits	The importance of doing well and doing my best for others	Acceptance	The idealised hospice – the supportive white cloud
	From the outside in – changing roles	Managing patients' fears	The patients tell me a lot
			The value of personal experience in connecting with others

Table 4. Example transcript showing themes

Time	Person	Text	Annotations about what is interesting/significant or summary comment	Emerging themes	Sub Themes	Themes
	I:	So, when you first became a volunteer about a year ago, what were your initial reactions to being in that role?				
00.21.27	P:	Erm, I was nervous at first. Erm…I didn't really, I've never done any kind of catering role before so not in this kind of environment, so I didn't really know what to expect too much on my first shift. You get told what you're gonna do but I didn't really know what to expect, how it was going to work, so your first couple of shifts you shadow somebody anyway. So, you're never chucked in at the deep end of your own. I suppose I was quite wary because it was gonna be my first time knocking on doors and meeting patients that I'd never met before. It was that first kind of experience with dealing with other people's death and end-of-life care and	Nervous when first started – new role Didn't know what to expect Shadow another volunteer at first Felt wary at first – meeting new people First experience dealing with other people's difficulties and	Managing uncertainty Being supported by another volunteer Managing uncertainty New experiences	It can be tough Relationships with volunteers/ the supportive white cloud It can be tough Managing other's death	It can be challenging The importance of connection It can be challenging Managing death

		other people's families. And I thought, I wasn't quite sure how I was going, how I would deal with that kind of situation if family member was to ask me something or I walk in and a family member would be upset or something. That was kind of my biggest fear, not being able to help somebody. And the practical stuff of setting the trolley up and all that kind of stuff, that didn't bother me at all. I wasn't really fussed about that. I was nervous about meeting the person I was shadowing as well because I didn't know what they were gonna be like, how I was gonna get on with them or anything like that. But I was also really excited to get started, I couldn't wait to get started.	families. Didn't know how she would manage this. Biggest fear – not being able to help somebody Nervous about meeting the other volunteer Also felt excited to get started Mixed feelings	Fearful of doing enough Fear of meeting other volunteers Excitement at new role	Am I good enough? Am I giving enough? Relationships with volunteers From the outside in – changing roles	It can be challenging The importance of connection It's where I'm meant to be
	I:	And when you did get started, what was it like meeting the person you were shadowing?				
00.23.00	P:	Well, she was late [laughs]. To be honest, my very first experience of volunteering on a		Initial challenges		

		shift wasn't the best because I turned up and we were told, "right on your first shift you collect your badge and what not, see if there's any paperwork in this tray that's on the reception desk and then you report to the sister's office, the ward office, tell them that you're here and then they'll go and find whoever it is that you're shadowing". So, I was nervous about doing that and when I did knock on the door, I kind of got scowled at a little bit. It was a really busy night, the person that I was shadowing wasn't there yet and I pretty much got told to sit in chapel and wait and if they didn't turn up then I'll have to go home coz there's nobody that could show me what to do that night. And I was kind of sat there like 'oh' that's not the best. Anyway, she did turn up so [laughs].	First experience of volunteering wasn't good Got scowled at by nurse Disappointed by first experience	Initial challenges Initial challenges	It can be frustrating It can be frustrating It can be frustrating	It can be challenging It can be challenging It can be challenging

	I:	What did that feel like when you had that experience?				
	P:	That was my first kind of seeing the nurses as different people. Yeah, that was kind of like oh god. I almost nearly regretted it. Coz I thought oh this isn't, I wanted that same feeling that I had when that nurse was comforting me that day. I wanted that kind of environment all the time, just to be that whole kind of, like you're in a big woolly blanket. And it wasn't [laughs]. But it's alright [name] turned up and everything was fine after that [laughs].	Saw nurses as different people Almost regretted volunteering – could put people off Wanted the same feeling she had as a visitor – wanted that all the time. Woolly blanket.	Different experience being a visitor and volunteer Initial challenges Wanted to connect with the nurses/hospice	It can be frustrating It can be tough Idealised hospice / the supportive white cloud	It can be challenging It can be challenging The importance of connection

Theme one: It can be challenging

A commonly reported concept was difficult experiences and challenges faced when volunteering. How participants managed this and what helped them to continue volunteering are interpreted. For example, some participants felt that faith supported them, and others discussed the importance of recognising their limits.

One challenge was feeling that they were not giving enough of themselves to the hospice whether that be in their abilities or in time:

> *"Initially I was concerned that there wouldn't be a scope for somebody that was working full-time and didn't drive" (P1).*

It appeared that this participant felt others would be better placed to support patients and that she was not 'good enough' or did not have the right skills and abilities. This could lead to volunteers experiencing a lack of confidence in the role and uncertainty about whether they were meeting the needs of patients:

> *"I just felt I never said the right thing…it worried me…I just felt inadequate" (P10).*

Others focused on their ability to fulfil their role to a good level due to lack of experience in managing other people's experience of death and dying:

> *"It was that first kind of experience with dealing with other people's death…I wasn't quite sure…how I would deal with that kind of situation if a family member was to ask me something or I walk in and a family member would be upset…That was kind of my biggest fear, not being able to help somebody" (P6).*

Feeling that they were not giving enough, were not 'good enough' or uncertainty surrounding how to interact with patients and families could lead to volunteers feeling deflated, affect their sense of worth and develop feelings of failure. It could also lead to volunteers struggling to say 'no' to the hospice when they requested support; this could be driven by the above feelings. This indicates the importance of volunteers' boundaries. Volunteers had differing views on boundaries, for example, some struggled when patients left the hospice and were unable to maintain contact with them after building relationships:

> *"There's a lot of them that I'd like to give them a ring…Coz some of them are on their own and they're lonely. But we're not allowed to do it…I'd like to keep in touch" (P4).*

In contrast, others focused more on the importance of boundaries:

> *"It's about retaining the little bit of distance…once it becomes personal you end up like part of it. You're part of that emotion so you're not being supportive. You might need more support than that person…if you allow that to take over" (P7).*

Recognising limits as a volunteer was important to enable the continuation of support for patients, however sometimes this was difficult, and participants needed a break from volunteering to safeguard their emotional well-being. One participant highlighted that the length of time with a patient could impact differently on emotional well-being:

> *"I thought I just need to take a little breather…it's very sad when anybody passes but when you're, sometimes befriending can be a couple of weeks…months…But this was four, nearly four and a half years." (P7).*

Other challenges included the lack of information from the hospice regarding patients:

> *"I thought he was having a heart attack…I swung round to see if he was alright…his physical features told me he was having a heart attack and it wasn't a heart attack and I should've been told about that…I was…a little bit annoyed with them here…We've got to know how the patient, what issues" (P9).*

This lack of information made this participant feel scared for the patient's life and he had subsequent feelings of anger. This could result in a volunteer feeling as though they are not important enough to receive information from the hospice or highlight a disparity between paid staff and volunteers. As volunteers often did not get informed about patients' illnesses it could be shocking if patients chose to disclose this information and talk more openly about the end of life. Some participants described situations where it was hard to manage this:

> *"I have cried in front of somebody…he was telling me that he was gonna be getting married and he was telling me all what was wrong with him…I just started crying and I went away. I said, "I'm sorry" I said, "I've never got upset before" (P5).*

Although hospices in the UK regularly facilitate weddings, this could have evoked feelings of pity from the participant related to the life that this patient would be leaving behind. Multiple participants described the natural human reaction of managing death:

"You're not human if you don't feel it inside" (P5).

Some participants described thinking about themselves as the patient and how this affected them:

"You're bound to sort of reflect…you start putting…yourself in that bedside position" (P3).

P4 also considered mortality:

"I look at some of these patients and you think to yourself why them and not me? Especially if they're young, you think how unfair is that?" (P4).

These comments indicate that an individual can go through life not considering death but volunteering can bring this to the forefront of one's mind and encourage consideration of mortality.

Despite the number of challenges volunteers faced, participants described things that overshadowed the challenges and made them want to continue volunteering. One participant's faith supported her in managing the challenges of death:

"I can't feel depressed about death. I can see it's sad…see if I was an atheist, I don't know how I'd cope…I just think that death is an inevitable part of life…it's not the end…I think that keeps me sane about all the death and the dying" (P10).

Some participants accessed support from other volunteers:

> *"Well, if we find ourselves emotional…we would just normally take a step back and we're quite open with each other about how we feel…even to the extent of just withdrawing for a short time...And discussing til we, until we just recompose" (P7).*

Others utilised a more formalised support system provided by the hospice. This 'buddy system' (a fellow volunteer) facilitated feelings of security within their role:

> *"I think knowing that they're there and that you're not on your own is important…sometimes you think, mm am I doing it right? Am I doing it wrong?...it's not something you necessarily want to take to the hospice. But you can just run it past somebody else that's doing the same role" (P1).*

It is unclear whether each hospice site had a 'buddy system' established.

Theme two: It's where I'm meant to be

The hospice being a huge part of volunteers' lives, the impact the hospice has on volunteers and how they benefit from their role are captured here. The volunteers' journeys of discovery and how important they feel it is for them to 'do well' is also encompassed. Changing roles from visitor to volunteer and 'moving from the outside in' are discussed.

Participants talked about the hospice passionately and many expressed it being a huge part of their lives with their role providing them with satisfaction. Some participants appeared not to

be content in their day-to-day life therefore the hospice provided them with an opportunity to feel fulfilled:

> *"I hate my day job and I don't have any job satisfaction…I get here and I know I've done something that's rewarding…valuable, I carry that with me for the rest of the week…that's my little recharge every Sunday" (P6).*

It provided participants with something valuable and meaningful to draw upon in other areas of their lives. Some talked about it being central:

> *"…the main thing in our lives really…all our estate will go here" (P3).*

Indicating that they would donate their estate to the hospice shows the importance of the hospice in this participant's life and how highly they regard it. It also shows the importance of being connected with the hospice in both life and death. One participant fervently discussed volunteering in the hospice as something that was meant to be:

> *"it was something I somehow felt drawn to, but I can't describe it…I just feel at home, really at home. It's like I've always been there," (P8).*

For this participant it seemed that she had discovered more of herself since volunteering and that this had always been a dream for her:

> *"I wish I'd gone long, long ago…Every time we went past the hospice I used to say, "one day I'm going to volunteer there"" (P8).*

It appeared she felt she belonged in the hospice and it was a place of comfort and community.

Others talked about the personal benefits of volunteering. Many felt it was rewarding, a privilege and community-spirited:

> *"I do enjoy it…when you go home at night and you get a bit of satisfaction knowing you've done this" (P2).*

Some felt that the hospice instilled hope and reminded them about the goodness in people:

> *"This place has given me hope…I don't know where else there would be such a gathering of human beings that are absolutely chuck full of kindness and humanity and sympathy and empathy and just wonderful people" (P10).*

This showed that participants got back what they put into the hospice as there were defined personal benefits. This may have helped to mitigate against the challenges.

Some participants felt that it was important to do well in their roles, for example fulfilling patients' needs and coping with the emotions of working in an end-of-life setting. A volunteer driver found a patient dead when he arrived to pick him up and said:

> *"That was it…I didn't crumble or anything…I don't know whether I had a cup of tea. I think I went home…I can't remember. It was so long ago" (P2).*

He minimised this experience and portrayed that this had not affected him. He may have felt he would not be effective in his role if he let his emotions show or it could have been a coping mechanism to enable him to continue:

> *"I think you just get immune to it. It just goes in at one ear and out at the other. Because, if you let it play on your mind you wouldn't do it you know" (P2).*

Others felt as though doing well meant making patients feel comfortable and being very considerate of their needs:

> *"You've got to make sure you don't overwhelm the people. You're not in their face…So, it's trying not to be over, it's not called overfamiliar, it's…You're not trying to be in their face" (P9).*

Most participants experienced being a visitor in the hospice prior to volunteering. They discussed changing roles from visitor to volunteer, the reasons they wanted to do this and what it meant to them:

> *"…when I came in, recognised the people as I say some of the nurses who were caring for my wife were still here and still are. So, I felt that was nice, you know" (P7).*

Some participants wanted to maintain a connection with the hospice and be closer to their loved ones. They described their experiences as visitors and how they had developed as volunteers:

> *"I was…inconsolable at times and the nurses would sit with me in the relatives' room and I'd have a natter with them…I just really warmed to the place…it's just such a comforting place…I'd said to my friend…"I want to get involved in the hospice, I want to give something back". I think what they did for her was absolutely marvellous and you just couldn't have asked for better care and I promised her that I would get involved in the hospice, so I did" (P6).*

However, this participant also discussed the hospice being different to what she had experienced as a visitor and that this was difficult to accept:

> *"That was my first kind of seeing the nurses as different people…I almost nearly regretted it. Coz I…wanted that same feeling that I had when that nurse was comforting me that day. I wanted that kind of environment all the time, just to be that whole kind of, like you're in a big woolly blanket. And it wasn't" (P6).*

This participant felt that the nursing staff did not have as much time for her as they did when she was a visitor and it appeared that she felt less important to them. This was a shift in their relationships she had to learn to manage. Overall, participants had a strong desire to be part of the hospice community and reaped benefits from volunteering.

Theme three: Managing death

Volunteers' views on death and not being frightened by it are discussed within this theme, including beliefs about life and death and how these impact on the fulfilment of their role.

This section also discusses acceptance of life and death and how volunteers' have learned to manage patients' fears about dying.

Participants expressed how death not frightening them enabled them to effectively support people at the end of life. P10 described differences between her perception of death and other people's views on death:

> *"Some people are terribly afraid of death, they don't want to be anywhere near it and yet it can be beautiful when people are slipping away calmly and serenely" (P10).*

It seemed this participant had considered people's differing experiences of dying which could help her to support patients and families. She described why she is not frightened of death and how she managed her feelings around this:

> *"I just think none of us have any control over it…What's to be will happen…I'm a firm believer that you don't get bigger problems than you get strength to bear them... I suppose that's perhaps faith based in a loving God"(P10).*

She appeared to value having a faith that supported her to make sense of and cope with death. Others spoke about death more frankly:

> *"I just accept life and death as it is" (P9).*

> *"I blank it, it doesn't bother me at all…time and time again…they die" (P2).*

Participants discussed their personal beliefs regarding life and death. P2 described death and illness not discriminating against people based on their status within society:

> *"…as you know with cancer it doesn't stop. It affects all walks of life. I had…the retired head of a sixth form college in the front and in the back, I had a binman. A road sweeper…these people went together in the hospice and they were all one really because whatever they did in their life, it didn't matter…". (P2)*

This participant considered people's roles in society and equality. This stood out to him as a meaningful experience. Another participant spoke about a hunger for life and being grateful for the time you have:

> *"I think with life you just want every day you can have…I always say your greatest gift is the fact you've been born. You know, the fact you've got life and can experience life and I find you can, you can have a quality of life even if you're severely disabled or sick" (P8).*

Quality of life was important, and P8 tries to support patients to have the best quality of life possible.

Some spoke of their beliefs that death was meant for older people. Multiple participants discussed finding it more challenging to accept the dying and death of younger patients:

> *"…when it's somebody young with a young family they've not really had life have they? So, in some ways they've been robbed of what people normally expect from*

life…Whereas somebody who's got their grandchildren…It's sad when anybody died but least, that's life isn't it?" (P8).

It seemed that there was more of an acceptance amongst participants when the patient had experienced a full and long life.

Participants also discussed patients' experience of dying and how they support patients in their hospice journey. Participants described how they experienced patients when they first came to the hospice and how patients' fear subsided:

"They come in so trepidation and then you can sort of see the relaxing and feeling at home" (P8).

Participants seemed to work hard to make patients comfortable and wanted to distil fears. Some felt this initial fear was due to people's perceptions of what a hospice would be like:

"It's the word hospice that puts a lot of people off. And I just say, 'it's nothing like that'. I don't come away upset or thinking about it because they're all lovely, it's calm, it's a nice, calm place. There's no screaming and carrying on" (P5).

One participant described conversations with patients about the perceptions of hospices:

"*There was only conversation yesterday amongst patients. Saying please distil the myth that a hospice is somewhere to go to die. You know, that it's not and it' so much more" (P8).*

This could put responsibility onto volunteers to share their experience of hospices within their communities.

Participants found that some patients were at peace with dying:

> *"…sometimes it's those last weeks that give people a certain dimension…A chance to make peace with their family and say goodbye and perhaps right life's wrongs…this chap…He said, "oh I've said all my goodbyes" he said, "I'm ready". And I thought gosh that's marvellous isn't it to be able to say that" (P10).*

This participant was shocked that a patient would be at peace with dying and may have, more often, experienced patients being fearful of death. However, she also spoke about her general experience in the hospice which indicated that patients do tend to be at peace:

> *"There are some tears shed but very often there are smiles as well" (P10).*

Another participant described the importance of being alongside patients during their time in the hospice:

> *"I never used to like to think that anybody was on their own. I would even, on my break, go and have a cup of tea with someone you know just to be there. And the family would come then, and I'd just go walk away" (P5).*

This also indicates this participant's belief that family should have space with their loved ones and volunteers should have an understanding of their place within the hospice.

Overall it seemed that participants managed death well and had strategies to assist them with this. However, certain experiences were more difficult, such as seeing younger patients approaching the end of life. Participants were able to speak openly on their beliefs about life and death.

Theme four: The importance of connection

A widely reported concept across participants was the connection that volunteers form with patients and the relationships that form between volunteers. Also included is how volunteers feel everyone should be valued, the importance of support, flexibility and how much patients share with volunteers about their personal life. The value of volunteers' personal experiences of death and dying and the impact of this on their role is considered. Some volunteers appeared to hold the hospice in an idealised light due to their own connection with the hospice and this is also discussed.

Participants discussed the strong connections and relationships formed with patients. Volunteers can spend extended periods of time with patients:

"You're talking about relationships that go over a sixteen-week period" (P3).

This indicates that the length of time can impact on the intensity of the relationship. Forming long-standing relationships with patients can be challenging when this ends:

"It's very upsetting because you've been with that man or that lady for sixteen weeks and then they go…it's a shame when the sixteen weeks come to an end" (P4).

It can be challenging for volunteers to manage the high turnover of patients after getting to know them and supporting them. This is understandable as one participant explained:

"Sometimes they share some quite private information" (P7).

In social relationships more generally, if someone is sharing personal information it can form stronger connections as this shows the development of the relationship. Participants discussed how they connected and formed good relationships with patients:

"I think our role is to be a listening ear and let the patients talk to us about things that perhaps they don't want to burden their family with" (P10).

Although this could also be an emotional burden for volunteers, some participants spoke about the enjoyment they got from connecting with patients and meeting new people:

"It's a learning curve…you pick something up new every day…people with so many different tales to tell…I find it interesting" (P2).

It seemed that volunteers would become acquainted with many patients and needed the quality of confidence to initiate that conversations:

"…you don't know who they are. But it's just that you know, just that bit of friendship if you will" (P3).

One participant described reciprocity that developed in her relationship with patients:

"When she was in the hospital she'd be saying, "I don't want you walking down them corridors on your own"…she's worrying about me…so you can get it both ways…They get to know you and care about you as much as you hopefully care about them" (P1).

It seemed important for her to know that she was valued by the patient. Reciprocity appeared to be reflected widely in relationships between volunteers and patients and sometimes with family members. Participants could form quick and safe connections with family members of patients:

"I just talked to her and just while she composed herself…I just gave her a big hug and she was crying but it was…like a little private moment really. For her. For me. Just thinking that, there's me who she only knew very vaguely but she was being very open with me and then she was hugging me and crying" (P7).

It seemed important to this participant that support was provided for family members and he appeared to find the moment special. He described another experience:

> *"I'd sit with his wife and just, she would just offload and be in tears and you know she would just be letting it all, because she was under tremendous pressure and stress" (P7).*

With family members that volunteers have connected with, it can be challenging to identify when to cease communicating with them after the death of their loved one. P1 managed this by being guided by the family:

> *"If they wanted to cut off dead, you know sort of when the person passes, fine…But if they need a little more sort of slowly releasing then I'm happy with that as well.".(P1)*

However, the family's needs may not reflect what is most suitable for the volunteer.

Participants discussed the value of connection with other volunteers and the hospice. Some felt that the hospice provided them with community and fulfilment in life:

> *"I do think you have to seek out community…no man is an island" (P10).*

Similarly, P2 said:

> *"I don't have any hobbies…So, it's just a way, it just keeps me going and gets me up and gets me out" (P2).*

P4 described the togetherness of staff and volunteers:

> *"It's like we're all a team…there's no difference between paid staff and volunteers. We're altogether there with the patients doing what we want to do for them" (P4).*

This indicates the value in paid staff and volunteers being treated equally and supporting volunteers to feel valued and connected to the hospice. Participants valued the connection with and enjoyed their time in the hospice. P3 feared that this would end based on previous experiences volunteering and said:

> *"That's what I'm frightened of here…that you see something that you're not keen on…Is that being naïve of me? That everything should be sort of sweetness and light". (P3)*

It seemed as though this participant had idealised what the hospice should be like and did not allow room for error. However, they had awareness of this which is important.

Connection played a huge part in the volunteers' role with patients, other volunteers and the hospice. Humans seek connection and, for some volunteers who lived alone, it provided them with a community that they were not receiving elsewhere.

Discussion

Main findings

Being a palliative care volunteer impacted on emotional well-being positively and negatively. Positive impacts included feeling 'it's where I'm meant to be' and 'the importance of connection'. It enhanced the volunteers' lives in a variety of ways. 'Managing death' could have a positive impact as it helped participants to understand their beliefs about life and death

thus contributing to personal development, however they also had to find ways to manage patients' fears about death. Negative impacts included challenges and frustrations that the role brought: 'it can be challenging'. These are important considerations in understanding support volunteers could benefit from.

Strengths and limitations

This study aimed to give palliative care volunteers a voice about how their role impacts on emotional well-being to widen the evidence base. Hospice staff did not know which volunteers were participating unless the volunteer chose to disclose this which provided an opportunity for participants to confidentially share their experiences. The data collection process was flexible, with the interview location chosen by participants; this could have supported the uptake of respondents and contributed to the sufficient data collected. Hospice volunteers were consulted on the research materials and suggestions were incorporated. This involved them in the research design which has been argued to improve the quality of research(53). The COREQ(54) reporting guidelines were adhered to.

Participants may have felt a loyalty to the hospice, therefore could have focused more on positive experiences. The self-selection of participants may have meant that those who participated had stronger or more positive views and may not have been representative of the wider volunteer population. For a more balanced view and to understand the wider experience of palliative care volunteers, it may have been useful to interview volunteers who had ceased volunteering as they may have found the role more emotionally challenging. Participants were obtained from a limited number of hospices due to time constraints. All participants were white British so there was little demographic variability, however this is representative of the palliative care volunteer population in the area. Hospices in other areas

may have more demographic variability and possibly different experiences. This limits the transferability to other settings; however, homogeneity is a feature of IPA, so this is not problematic(47).

What this study adds

Difficult experiences were central to volunteers' roles. Previous research identified that challenging experiences can include seeing suffering, particularly in younger patients(55)(56), time constraints for volunteers(57), not feeling confident in communicating with patients and how well volunteers' felt they were fulfilling their role(58). These were also identified in the current research. Additionally, challenges of 'not being good enough', not being able to do 'enough' for patients and challenges regarding the hospice and its processes were identified. This included some participants reporting a lack of information about patients difficult and could affect them doing their role effectively. Nurses have supported this by indicating that feeling that volunteers should be aware of the patients' diagnoses and how they could support them effectively(59). These additional challenges are important as restrictions on information, and possibly on what volunteers can do with patients, could adversely affect the impact a volunteer can have(60) and it can be helpful to pre-warn volunteers about patients with physical disfigurements(61).

Previous research has identified boundary challenges, for example the patient not wanting the volunteer to leave could be difficult to manage(57). Being able to emotionally detach from patients has been found to be an effective coping strategy for some(60) whilst others use strategies which could be categorised as meaning-making through appraisal(57)(32)(56), problem-focused coping or emotion-focused coping(57)(32). The current study highlights boundary challenges with some volunteers wanting the hospice to allow the maintenance of

relationships with patients after they had left the hospice in contrast to others who discussed the importance and challenge of boundaries. It is useful to understand more about volunteers' boundaries as it could be a challenging balance when trying to maintain positive relationships and recognising personal limits and risk of burnout. It was important for participants to learn how to manage emotionally to enable them to continue volunteering. Personal faith was important for one participant, however she appreciated that others' faith needed to be respected; this is identified as meaning-making through appraisal(57)(32)(56). Others used internal support mechanisms, for example speaking with volunteer coordinators (problem-focused coping) or other volunteers, friends and family (emotion-focused coping)(57)(32).

Previous research has discussed some existential considerations for volunteers in palliative care(62) however, there has been little research into the effect volunteering in palliative care has on the individual's beliefs about life and death, with research focusing more on the psychosocial benefits of volunteering(63)(64). Most participants in the current research expressed that death did not frighten them which enabled them to volunteer. They also discussed their beliefs about life and death and that volunteering sparked existential considerations.

Previous research has identified many positive impacts of being a palliative care volunteer(65) including how the development of empathy, compassion and acceptance can positively impact the volunteers' wider life(58)(66) as well as the development of a sense of happiness and feeling useful, thus being personally rewarding(62)(56)(67). It is also widely reported that volunteering is positively associated with better emotional well-being during older age; this could be due to a sense of accomplishment and a bigger social network therefore indicating personal gains(68). The current research supports these understandings of

the positive impact of volunteering of emotional well-being including how volunteering is a huge part of the volunteers' lives.

Connection between volunteers, staff and patients were central to volunteers' experiences. Closeness could be represented by hugging, holding hands and crying together(56) and reciprocity within the patient-volunteer relationship is also shown(58). Reciprocity is an outcome of social exchange and can influence social support, physical and psychological well-being, particularly later in life(69). The role of a volunteer is social in nature and relationship building is important to both volunteer and patient(70). Volunteers also built relationships with patients' families who have rated palliative care volunteers highly on a list of characteristics and qualities(71), indicating that they value their input. The current research supports the importance of closeness, connection and reciprocity between patients and volunteers and enabled volunteers to feel valued as they could recognise patients' needs and do things that would be useful and appreciated. The current research showed that it was important for participants to feel connection to the hospice itself but also to other volunteers as this could provide another layer of support(60). The personal growth experienced by participants could counteract stressful or challenging experiences within their role(72). It is important for hospices to understand the aspects of the volunteers' role that are valued so highly to be able to promote this further thus impacting positively on volunteers' emotional well-being.

Recommendations for future research, policy and practice

Policy makers and practitioners should consider running focus groups with volunteers to discuss helpful coping mechanisms, where they might seek professional support and channels that could be accessed to discuss patients with whom they are struggling. This could identify

gaps in knowledge and availability of support. Reflective practice groups, led by clinical psychologists, could be useful for volunteers to discuss patients and families. Clinical psychologists would be well placed to deliver this and are increasingly providing this to paid staff. Reflective practice groups could be a space for volunteers to bring difficulties or to teach and discuss different aspects of therapeutic relationships, for example alliance ruptures, the emotional impact this could have and repairing ruptures. Similar strategies have been useful in supporting nurses in oncology and palliative care, for example providing education and training in how to manage stress, process emotion and learn from their experiences(73). This would help to foster resilience in volunteers and, as working in palliative care can be challenging due to death exposure, it is important to promote resilience as an available resource(74). However, it is noted that service pressures can limit the opportunity for such groups(75). Clinical psychologists would also be well placed to discuss common factors(76) to combat feelings of not being 'good enough' or not having enough skills. This could support volunteers to understand that no specific training is required to support someone at the end of life as the relationship with a patient is most important. As volunteers spend the most time with patients, it may also be useful to help them identify when a patient needs extra support and a referral to psychology.

Future research could focus on gender differences between volunteers and how they experience their roles. Research with people who decided to stop volunteering may also be useful to understand if there were any particular challenges or stressors.

Conclusions

The current study offers insights into the impact of volunteers' roles on their emotional well-being. Although there are psychosocial benefits for volunteers, it is also important to consider challenges and offer ongoing support to help volunteers manage these challenges.

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Appendices

Appendix A – Guidelines for publication

Palliative Medicine **Instructions to authors**

At *Palliative Medicine* we want to publish the highest possible quality of papers. Our instructions to authors therefore focus on what we want you to do to enhance the quality of your research reporting. We only have space for around 20% of papers submitted to us, so paying attention to high quality research reporting will enhance the chance of us being interested in your paper.

There are TWO mandatory uploads together with your paper: the reporting checklist for your study type and the authors' checklist to acknowledge that you have followed the instructions below.

These instructions to authors fall into four main sections.
First, an explanation of the type of papers we are interested in so you know you are writing for the right journal. **Second**, a clear description of what we want to see in your writing which you will need to take account of when you are drafting your paper, to promote the highest possible quality of reporting.
Third, specific instructions on formatting etc., as well as more detail on reporting specifications to meet journal and publisher style requirements.
Fourth, information on how to submit your article and what happens after you have submitted it, including information on Open Access options and publicising your published paper.

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1. What type of papers do we want to publish?

a) *Palliative Medicine* is a highly ranked, peer-reviewed scholarly journal dedicated to improving knowledge and clinical practice in palliative care. It reflects the multi-disciplinary and multi-professional approach that is the hallmark of effective palliative care. Papers are selected for publication based on their scientific excellence, contribution to knowledge, and their importance to contemporary palliative care. We welcome papers relating to palliative care clinical practice, policy, theory and methodological knowledge.

b) *Palliative Medicine* is an international journal with authors, reviewers and readers from around the world. You must make sure that your work is contextualised for such a readership, and where research is conducted within a single country, how the results contribute to an international knowledge base.

c) *Palliative Medicine* is a research journal, and primarily publishes papers which report original research and systematically constructed reviews. We also publish short reports, service evaluations/audits, research letters and case reports occasionally, but if you are

considering submitting these types of papers please take time to read our specific guidance on them below.

d) *Palliative Medicine* is the official research journal of the European Association for Palliative Care and a journal of the Association of Palliative Medicine. This Journal is a member of the Committee on Publication Ethics. This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

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2. How do we want papers to be written?

All papers submitted to *Palliative Medicine* are scrutinised carefully by a number of members of the editorial team before being sent for external peer review. A substantial number are declined at this point, before peer review. Common reasons are that the papers report work which does not appear to be novel or does not add to knowledge explicitly, or that the design or methods of the study are not appropriate to the question posed or poorly reported. We strongly suggest therefore that this information on writing and reporting is followed whilst drafting your paper, well before you consider submission to the journal, as there is evidence that this will enhance the clarity of your writing and message to readers. The SAGE Author Gateway has some general advice on how to get published, plus links to further resources.

a) ***Reporting guidelines***. All papers must be written following appropriate reporting guidelines, and a reporting guideline checklist indicating where required elements are found in the manuscript must be uploaded at the time of paper submission as a mandatory file (excluding research letters). A full list of reporting guidelines is found on the EQUATOR network website. Guidelines are known to improve the quality and comprehensiveness of research reporting, and we expect all relevant aspects of the guideline to be followed. Common guidelines include CONSORT (with any relevant extension) for trials, COREQ for qualitative research, PRISMA or ENTREQ for reviews. Interventional studies must also describe the intervention according to the TIDieR guidelines.

b) The ***key messages*** of the paper must be easy to see and interpret for readers. For this reason we ask you to pay close attention to the title, structured abstract and key statements. For some readers this may be all they look at to decide if they are interested in your paper, so they have to be informative, accurate, and meaningful to clinicians, researchers and policymakers. We have recommendations on titles, abstracts and key statements which are designed to improve the discoverability and usability of your papers and it is important that you read these and incorporate them into your manuscript.

c) Full details of ***ethics/research governance/data protection approvals*** must be given, with reference numbers, full names of the committee giving approval, and the dates of

approvals. If research ethics committee/IRB approvals were not required for your work please reference the law or regulation granting exemption, and/or submit a letter from the relevant authorities granting this study exemption. This must be clear within the body of the paper. We expect in all circumstances that the highest possible standards of research ethics and governance are followed and demonstrated throughout the paper.

d) The ***discussion section*** of your paper must be structured, to enhance readers' ability to find the information about your work and its applicability. We ask that you provide clear subheadings which address:

i) ***Main findings/results of the study***: A short statement of the principal findings of the study should be presented.

ii) ***Strengths and weaknesses/limitations of the study***: A discussion of the strengths and weaknesses/limitations of the study with reference to other studies or reviews in this area.

iii) ***What this study adds:*** A discussion of what is already known about this topic area and what this research/review adds, and a clear discussion of the implications of the research/review for clinical practice, theory or methods in this area. We suggest that you raise further research or review questions.

Specific instructions on titles, abstracts, keywords and key statements for all papers

a) **Titles**. A significant proportion of readers come to the *Palliative Medicine* site by running simple searches. It is important therefore that an article's title, keywords and abstract are written to be optimally "discoverable" by search engines. You must ensure that the main key phrase for the topic is in the article title. Make sure the title is clear, descriptive, unambiguous, and accurate, and reads well. Titles must include details of the methods used within the paper. We do not recommend the use of country names in titles as there is evidence this can restrict readership, countries can be mentioned in the abstract. There is evidence that putting the findings of the paper in the title can attract readership. An example of such a title would be: *Intervention A leads to a greater reduction in (primary) outcome x for people in their last year of life, compared to intervention B: A pragmatic randomised controlled trial*; or *The experience of X is challenging for family carers of people with advanced cancer: An ethnographic study*.

b) **Abstract**. Key tips for discoverability include repeating key phrases within the abstract and between the abstract and keywords – think about the key phrases you would type into a search engine if you were searching for the article. Repetition of a particular key phrase may strengthen the ranking of the article. Please read and follow these guidelines: http://www.uk.sagepub.com/authors/journal/readership.sp. Abstracts should not contain abbreviations or references. All our abstracts are structured, and should follow the formats below. There is some flexibility for audit/service evaluation as it is important that these are not presented as research:

i) ***Research Paper/Short Report/Audit/Service Evaluation abstract (250 words):***

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.

Aim: A clear statement of the main research aim(s), research question(s) or hypotheses to be tested. *Design*: A statement about the research strategy adopted. For intervention studies, a clear statement of the intervention is required. For clinical trials, the trial number should be given. Give brief details of data collection methods. For interventional studies please add a sentence about the intervention tested.

Setting/participants: Indicate the type of setting(s) the research was conducted in (e.g. primary/secondary care), the number of centres, and who participated, including a brief indication of inclusion/exclusion criteria, numbers of participants and any relevant characteristics.

Results: Report the main outcomes(s) or findings of the study. If appropriate, report levels of statistical significance and/or confidence intervals.

Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology. Give suggestions for further research.

ii) Systematically constructed review abstract (250 words)

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.

Aim: A clear statement of the review aim(s).

Design: A statement about the review strategy/methods adopted (e.g. meta-ethnography, realist synthesis, systematic review, meta-analysis). If prospectively registered (e.g. on PROSPERO), this information should be given here.

Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal.

Results: Report the main outcomes(s) /findings of the review.

Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

iii) **Case Report and Case Series abstracts (200 words)**

Both abstract and full submission should follow the same structured format of:

Background (including existing evidence, literature and related cases in the public domain)

Actual case including details of the practice challenge and details of ethical review

Possible courses of *action*

Formulation of a *plan*

Outcome with timescales and how success /failure was judged

Lessons from the case

View on research problems, *objectives or questions* generated by the case

c) **Keywords.** Please give at least four key words, and up to eight. At least one should be subject-related, and at least one relate to your chosen research design. All keywords should be MeSH headings and should be checked against this list http://www.nlm.nih.gov/mesh/. Please provide a justification for any keywords which are not MeSH headings.

d) **Key statements**

Palliative Medicine has a system where all research and review papers (not letters) are required to state clearly what is already known about the topic, what the paper adds, and implications for practice, theory, or policy. You are required to give these at the start of the manuscript, as part of your manuscript text. Please use these three specific headings (see below), with 1-3 separate bullet points for each heading. Please use clear, succinct, single sentences for each bullet point rather than complex or multiple sentences.

What is already known about the topic?

Short statement(s) about state of knowledge in this area.
You may highlight both what is known and what is not known.
Be specific rather than making broad or sweeping statements. Avoid statements such as 'little is known about ... x or y' in favour of statements specifying exactly what is known.

What this paper adds

Short specific statement(s) about what this paper adds.
These should be styled in terms of outcomes where possible (This study demonstrates that x intervention has a (specific) impact on y outcome) rather than study aims or process, (This study considers whether x intervention has an impact of y outcome).
Be as specific as possible. Avoid broad statements such as 'New Knowledge is added about ... ', rather be specific about exactly what this knowledge is. For example, rather than 'We add to the knowledge base on x' we would prefer the more specific statement 'x variable was found to increase the experience of y outcome (by z amount)'.
Ensure that these statements clearly relate to the findings of the study.

Implications for practice, theory or policy

Short specific statement(s) on the implications of this paper for practice, theory or policy. These should clearly draw from the findings of the study, without over stating their importance. to an international readership.

Specific guidance on paper types and word limits

a) ***Review Articles*** – 5,000 words. The reviews we publish are usually systematically constructed reviews, clearly following the relevant publication guidelines (such as PRISMA, RAMESES or ENTREQ) for the particular review style chosen. We are happy to consider a range of review types (systematic reviews, meta-analysis, metaethnography, realist review for example) for publication, but they must be methodologically clear and rigorously conducted. If reviews are registered (e.g. on PROSPERO https://www.crd.york.ac.uk/PROSPERO/) this should be stated and a link given within the paper. Please ensure that you include a PRISMA type flowchart for all reviews to enable readers to understand your search processes. All reviews should include sufficient detail on review question, inclusion and exclusion criteria, search strategies, data extraction and synthesis methods (as appropriate to the review design) for the study to be replicated. Please include a table of included studies. If some of these are large, you can consider

adding them a supplementary online only files, but these must be referred to within the text of the review. Please note our specific requirements on review abstracts above.

b) ***Original Articles*** – 3,000 words with up to six tables or figures. Original articles must report robust, ethically conducted research. We publish research using a range of designs, as appropriate to the question posed. Please see general advice above for information on the relevant reporting guidelines which must be followed, and our title and abstract requirements. Please also look at instructions for short reports and research letters which may be a better 'fit' for papers reporting smaller pilot, exploratory or feasibility studies.

For trials and interventional studies, we expect that the intervention is fully described using accepted guidelines (e.g. TIDieR) as well as being reported according to the appropriate guidelines (e.g. CONSORT or one of its extensions). *Palliative Medicine* endorses the ICMJE requirement that clinical trials are registered in a WHOapproved public trials registry at or before the time of first patient enrolment. However, consistent with the AllTrials campaign, retrospectively registered trials will be considered if the justification for late registration is acceptable. The trial registry name and URL, and registration number must be included at the end of the abstract. If the protocol has been published this should be referenced within the paper.

For papers reporting qualitative methods we prefer papers which state their particular qualitative approach (e.g. grounded theory, phenomenology, ethnography etc.) and articulate their methodological (epistemological and ontological) position, how this relates to their question and design, and which present a so called 'thick' description and interpretation of their findings clearly. Participants' quotations may be excluded from the word count, and we prefer that they are integrated into the text rather than presented separately. We still prefer, however, that these quotations are succinct and carefully chosen – it is rare that more than one quote is required to illustrate the point being made.

Papers which report primarily the development or testing of scales/measures or questionnaires must include a copy of the relevant instrument as a supplementary file (with translation into English if appropriate, as well as in the original language), and such papers will not be accepted without such a file. Authors are expected to obtain any copyright permissions required for such reproduction.

For research articles, authors are required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Full details of all research ethics committee (e.g. IRB) and/or organisational governance approvals must be given within the body of the text with reference number and date of approval. If such approvals were not required, information about the exemption from this (and on what authority) must be given within the text of the paper.

The date(s) of data collection must be given within the paper. If your data were collected more than five years before submission we expect a strong justification for why reporting these results is still relevant to the *Palliative Medicine* readership.

c) ***Short reports*** – 1,000-1,400 words. These should report research, but are usually small scale survey/pilot/feasibility studies etc., which would not warrant a full original research paper. Please see the original article section above for general instructions.

d) ***Case & Case Series Reports*** **-** A good case report, or preferably a case series, can inform an important part of healthcare development and improvement through the creation of links from practice to research and back to practice. To do so it must provide close analysis of practice-based examples, giving insights into what happens in clinical and other practices when empirical evidence-based options have been exhausted, and identify potential 'golden nuggets' to signpost for further research exploration.

Palliative Medicine is a research journal. As such we are interested in case and case series reports which achieve these goals. We publish case reports to highlight issues of practical interest and identify research questions for further study. Research focused learning points must be explicit within the report.

We understand a case series can legitimately be identified and analysed retrospectively, particularly in areas of evolving and challenging practice. However, prospective planning of data collection will usually strengthen the findings and implications and if so if you are planning a case study series using prospective research methods please review this methodological paper http://journals.sagepub.com/doi/pdf/10.1177/0269216311419883 and consider whether to submit your work as a case series report or an original research article, with appropriate justification of your choice in your covering submission letter.

Essential elements of a case or case series report in *Palliative Medicine:*

- There must be a clear practice-based challenge that the report seeks to address: the challenge may be related to physical (e.g. medications and symptom control), social, psychological, spiritual or ethical issues but it must be a challenge faced in frontline palliative care practice.
- Evidence of reasonable international literature review, including other case reports or series on the same / similar subject matters must be included as must evidence of seeking to identify consensus of practice internationally regarding comparable cases.
- When similar cases or case series have been previously published then submitting authors are required to create a referenced case series from the previous cases as background to their own and to highlight how this informed actions in their own cases. In addition, submitting authors must justify how a further publication will take the field forward.
- The actual cases should be presented briefly (150 words or less is recommended) at the start of the submission, followed by up to four

possible courses of action posed in response to the question ‘What would you do next?’

- A clear explanation of how a plan was prospectively formulated to assess the options and manage the case must be given. This should include the theoretical basis of any interventions and the underpinning reasoning behind decision making.

- Explicit details of critical elements of the case should be given, while seeking to preserve anonymity of individual patients / other persons not included in the authorship of the submission. We expect the majority of cases to be anonymised to the extent that someone who knew the patient could still not positively identify them. If this is not possible, for example because specific details or photographs are required to present the case, then

  there must be inclusion of a statement within the submission confirming that all individuals and organisations potentially identifiable from the case have agreed to its publication. Further to this, copies of written informed consent from patients and other non-professional members of the team as well as any professionals should be submitted as supplementary files. This must include the provisional title of the submission, consent for all material (including photos, images, text or other material) to appear in the Sage publication *Palliative Medicine* and related forms of publication such as, but not limited, social media associated with the journal, blogs and press releases. The person consenting must confirm they have seen the material, read the submission and that they are legally entitled to give their consent. They should confirm that they understand publishing of the material without their name attached does not guarantee complete anonymity as it is possible someone may recognise them or their case. They should confirm that they understand potential distribution is worldwide and access is not controlled by the journal or Sage, and also that they will not receive any financial benefit from publication. They must confirm that they understand consent cannot be revoked post publication and that their consent form will be retained securely by Sage.

- If the patient has died, we would expect the authors to request permission from a person with Lasting Power of Attorney or in the absence of LPA, a relative, and to make this clear on the consent form and in the submission. If no written consent is possible from either the patient or relative, we will consider the utility of the case carefully against the likelihood of identification or potential distress. It is likely that in this position more information will have to be removed from the case to reduce the possibility of identification, and this will have to be made clear in the submission.

- Details of any relevant ethical approval processes for interventions should be included. In the event of a submission describing an intervention not subject to formal governance or ethical review then authors should provide justification of the reasons for this e.g. not required in the local jurisdiction for this type of research, clinical cases were shared decision making took place for a novel management with a specific patient and set of clinicians in the absence of no other options and in response to an urgent need. It would still be expected that such cases would have been discussed, including potential ethical issues, among the clinical multidisciplinary team and an explanation of this and how the work/practice was conducted ethically and with integrity must included in the submission. Authors should include explanation of how any novel treatment was discussed with patients prior to use.

- We are particularly interested in how case / case series submissions might direct and instigate further research and ultimately lead to better evidenced practices:

    - The outcome of the case / case series with details of any outcome measures used should be given.

    - The case must conclude with a view on research problems, objectives or questions generated through the challenge of the case and how these might be addressed. In simpler terms this might be posed as answering a 'so what?' question.

- While not specifically excluded extremely rare cases are likely to be of less interest to our wider readership and so priority will be given to publishing cases that build a picture of contemporary practice and collective consensus on managing issues at the frontline of practice while awaiting further research evidence.

- Appropriate case / case series EQUATOR reporting guidelines should be used. See:
  https://www.equator-network.org/

- The submission must not exceed 1500 words plus 2 tables or figures, acknowledgements, 10 references, and a 200-word structured abstract plus separately three key learning points (written as 1-2 sentence bullet points) for practice / research.

Further requirements:

- Case reports / case series should include the words 'case report' or 'case series' as appropriate in the title and keywords. Please do not use 'case study' as this leads to confusion with the research strategy of the same name.

- Drug names should be generic not proprietary.
- Details of management should be specific and described to be understandable by those who may follow different protocols in different contexts.
- Both abstract and full submission should follow the same structured format of: ○ Background (including existing evidence, literature and related cases in the public domain)
    - Actual case including details of the practice challenge and details of ethical review ○ Possible courses of action ○ Formulation of a plan
    - Outcome with timescales and how success /failure was judged ○ Lessons from the case
    - View on research problems, objectives or questions generated by the case

e) **Practice Reviews** - can either be commissioned by the Editor in Chief or agreed by submission. For the latter an initial outline pitch of a practice review proposal should be submitted for consideration by the Editor in Chief by emailing Debbie.Ashby@bristol.ac.uk in the first instance rather than a submission being made directly through Manuscript Central. This should include a brief summary of the anticipated extent and quality of literature supporting the proposed review.

Not all submitted proposals will be accepted, and for those that are, there may be an informal work-up process required to reach agreement prior to the pitch being accepted. **The review must have its own novel research question that the authors seek to answer** (or if an update of a previous review, justification for why an update is needed e.g. significant time has elapsed and there is a significant body of new empirical evidence).

Once accepted pitched proposals will proceed in the same way as commissioned reviews. Commissioned reviews will occur a few times a year and may be related to themed issues, virtual issues or stand-alone. All reviews will be subject to peer-review, when possible by a member of the journal's Editorial Board in addition to external review.

The purpose of practice reviews is to provide a 'stock take' or overview of the current 'state of the science' in an area of practice with a supporting evidence-based summary of guidance and recommendations which can be drawn from evidence about what is known to be beneficial or not. Reviews might cover newly emergent 'hot topics' but equally might be the basis of establishing the need for further research in a long-established topic area by considering the evidence base on which current practices are based and what would take the field forward.

Practice review subjects can be clinical, ethical or relate to another aspect of palliative care such as spiritual, social or psychological care or professional development. Review subjects which are relevant to the shared practices of multidisciplinary teams are particularly welcome.

Reviews should both orientated to recommendations for frontline practice and identification of scientific equipoise, i.e. absence of studies, with suggestions for further research. The implications of the review findings must be considered from the perspective of policy-makers, researchers, clinicians, ethicists and funders of research or quality improvement interventions. Review authors should aim to give a clear steer on what might be the most important gaps to be addressed through further research.

Purely descriptive summaries of evidence will not be accepted.

We ask that these aims are achieved by following the structure below in order to generate learning for both our practitioner and researcher audience. We are very grateful to Erik Driessen, Editor-inChief, and Robert McKinley, Section Editor, *Perspectives on Medical Education* for letting us adapt the format (McKinley, R. & Scheele, F. Perspect Med Educ (2015) 4: 275. https://doi.org/10.1007/s40037-015-0230-8; https://www.springer.com/education+%26+language/journal/40037?detailsPage=editorialBoard
).

Review presentation and structure - submitting authors should provide an overview of "Dos, Don'ts and Don't Knows" on a specific subject in clinical practice. Following a brief introduction, including the context, scope and methods used to conduct the review the remainder of the submission should be divided into a tabulated digest summarising each aspect of the evidence item by item and a review article providing the relevant supporting evidence, and indicating the strength of the evidence for each particular item.

- Dos – should be recommendations for practice that can be made with a supporting body of evidence for effectiveness or efficiency.
- Don'ts – should be recommendations against activities for which there is a supporting body of evidence to show inefficiency, ineffectiveness, or indeed harm.
- Don't knows – should be identified areas for further research as there is either an absence of evidence or the current evidence is unclear or not of convincing quality or rigour. Don't knows should be expressed as questions which if answered through further research would have an impact on clinical practice.

The digest table should be provided using this format:

Table 1. Summary of guidelines/recommendations for XXX

	Aspect A	Strength of recommendation
Do's		
Don'ts		
Don't knows		
	Aspect B	
Do's		
Don'ts		
Don't knows		

The choice of subject for the review should be guided by identification of the subject as an area of importance to clinical practice, in which there is some evidence for aspects of practice. The scope of the review will vary from subject to subject but should be broad enough to take into account different settings, both in terms of considering an international audience and across different areas of palliative care, i.e. hospice, hospital and community. Within the subject the dos, don'ts and don't knows should be items of importance to practitioners and will usually relate to common choices and decisions required in providing clinical care for patients with particular symptoms or diseases. All items should be made as specific as possible. Authors are likely to find it helpful to collaborate as a team and to pull together a provisional list of do's, don'ts and don't knows prior to conducting their review of the evidence which can then be revised in the light of the review findings.

Authors are free to choose their own methodology and methods for the review process, but this must be justified and appropriate to the subject and review question chosen. Practice reviews should be consistent with relevant publication guidelines (such as PRISMA, RAMESES or ENTREQ) for the particular review style chosen. We are happy to consider a range of review types (systematic reviews, meta-analysis, meta-ethnography, realist review for example) for publication, but they must be methodologically clear and rigorously conducted. If reviews are registered (e.g. on PROSPERO https://www.crd.york.ac.uk/PROSPERO/) this should be stated and a link given within the paper.

Judgements about the strength of evidence should allow for multiple types of evidence to be considered so that readers are provided with an overview of what exists. Authors can choose their own framework for assessing the strength of evidence but the review should not be limited to particular types of studies. A useful guide to rating strength is below:

Strength of recommendation:
Strong: A large and consistent body of evidence such as a systematic review

Moderate: Solid empiric evidence from one or more papers plus the consensus of the authors Tentative: Limited empiric evidence plus the consensus of the authors

Review formatting and additional requirements

- In addition to the tabulated digest of recommendations and further research requirements, the main content of the review must not exceed 2000 words
- A PRISMA type flowchart should be included as a supplementary online file
- Included studies must all feature within the reference list and a further table detailing these should also be provided as a supplementary online file.
- Any limits on the timeframe of the review must be clearly justified.
- A structured abstract of 250 words or less must be provided. The structure should be:

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.
Aim: A clear statement of the review aim(s) and / or research question it seeks to answer. Purely descriptive summaries of evidence not synthesised into do's, don'ts and don't knows will not be accepted.
*Desig*n: A statement about the review strategy/methods adopted (e.g. meta-ethnography, realist synthesis, systematic review, meta-analysis). If prospectively registered (e.g. on PROSPERO), this information should be given here. Use of appropriate quality framework / guidelines to conduct the review should be included.
Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal. As a minimum a scoping review using recognised methods must be conducted.

Results: Report the main outcomes(s) /findings of the review. This should include key statements on answering the review question/aims, and the meaning of the findings.
Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

f) ***Audit and Service Evaluation.*** 1, 000 – 1,400 words. We accept audit and service evaluation reports, but these should be of *exceptional* quality and interest. They should be identified clearly as audit or service evaluation in the title. These should be reported robustly – we expect audits to discuss the audit cycle and feedback, and service evaluations to report sufficient contextual information on the service being evaluated. They should be used to raise future research questions. Full details of all relevant organisational permissions and consents should be reported.

g) ***Research letters.*** Maximum 750 words. We occasionally publish short research letters (no abstract required, no more than three references). These are usually offered to authors submitting original papers or short reports which we feel should be disseminated, but in a more succinct form.

h) ***Letters to the editors***. Maximum 500 words. We welcome correspondence relating to issues of general interest to our readership, or in response to a publication. Such letters should be succinct, generally no more than 500 words. NB: word count excludes references, tables and figures' references. We discourage the use of abbreviations strongly unless these are internationally known and accepted. Papers which use non standard abbreviations to reduce word count will be asked to replace these in full, but still adhere to the word count. We particularly ask that there are no abbreviations in the abstract.

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3. Journal publishing and formatting requirements

Declarations. Authors should include a clear declarations section at the end of the manuscript. This should contain five sections on authorship, funding, conflicts of interest, ethics and consent and data sharing. You may also include an acknowledgements section.

Authorship. Papers should have a short section at the end identifying the roles of each author of the paper. Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should check carefully that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

(i) Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data,

(ii) Drafted the article or revised it critically for important intellectual content,

(iii) Approved the version to be published,

(iv) Have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should meet the criteria for authorship fully.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

Funding. We require all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: 'This research received no specific grant from any funding agency in the public, commercial, or notfor-profit sectors'.

Declaration of conflicts of interest. It is the policy of *Palliative Medicine* to require a declaration of conflicting interests from all authors, enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state 'The Author(s) declare(s) that there is no conflict of interest'.
For guidance on conflict of interest statements, please see the ICMJE recommendations here.

Research ethics and patient consent. Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki. Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or IRB provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Please also refer to the ICMJE Recommendations for the Protection of Research Participants

Data management and sharing. SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles. *Palliative Medicine* requests all authors to provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include, but are not limited to, statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. The editor may consider limited embargoes on proprietary data. The editor can also grant exceptions for data that cannot legally or ethically be released. All data

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Section Three: Critical Appraisal

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Critical Appraisal

Findings

There are positive and negative ways that being a palliative care volunteer impacts on emotional well-being. Participants felt ‘it’s where I’m meant to be’ and ‘the importance of connection’. ‘Managing death’ helped some to understand their personal beliefs about life and death thus developing as a person, however it could also be difficult to manage patients’ fears about death. Participants noted a number of challenges and frustrations from volunteering: ‘it can be challenging’. These results help to understand the support a volunteer could benefit from and the focus organisations could take to implement this.

Strengths and limitations

The systematic literature review conducted provided a basis for consideration of the development of the research project. I was able to draw on experiences from the included papers and learn from their limitations, including the quality of methodological reporting. As the review highlighted a gap in the literature regarding research specifically focused on the impact of volunteers’ roles on their emotional well-being, I was able to use this information to inform my design, format and research question.

The research was only conducted with participants volunteering in hospices in the North West of England which, at first, I considered to be a limitation as experiences nationally or internationally could differ. However, interpretative phenomenological analysis (IPA) is idiographic and aims to understand how a phenomenon has been experienced by a homogenous group of people(1) so the lack of variability within the sample was not deemed to be a limitation. IPA is wary of claiming that results can be transferable or generalised to

the wider population, but findings can be cautiously made to a similar sample as it is idiographic(2). Within IPA it is deemed appropriate to consider theoretical generalisability through one's own findings and other research(2). For example, the papers within the literature review indicated that there may be some similarities in the emotional experience of volunteering globally, due to the variation of countries that the included papers came from.

The inclusion criteria stated that participants had to be in patient-facing roles. However, if I were starting the project again, I would recruit 'volunteers who only volunteer in a patient-facing role'. Some participants volunteered in both patient-facing and non-patient-facing roles and sometimes spoke about their non-patient-facing role. I encouraged them to discuss the patient-facing role, however it was clear that both roles were important, and they did not necessarily understand why their patient-facing role was being prioritised in this research. Having volunteers who only volunteered in patient-facing roles would have increased the homogeneity of the sample as it would have made them an even more select group(3). This further supports the theoretical underpinnings of IPA as homogeneity fits with the philosophy and analysis process(4). Patient-facing roles were selected because this group may have different experiences to non-patient-facing volunteers in relation to how their role impacts on emotional well-being: due to their role providing the opportunity to form strong relationships with patients and families. I also anticipated that, due to the amount of time spent supporting patients, they may hear or see more distressing things.

I considered gender differences in emotional experience and expression as there were both male and female participants. Although a common stereotype within society is that women are more emotional than men, it is unclear whether there are distinct differences in their emotional experiences(5). Culture and ethnicity can also affect emotional experiences and

has been widely researched with some viewing emotion as universal and others viewing it as social(6). However, it is not clear whether an individual's culture can affect how they feel and express emotions(7). All participants identified as White British and lived and volunteered in a similar geographical area, therefore I would not have expected to see cross-cultural differences in the expression of emotion. However, if the sample had been more varied, this may have been considered further in relation to the homogeneity of the sample. Another consideration was socio-economic status and how this could affect emotional experiences. The reverse capacity model indicates that those from a lower socio-economic group may have less available psychosocial resources due to more stress exposure throughout life, heightening negative emotions and decreasing positive emotions(8). People from a lower socio-economic background may also show an increased reactivity to stress(9). The socio-economic status of the participants was unknown, however in the geographical areas of data collection there are large discrepancies between people in terms of socio-economic status. This could have affected how participants interpreted and understood their emotional experiences related to their role.

Future research

- Research should focus on volunteers who have ceased volunteering to understand the emotional impact of their role. It is often unclear why people stop volunteering in a palliative care setting. Palliative care settings have a responsibility to understand why volunteers leave and make necessary changes. There may be a number of things we could learn from this, for example people may have needed more emotional support, more flexibility to lessen the impact on their wider life or simply not enjoy the role. Understanding these areas could help hospices to implement increased support for volunteers to addresses some of these issues.

- It would be useful to consider gender and socio-economic differences between volunteers and how the experience of their role may differ. For example, they may have different styles of coping or accessing support within the hospice. They also may have different ideas on what might be the most useful support for them. This would help palliative care settings to understand what would be most useful overall.
- Research with volunteer coordinators and other key staff who regularly interact with volunteers should be conducted, focusing on their awareness of key signs and symptoms of a volunteer not coping effectively and understand what they could do to support them. This would provide information about the level of knowledge and confidence of staff supporting volunteers and if there are any gaps that training or further support could fill.
- If reflective practice groups were implemented in palliative care settings for volunteers, their effectiveness could be evaluated.
- Other studies could look at barriers or challenges to volunteers' self-care to see how palliative care settings could support them in developing methods of self-care.

The relevance to clinical psychology

This research was relevant to clinical psychology as the emotional well-being and psychological needs of hospice volunteers were considered. There was also an attempt to learn more about the advantages and disadvantages of being a hospice volunteer and the impact this could have on an individual and their wider life. Clinical psychologists are well placed to implement support for volunteers or provide consultancy to the hospice surrounding supporting volunteers effectively. Based on the results and the highlighted challenges, this would be useful to set up within hospice settings. This has been previously implemented in a peer mentor service for people with spinal cord injury where clinical psychologists have led

supervision meetings(10). Clinical psychologists are required to provide such support, supervision and consultation to paid members of the multi-disciplinary team in hospices(11)(12), so would be well placed to provide this support to volunteers. Clinical psychologists could also be involved in developing NICE and NHS guidelines, service literature and setting up supervision or reflective practice groups. Clinical psychologists could work more closely with volunteer coordinators to identify signs of distress to look out for in their volunteers. This is important as lots of volunteers do not often physically come into the hospice due to being a hospice neighbour, so hospice staff may not know if they were struggling.

Clinical psychologists could be instrumental in advocating for Schwartz Rounds to be implemented. Schwartz rounds are open to all staff, including volunteers, and are an opportunity for those involved in a patient's care to reflect on the emotional impact of their work(13). Volunteers would be involved with the rest of the hospice team in processing their connection with a patient and the impact that working with them has had. Schwartz rounds are usually co-facilitated with a medical doctor and a psychosocial practitioner(14) and have been found to improve interprofessional relationships due to increased understanding of others' roles(15) and they have been received positively by those involved(16). Based on the results of the current study, this could support connection with the hospice which volunteers feel is important, support them in managing death and the challenges of their role and contributing to the sense of 'it's where I'm meant to be' because they are being involved and treated as equal to other team members.

The research journey

My research journey began as I chose a topic that was personally and professionally interesting. I worked in a hospice for six months as one of my training placements and spent time with a number of volunteers who I felt were meaningfully contributing to the hospice. It materialised that volunteers did not receive formal support. This surprised me as I was aware of the support provided to nurses, doctors, psychologists and other members of the healthcare team. For example, reflective practice sessions were facilitated by a clinical psychologist for nurses to explore the impact of their role and to discuss challenges. Multi-disciplinary team meetings were another avenue for paid staff to explore difficulties with patients or receive support and guidance from other team members. Volunteers were not permitted in these meetings so were not given this opportunity despite spending lots of time with patients. I wondered how volunteers managed their role in relation to emotional well-being and started searching the literature to investigate what had previously been found. There was very little on this topic so I felt it would be a useful area to explore further. From working in a hospice and interacting with volunteers, I expected the results of this research to be more focused on volunteers'' personal experiences of death and dying and how this impacted on them carrying out their role. Although this was mentioned by some volunteers, it was not the focus of their discussions.

Moving from clinician to researcher

As the research focused on the emotional well-being of participants, the research interviews had components that were comparable to therapeutic conversations about death and dying. I considered this prior to the interviews and held this in mind throughout, attempting to refrain from entering into a therapeutic style of questioning. This is because it was a limited single interview with no continuity therefore, if unresolved issues arose, I would be unable to offer any continued emotional support (17). This was challenging at times, particularly when some

participants became emotional when discussing how their role impacted on their emotional well-being. In two interviews, the participant and I agreed that the audio recorder would be turned off when they became tearful to give them a chance to reflect on how they were feeling and if they wanted to continue. Both participants apologised for crying and were reassured that the topic could be difficult to discuss. Both decided to continue with the interview. I felt that my experience as a psychologist assisted me in the research interviews as I had good transferable skills to engage individuals, which is needed both within therapy and research, for example using active listening skills(18). Many participants commented that they felt pleased to have been given the opportunity to participate and that the impact of volunteers' roles was being researched. I felt that these volunteers experienced feelings of being valued and that research on volunteers highlighted their importance within the hospice system. The experience of conducting these interviews made me wonder whether the interviews themselves acted as an inadvertent form of emotional support for some volunteers which highlights the need for support to be offered to them.

Conducting interviews centred on end-of-life care was extremely interesting and powerful; it is common for researchers to be emotionally affected by research that needs a great deal of emotional energy(19). Although I had experience of working in a hospice and was practised at supporting patients at the end of life, I had little experience with staff or volunteers in end-of-life settings and listening to their experiences of how this impacted on themselves. I felt deeply connected to their experiences and this also presented itself during transcription where I felt that the interviews were challenging to transcribe for extended periods of time. I managed this by reflecting on the interviews immediately afterwards and writing notes about my impression of the interviews and my personal reaction to the interviews. During transcription, I ensured that I took regular breaks and reflected on interviews which were

more emotionally demanding to transcribe. Qualitative research can emotionally affect researchers(20); self-reflexivity has been shown to be helpful in managing this in research on loss and grief, as well as supervision(21). There were also support mechanisms in place for the researcher within supervision and peer support which enabled the researcher to discuss the emotional impact of the research.

Boundaries

The majority of participants wanted to talk about my training and where I wanted to work upon qualification after the interview had finished. This surprised me because, as a clinician, patients do not often ask personal questions within therapy and I had not considered how much I wanted to share with participants. I felt that they were seeking a reciprocal relationship and, as I had taken such interest in their roles throughout the interviews, they were showing an interest in my role. Having not considered this prior to the interview, I decided that I would share this information with them. I feel that this challenged my perception of boundaries as I was unsure what was generally perceived to be 'correct' boundaries between researchers and participants. Usually with patients I would share limited information as I believe therapy sessions should be focused on the patient and would explore with them why it was important to know this about me. However, it felt different as a researcher as I had completed the intention of the meeting(17). This is different to doing therapy where the work is ongoing and the focus should be mainly on the patient, whilst providing enough information to build a therapeutic relationship. I have continued to reflect on this and considered how I would manage this in future research. Boundaries between the researcher and participant have been considered in the literature. The insider versus outsider role continuum is where participants feel that the researcher shares something with the participant that gives them 'insider' knowledge about a particular topic or that the researcher

does not have their own experiences to help them to understand the experience of participants (22). It could also be somewhere along this continuum. I felt that participants saw me more towards the 'insider' end of the continuum because I had some knowledge and experience of working in palliative care. This could have enabled them to open up more about difficult experiences as they may have felt I would empathise and understand. It has been suggested that being an 'insider' researcher has advantages as it can help a researcher to gather information more quickly(23). However, there are also disadvantages to this as, if researchers feel they are an 'insider', this could lead to them missing relevant information or have a bias towards the data (24). Supervision was a useful way to consider ethical and practical dilemmas in the dual roles of researcher and clinician(17).

Research methods

I chose qualitative methodology due to the exploratory nature of the research question, therefore needing to gather detailed information about volunteers' experiences rather than questionnaires with limited choices for responses. IPA has been used widely within health and clinical psychology(25). It enables interpretation of the data and attempts to stay close to the participants meaning-making of their experiences whilst recognising that the results are ultimately the researcher's meaning-making of participants' meaning-making (the double hermeneutic)(26).

This research aimed to investigate experiences of people doing a similar role (patient-facing hospice volunteers) therefore all participants had this in common. As IPA is idiographic in nature, it focuses on similarities and differences within a small group of participants rather than trying to generalise findings(4). For example, the current study does not capture any experiences of hospice volunteers who are in non-patient-facing roles or volunteers who have

left the role. These findings are not intended to represent the wider volunteer population but to display the meaning-making of experiences of the interviewed participants to give insight into the impact of the role on emotional well-being. IPA also appreciates that individuals' experiences are subject to both themselves and their environment(27). I took a critical realist position within the research, common within IPA(28), which fits with the opinion that knowledge is culturally relevant. For example, it represents the view that reality exists independently of humans, however we cannot access this reality directly and there will be bias due to interpreting this reality in a way that is partially contrasted and affected by the researcher. This seemed appropriate for the current study as I wanted to understand participants' experiences of emotional well-being in a specific context.

IPA aims to attain a rich and detailed account of individuals' experiences, however, during analysis this is inevitably combined with others' experiences. It is important not to lose the individuality of participants when themes emerge, therefore I consciously looked back to each transcript and considered how they contributed to each theme. I transcribed the interviews, which helped bring me closer to the data, and it was a valuable process as it reminded me of the interviews. However, this was challenging to complete given the timescale and during the transcription it could become emotive listening back to participants' accounts of their experiences. I kept a reflective journal throughout the thesis process and commented on my feelings about the interviews after they were conducted, during transcription and analysis. This helped me to immerse myself within the data and keep track of my thoughts surrounding the data. Supervision was also utilised to support the development of emerging themes.

Consideration of my personal experiences on the topic

Many researchers have encouraged reflexivity when conducting qualitative research to be aware of potential biases that could affect the interpretation and analysis of data(29). I felt this was an important consideration to develop my understanding of how much I could bracket my potential biases, including ideas and beliefs generated from personal experience and influences from previous literature. However, it is not believed that this can be done entirely and appreciated that the researcher is a big part of the research process(30). This is important as the aim of the research is to express findings that are close to the participants' meaning-making of their own experiences. I found this an interesting process to engage in and kept a reflective diary. This was helpful to complete immediately after interviews and helped to capture my initial thoughts, the experiences that the participants had described and how I felt the interview had gone. I also noted any biases such as experiences that touched me and any similarities or differences to the literature that I was aware of. Although I had not volunteered in a hospice, I had volunteered in a dementia unit so felt I had some awareness of issues faced by volunteers generally and how my role had impacted on my emotional well-being. I also had experience of being a relative visiting a patient in a hospice although did not have much contact with volunteers. After each interview, I felt a pull towards volunteering in a hospice. I felt inspired and that I wanted to 'give back' to the community and to a place that had provided me with such a good placement. However, as time went on, I realised that, at this point in my life, with multiple demands, I would not be able to give as much as I wanted to. This reflected some of what the participants were saying in their interviews. When speaking to family and friends about this research, I received a lot of praise and recognition with comments on what a great area it was to research. I felt that this somewhat reflected the participants talking about what they get from volunteering in the hospice. Family and friends also said that it had made them consider if they wanted to volunteer in a hospice.

Disseminating the research

When approaching the hospices to obtain governance approval, they asked to have a copy of the findings upon completion so that they could appropriately disseminate and consider the findings for their hospice. I also offered participants a summary of the results and all participants wanted a copy of this. I explained that there would be a delay due to the timescale of the project. I will be distributing this shortly. Feedback does not identify participants or hospices. I believe that it is important for both the institution and participants to receive feedback about research in which they have taken part, and this is not always done by researchers. I will also be disseminating the research at the Lancaster Doctorate in Clinical Psychology presentation day as well as attempting publication in the identified journal.

The Covid-19 pandemic

The Covid-19 pandemic meant that the UK entered lockdown as I was finishing writing the thesis and, due to the topic of the thesis, I felt this impacted on me as I was writing. This is because death began to be discussed more widely in both the media, in society and amongst friends and family. Previously, death was something that I felt was not openly discussed, although I would try to encourage these conversations. The value of volunteering has also been highlighted during this pandemic as many people have signed up to the NHS volunteer support scheme. Data collection and analysis had been completed by this point, so the pandemic did not affect this part of the thesis. However, I considered the age of many of the volunteers (many being over 70 years old) and how it would mean that they may have been self-isolating for a period of time prior to the UK-wide lockdown(31). Studies have reported the interruption of hospice volunteers' support due to the pandemic(32). There have also been suggestions that hospice volunteers could communicate with patients and families via telephone and provide psychological support(33). This means that volunteers could be

expected to provide support in an extremely uncertain time in their own lives without appropriate supervision. This should be addressed as soon as possible and reflected upon post-pandemic. Based on the interviews which highlighted the importance of their role, with it being a huge part of their life and them benefiting socially from the experience, I wondered how the pandemic was affecting them and their perception of their place in the world. I also considered the impact on the patients with day therapy units being closed and how many patients would miss the interaction with staff and volunteers. The general population have concerns related to the impact of the pandemic on their emotional well-being(34). Older people are also vulnerable to experiencing feelings of social isolation and loneliness in this period which can affect physical and mental health(31). Therefore, those who are outpatients with the hospice are an even more vulnerable group who may be at risk of deteriorating health. If volunteers are then encouraged to contact patients to have therapeutic conversations, this could negatively impact the volunteer's emotional well-being and they could feel helpless. An ageist discourse has also been seen throughout the pandemic which could lead to older people feeling worthless, unvalued and even in the way(31). Paid staff are also seeing an increased pressure, particularly without the support of many volunteers. I feel that the pandemic could highlight the importance of volunteers in the hospice and the value of their interaction with patients and families. It will be interesting to see the impact this has on the future for volunteers and their place within the hospice.

Conclusion

This critical appraisal has explored some issues that were experienced throughout the research process by focusing on my personal reflections. This is an important piece of research as it highlights the emotional experiences of hospice volunteers and suggests how they could more formally be supported going forward. They are a vital cog in the wheel of

the hospice and increased research and implementation of support for volunteers may show them just how valued they are.

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Section Four: Ethics documents

Helena Coleman

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Lancaster University

Faculty of Health and Medicine Research Ethics Committee (FHMREC) application for ethical approval

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project: The impact on emotional well-being: experiences of being a palliative care volunteer. An interpretative phenomenological analysis.

Name of applicant/researcher: Helena Coleman

ACP ID number (if applicable)*: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:
E-mail: h.coleman@lancaster.ac.uk **Telephone**: 07813397959 (please give a number on which you can be contacted at short notice)

Address: Doctorate in Clinical Psychology, Furness College, Lancaster University, Lancaster, LA1 4YG

3. **Names and appointments of all members of the research team (including degree where applicable)**

Helena Coleman – Trainee Clinical Psychologist
Catherine Walshe – Head of Department, International Observatory on End of Life Care
Andy Thomas – Clinical Psychologist

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:
Catherine Walshe – Research Supervisor, Head of Department, International Observatory on End of Life Care
Andy Thomas – Field Supervisor, Clinical Psychologist, Trinity Hospice

SECTION TWO
Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' n o
4c. If yes, where relevant has permission / agreement been secured from the website moderator? n o
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? n o
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder
7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Volunteers are essential to the palliative care system, particularly in hospice settings, with more than 100000 volunteers across the UK; these services would struggle with current provision without volunteers' support. The current study aims to examine hospice volunteers' experiences of the impact of their role on their emotional well-being. This research will be qualitative and use Interpretative Phenomenological Analysis. Participants will be aged 18 or over, be English speaking, have the capacity to consent and are currently volunteering in hospice care in a patient facing role. I plan to recruit from three hospices in the North West of England and use semi-structured interviews to collect the data. The current study aims to build upon what is already known about volunteers in hospice settings and provide a more in-depth examination of volunteer's experiences. In doing this, more can be learnt about the role of the volunteer and their psychological needs.

2. **Anticipated project dates (month and year only**)

Start date: May 2019 End date August 2020

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

The aim is to recruit people who volunteer for a hospice in the North West in a patient facing role. It is anticipated that around 6-10 participants are likely to be required, congruent with many IPA studies (Smith, Flowers, Larkin, 2009), but this final number cannot be known until data collection commences. Participants can be of any gender.

The inclusion criteria are volunteers in hospice care in a patient facing role, adults aged 18 or above, English speaking and those who have the capacity to consent. Participants must be English speaking due to limited funding for research (and thus translation/interpretation costs) and limited time for collecting and analysing data in other languages.

The exclusion criteria are those who have worked in a volunteer role within a hospice setting for less than one month.

Demographic details will be collected from participants and reported on as this could be relevant to the results. These details will include gender, age, ethnicity, marital status, how long the individual has volunteered in the hospice and if they have experienced a close friend or relative have end-of-life care within a hospice setting.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be recruited from three hospices in the North West of England. The identified hospices are [redacted] The participating hospices would not be identified in any outputs and would be referred to as "hospices in the North West of England". We are interested in people's intrinsic experiences and believe that there could be some site-specific factors. Therefore, the preference would be to recruit approximately 3 people from each hospice and purposive sampling will used to do this.

Following written governance approvals from each hospice, volunteer coordinators within each hospice will circulate information (invitation letter, participant information sheet and reply slip with my contact details on) about the study to eligible volunteers by post, email or on collection, depending on their usual modes of communication. Those who are interested will be asked to contact Helena Coleman (by telephone, email or posted reply slip). Freepost envelopes will be provided with the circulated information. Volunteers can opt to give the reply slip to their volunteer coordinator as this may be their preferred method of communication. By doing so, they would be aware that the volunteer coordinator would then know they were participating in the study. This would be the choice of the volunteer as other options enable them to directly communicate with the researcher. This would also include people in the study who do not have access to phone, post or

email. For all volunteers who contact Helena Coleman to say they are interested, she will liaise directly with them to discuss the study and arrange an interview.

If there is a lack of participants from these three hospices, other hospices (initially in the North West) will be approached.

Recruitment will close by December 2019 due to time limitations on the project.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Semi-structured interviews will be used to collect the data, commonly used within IPA. This has been chosen as IPA aims to elicit rich, detailed data (Pietkiewicz & Smith, 2012). Semi-structured interviews are in-depth and allow an opportunity for this rich data to be generated. Semi-structured interviews have been chosen to allow specific topics to be covered with space and flexibility for participants to discuss their own ideas which may not be included in the initial interview schedule. Please see the topic guide for the interviews. Interviews can be offered face-to-face or via telephone, depending on the preference of the participant. The interviews will be audio-recorded and transcribed verbatim by the researcher.

Interpretative Phenomenological Analysis (IPA) will be used as the method of analysis. This has been chosen as it focuses on people's experience, aims to explore the participant's view of their inner world and gain a deeper understanding of a particular aspect of human experience (van Manen, 1984). IPA is a double hermeneutic as the research is making sense of the interviewee making sense of their experience (Smith & Osborn, 2003). IPA is most suitable for small homogenous samples (Smith, 2015) and the small homogeneous sample here are hospice volunteers in patient facing roles. Line-by-line analysis on each transcript will highlight descriptive, linguistic and conceptual comments. Emergent themes will then be developed. This process will be repeated for each transcript. Patterns across cases will then be documented. Through this process, participants' individualism will be maintained whilst also developing higher order concepts. Analysis will be managed using NVivo software.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

All documents and audio files will be password protected and all data stored electronically on a secure drive (H Drive) allocated by Lancaster University. Physical copies of consent forms will be scanned and stored securely on this H Drive. The physical consent forms may be stored and archived. At the end of the study, the anonymised transcripts will be transferred electronically to the DClinPsy Research Coordinator using a secure method supported by the University. They will be instructed with a date of when to delete the anonymised transcripts. These transcripts will be stored for 10 years before being deleted by the DClinPsy Research Coordinator. Files containing participant's personal/identifying details will be kept in a separate secure file from the anonymised transcripts with an ID number used to match participants identifying details to their transcripts. All personal/identifying details relating to the participants will be deleted within 6 months of the project completion date.

7. Will audio or video recording take place? ☐ no ☒ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

Audio data generated from the interviews will be deleted from any encrypted portable device used as soon as possible and transferred via the secure University VPN. These will be stored on a secure drive (H Drive). For the likely short time between the interview and transfer, the audio data on the portable device will be stored as securely as possible and kept with the lead researcher. In all other cases, where they are used for identifiable data, portable devices (USB drives) will be encrypted.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio recordings will be deleted once the thesis has been examined in case original recordings are needed for any reason.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder
8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

All relevant files with documentation will be offered to the UK Data Archive as per the standard ESRC procedures. If the UK Data Archive will not accept the offered data, it will be stored in Lancaster University's data repository (via Pure) where it will be preserved according to Lancaster University's Data Policy for a minimum of 10 years. The DClinPsy Research Coordinator will delete the data after 10 years.

8b. Are there any restrictions on sharing your data ?

Due to the small sample size, even after full anonymization there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request with genuine researchers. Access will be granted on a case by case basis by the Faculty of Health and Medicine.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Participants will receive an information sheet about the study and contact the researcher if they are interested in taking part. The researcher will then talk through the study with them and arrange a time to conduct the interview. At the interview, the participant will be asked to read through and sign a consent form. These written consent forms will be scanned and stored securely on the VPN and paper copies shredded. They will have the opportunity to ask questions. The researcher will explain that participants can withdraw at any time during the study being conducted. it will also be made clear that they can withdraw after the interview is finished but that there is a limited time in which they can do this. Whilst every effort would be made to withdraw their data for the data set, this may not possible once data has been pooled for analysis.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

This project may include topics that are distressing for the participants. However, possible sources of support have been provided in the participant and parent information sheet and debrief sheet as a precaution. If participants are distressed during the interview, the interview will be stopped, and participants will be asked if they want to continue. Participants may choose to terminate the interview at this point or take a break. Sources of support will be incorporated into the debrief sheet should participants need it. There is a distress protocol in place.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

It is anticipated that the majority of these interviews will be taking place at the hospices. However, the researcher may be lone working for some of these interviews which could take place in the participants' home or at Lancaster University. The research and field supervisors will be informed via phone or email when lone working commences and when it has been completed. The researcher will also follow the Lancashire Care Foundation Trust lone worker policy as this is the trust the researcher is employed by.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

People may find it a positive experience to participate in this project because they are getting the chance to share their experiences.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:
N/A

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Data collection
All information will be confidential at the data collection phase unless the researcher deems there is a risk to the participant or a risk to someone else which has been disclosed through the interview process. In this instance, the researcher would explain to the participant, where possible, that they need to share this information with either the hospice or other organisation in order to keep them or someone else safe from harm.

Process of analysis
All information will be anonymised when transcribed and will be transcribed by the researcher. In submission for examination and publication, confidentiality cannot be maintained as direct quotes from participants will be used, however anonymity will be maintained. Anonymity will be

maintained through the use of pseudonyms to represent participants, rather than their real names. The names of the hospices will also be anonymised.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The researcher will discuss the participant information sheet, consent form and debrief sheet with a hospice volunteer in a patient facing role. They will also be consulted on the interview schedule and a pilot interview will be conducted with one volunteer to assist in the development of the questions.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

I will produce a summary of the results for the participants and any other stakeholders. I could disseminate findings on the thesis presentation day. The results will also be discussed with the hospices with a view to integrating any recommendations into their practice.

Results of this project will be submitted for the researcher's thesis and submitted for publication in academic/professional journals.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

SECTION FOUR: signature

Applicant electronic signature: H.Coleman Date 14.05.2019

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Catherine Walshe Date application discussed 14.05.2019

Submission Guidance

1. **Submit your FHMREC application by email to Diane Hopkins (**fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    i. **FHMREC application form.**
    Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    ii. **Supporting materials.**
    Collate the **following materials for your study, if relevant, into a single word document:**
        a. **Your full research proposal (background, literature review, methodology/methods, ethical considerations).**
        b. Advertising materials (posters, e-mails)
        c. Letters/emails of invitation to participate
        d. Participant information sheets
        e. Consent forms
        f. Questionnaires, surveys, demographic sheets
        g. Interview schedules, interview question guides, focus group scripts
        h. Debriefing sheets, resource lists

    Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
    ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:
        a. existing documents/data only;
        b. the evaluation of an existing project with no direct contact with human participants;

c. service evaluations.

3. **<u>You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application</u>**

Faculty of Health and Medicine Research Ethics Committee (FHMREC) Supporting documents for ethical approval

The impact on emotional well-being: experiences of being a palliative care volunteer. An interpretative phenomenological analysis.

Applicant: Helena Coleman

Research Supervisor: Catherine Walshe Field Supervisor: Andy Thomas

Study Summary

Study Title	The impact on emotional well-being: experiences of being a palliative care volunteer. An interpretative phenomenological analysis.
Study Design	Interpretative Phenomenological Analysis
Study Participants	Hospice volunteers in patient facing roles from three North West hospices
Planned Size of Sample	6-10 participants
Follow up duration	No follow up
Planned Study Period	May 2019 – May 2020
Research Question/Aim(s)	To explore palliative care volunteers' experiences of the impact on emotional well-being from working in adult hospice care.

Introduction

Volunteers are an integral part of the palliative care system, particularly in hospice settings, with more than 100000 volunteers across the UK; these services would struggle to continue with current provision without volunteers' support (Help the Hospices, 2012). Palliative care is an approach aimed at improving the quality of life of individuals living with an incurable illness (World Health Organisation [WHO], 2002). There is an increasing demand on hospice and palliative care services due to the ageing population (World Palliative Care Alliance & WHO, 2014). Therefore, there is an increasing role for volunteers providing support to patients. Volunteers in adult settings can be involved in a number of areas, including bereavement services, providing emotional support to patients and being with patients at the end of their life; this indicates that volunteers are increasingly involved in providing psychosocial care to patients (Burbeck et al., 2014).

Research highlights that volunteering in a number of settings has positive impacts for the volunteer on areas such as mental health, life satisfaction and social interaction (Casiday, Kinsman, Fisher & Bambra, 2008). In contrast, a number of stressors for palliative care volunteers related to their role are: poor communication, lack of emotional support, feeling undervalued and the need for training (MacLeod, Skinner & Low, 2011). However, there has been little research into the impact on the volunteer of their role within a hospice setting. Instead, research has focused on personality characteristics of palliative care volunteers (Claxton-Oldfield & Banzen, 2010) and the reasons for becoming a volunteer (Nissim et al., 2016; Plannalp &Trost, 2009). It has also focused on the impact volunteers have on patients, their families and carers (Cassidy, Kinsman, Fisher & Bambra, 2008; Candy, France, Low, Sampson, 2015).

Although previous research does not focus on volunteers' experiences of their role within hospice settings, research indicates that those in paid roles can experience

psychological distress and a number of emotional demands (Hill, Dempster, Donnelly & McCorry, 2016). Working within palliative care brings unique experiences for staff and empirical evidence has shown that emotional risks, such as stress, burnout and mental health difficulties, are apparent in some staff within this setting (Kamau, Medisauskaite & Lopes, 2014). There have been a number of suggestions to support staff working in palliative care settings, such as training and support in developing individualised coping strategies to encourage self-care and resilience (Swetz et al., 2009). However, most of this research has focused primarily on paid staff rather than what could be useful to support volunteers in their roles.

There has recently been an increased interest in volunteers within palliative care, with research focusing on improving and developing volunteers' roles (Candy, France, Low, Sampson, 2015). However, this appears to be mainly based on maximising the benefit of having volunteers in such settings. Due to the reliance on volunteers' support, research is needed to understand the experiences of volunteering in a hospice setting. Volunteers report that they have been changed in some way by their experience of being a hospice volunteer (Claxton-Oldfield & Claxton-Oldfield, 2007). If volunteers' experiences were communicated effectively, this could help retain and recruit into these roles, whilst creating more positive experiences for the volunteers.

The current study aims to build upon what is already known about volunteers in hospice settings and to provide a more in-depth examination of volunteers' experiences of how their role may impact on their emotional well-being. In doing this, research findings may be applied within palliative care settings to support volunteers in their roles, ultimately impacting on the support patients receive.

This is relevant to the field of clinical psychology as we can learn more about the advantages and disadvantages of being a volunteer. Based on the results of this study, clinical

psychologists could be involved in informing or providing consultancy in how to address psychological needs of volunteers. Clinical psychologists are required to provide such support, supervision and consultation to paid members of the mutli-disciplinary team in hospices (Hayley, Larson, Kasl-Godley, Neimeyer & Kwilosz, 2003; NICE, 2004), so would be well placed to provide this support in relation to volunteers. This led to the development of the following research question: 'What are palliative care volunteers' experiences of the impact on their emotional well-being from working in adult hospice care?'.

Method

Design

A qualitative Interpretative Phenomenological Analysis (IPA) methodology was selected to explore hospice volunteers' experiences of their role in relation to emotional well-being. This is suitable as this is a scoping, exploratory study due to little research on this topic. Quantitative research would not have permitted the exploration of participants' experiences and meaning-making (Harris, 2012).

IPA (Smith, 1996) has been selected because its epistemology suggests that, through interpretative methodology, it is possible to access someone's 'inner world' and how they make meaning out of their experiences (Biggerstaff & Thompson, 2008). This reflects the aims of this research. IPA is also a double hermeneutic (the researcher is making sense of the interviewee's sense-making) (Smith & Osborn, 2003). This means that the researcher and participant will co-construct an understanding of this topic (Pringle, Drummond, McLafferty & Hendry, 2011).

In contrast to other phenomenological approaches, IPA is also able to highlight differences through identifying both convergent and divergent themes. This helps the researcher to represent each participant's experience, congruent with IPA's idiographic

approach (Smith & Eatough, 2007). The detailed accounts from participants will provide increased understanding of the experience of being a hospice volunteer.

Epistemology has also played a part in the methodological decision. The researcher has adopted a critical realist position, typical in IPA (Smith & Eatough, 2007). Therefore, the researcher believes that we make sense of a reality, which occurs separately to our thoughts, that is influenced by our social experiences (Harris, 2012).

Setting

Data will be collected from three hospices in North West England.

Participants

IPA is idiographic in nature and aims to understand how something has been experienced and understood by certain people (Smith, Flowers & Larkin, 2009). Therefore, IPA research tends to have a small, homogenous sample, purposively selected (Smith, 2015). For this project, 6-10 hospice volunteers in patient-facing roles will be the homogenous sample recruited. The inclusion criteria are: people volunteering in a hospice setting, in patient-facing roles; English speaking; aged 18 or above; and those who have the capacity to consent. Participants must be English speaking due to limited funding for research (thus translation/interpretation costs) and limited time for collecting and analysing data in other languages. The exclusion criteria are those who have been volunteering for less than one month. Demographic details, such as gender, age, ethnicity, marital status, length of time they have volunteered and whether or not they have experienced a close friend or relative have end-of-life care within a hospice setting, will be collected. The hospices to recruit from were selected due to location and contacts through the field supervisor.

Sampling

Purposive sampling of volunteers in hospices will be used. We are interested in individual's intrinsic experiences and believe that there could be some site-specific factors.

Therefore, the preference would be to recruit approximately three participants from each hospice.

Recruitment

The volunteer coordinators at each hospice will circulate information (invitation letter [appendix B], participant information sheet and reply slip with the researcher's contact details on [appendix A]) about the study to all eligible volunteers. They will do this by post, email or on collection, depending on how they usually communicate information to volunteers. Those who are interested in taking part will be asked to contact the lead researcher (by telephone, email or posted reply slip). Freepost envelopes will be provided with the circulated information. For all volunteers who make contact, the lead researcher will then explain the study to them in more details and arrange interviews should they still wish to take part. The first 6-10 participants identified will be included in the study. If there is a lack of participation, further hospices will be approached. Recruitment will close in December 2019 due to time limitations on the project.

Data collection

On the day of the interview, each participant will be given a chance to reread the participant information sheet [appendix A] and ask any questions. They will then be asked to sign a consent form [appendix C]. It will be explained that participants can withdraw at any time during the interview. It will also be explained that they can withdraw their data up to two weeks after the interview. Participants will be made aware that if they request their data to be withdrawn after data has been pooled for analysis, it may not be possible to withdraw their data. However, every effort would be made to do this. Demographic details, such as gender, age, ethnicity, marital status, length of time they have volunteered and whether or not they have experienced a close friend or relative have end-of-life care within a hospice setting, will be collected.

Face-to-face semi-structured interviews will be conducted, commonly used within IPA. The interview schedule [appendix G] was generated based on previous literature and in accordance with the recommendations for IPA (Smith, Flowers & Larkin, 2009). Two volunteers read the interview schedule [appendix G] prior to the data collection. They also read the consent form [appendix C], participant information sheet [appendix A] and participant debrief sheet [appendix F] and suggested some amendments which have been incorporated. Semi-structured interviews were chosen as IPA aims to elicit rich, detailed data (Pietkiewicz & Smith, 2012). Semi-structured interviews are in-depth and allow an opportunity for this rich data to be generated. Semi-structured interviews have been chosen to allow specific topics to be covered with space and flexibility for participants to discuss their own ideas which may not be included in the initial interview schedule.

The interviews will be audio-recorded and transcribed verbatim by the researcher. After the first interview, the data will be discussed with the research supervisor and the interview schedule will be reviewed and additional questions or prompts may be incorporated if necessary.

Analysis

The data will be analysed using IPA (Smith, 1996). This has been chosen as it focuses on people's experience, aims to explore the participant's view of their inner world and gain a deeper understanding of a particular aspect of human experience (van Manen, 1984). IPA is a double hermeneutic as the researcher is making sense of the interviewee making sense of their experience (Smith & Osborn, 2003). IPA is most suitable for small homogenous samples (Smith, 2015) and the small homogeneous sample here are hospice volunteers in patient facing roles. Line-by-line analysis on each transcript will highlight descriptive, linguistic and conceptual comments. Emergent themes will then be developed. This process will be repeated for each transcript. Patterns across cases will then be documented. Through

this process, participants' individualism will be maintained whilst also developing higher order concepts (Smith et al., 2009). Analysis will be managed using NVivo software.

Ethical Issues

Disclosure of risk issues from participants

If a participant reports a risk to themselves or to someone else, the researcher will inform the participant that they will need to inform their supervisor or an onsite clinician. A joint decision will then be made of how to proceed with the lead researcher and supervisor. This would be dependent on the risk presented.

If a participant disclosed risk to patients, other volunteers or staff members within the hospice, the lead researcher will inform the participant that they will need to pass this on to the relevant people. A liaison will be identified at each hospice where any issues of risk regarding the hospice will be discussed.

Discomfort for participants

Participants may experience discomfort from talking about their experiences and a distress protocol [appendix D] is in place. If participants are distressed during the interview, the interview will be stopped, and participants will be asked if they want to continue. Participants may choose to terminate the interview at this point or take a break. Sources of support have been incorporated into the debrief sheet [appendix F] should participants need it.

Research Ethics Committee (REC) and other Regulatory review and reports

Full ethical approval will be sought from the Faculty of Health and Medicine Research Ethics Committee (FHMREC). Each hospice will be asked to provide written governance approval.

Data Management

Audio data generated from the interviews will be deleted from any encrypted portable device used as soon as possible and transferred to the secure University VPN. For the likely short time between the interview and transfer, the audio data on the portable devie will be stored as securely as possible and kept with the lead researcher. In all other cases, where they are used for identifiable data, portable devices (USB drives) will be encrypted.

All documents and audio files will be password protected and all data stored electronically on a secure drive (H Drive) allocated by Lancaster University. Physical copies of consent forms will be scanned and stored securely on this H Drive. The physical consent forms may be stored and archived. At the end of the study, the anonymised transcripts will be transferred electronically to the DClinPsy Research Coordinator using a secure method supported by the University. They will be instructed with a date of when to delete the anonymised transcripts. These transcripts will be stored for 10 years before being deleted by the DClinPsy Research Coordinator. Files containing participant's personal/identifying details will be kept in a separate secure file from the anonymised transcripts with an ID number used to match participants identifying details to their transcripts. All personal/identifying details relating to the participants will be deleted within 6 months of the project completion date

All researchers and study site staff will comply with GDPR and the Data Protection Act 2018 requirements for data collection, storage, processing and disclosure of personal information. Please see Lancaster University's webpage for more information about how Lancaster University processes personal data for research: www.lancaster.ac.uk/research/data-protection

Dissemination Policy

Dissemination is planned at professional and academic journals and at the Doctorate in Clinical Psychology thesis presentation day. A summary of the results will also be made

available to research participants and to the hospices from which they were recruited. The results will also be reported in the lead researcher's doctoral thesis.

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Appendix A – Participant Information Sheet

Participant Information Sheet

The impact on emotional well-being: experiences of being a palliative care volunteer

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Helena Coleman and I am conducting this research as a student at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to gain an understanding of hospice volunteers' experiences of their role.

Why have I been approached?

You have been approached because the study requires information from people who are hospice volunteers in patient facing roles. We have asked the volunteer coordinator at the hospice to distribute this information to those who volunteer in these roles.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

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

If you decide you would like to take part, you would be asked to meet with me for an audio-recorded interview about your experiences of being a volunteer. This interview will last for approximately one hour. If there is a large number of people who express an interest in participating, you may not be able to take part. However, if you are interested in the results of the research, I can send you a summary of the results on completion of the study.

Can I change my mind after agreeing to take part?

Yes – you can change your mind. If you want to withdraw during the interview, we will stop the interview and your data will not be used. You can also withdraw up to two weeks after the interview and your data will not be used. After I have pooled the data from everyone's interviews, it may not be possible to withdraw your data, but every effort will be made to do this.

Will my data be Identifiable?

The information you provide will be anonymised so no one will know what you have said. I will not tell other people what you have said directly, but in the summary of results you may see things that are familiar or similar to what you have said. Your name will not be attached to this.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined. The files will be encrypted (this means no one other than the researcher will be able to access them) and the computer itself is password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All personal data will be confidential and will be kept separately from your interview responses.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.

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

What will happen to the results?

The results will be summarised and reported in my thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

We expect there to be few risks with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

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

If you have any questions about the study, please contact the main researcher:
Helena Coleman – Trainee Clinical Psychologist
Email: h.coleman@lancaster.ac.uk
Phone: The DClinPsy provided phone number is currently not available but will be made available for the interviews and will be added to the PIS.

Catherine Walshe - Research Supervisor
Email: c.walshe@lancaster.ac.uk
Phone: 01524510124

Andy Thomas – Field Supervisor
Email: elaine.evans10@nhs.net (Secretary)
Phone: 01253359378

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith Tel: (01524) 592282
Research Director
Email: i.smith@lancaster.ac.uk
Division of Clinical Psychology
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

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

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, you can contact your line manager. The following resources may also be of assistance:

Samaritans
Phone: 116 123
Website: www.samaritans.org

Cruse Bereavement Helpline
Phone: 0808 808 1677
Website: www.cruse.org.uk

Appendix B – Letter to potential participants

Dear Volunteer,

My name is Helena Coleman and I am studying for my Doctorate in Clinical Psychology at Lancaster University. As part of my training, I am required to do a research project. I have decided to do this within palliative care and would like to interview hospice volunteers about their experience of being a volunteer. The interview will be informal and last approximately one hour.

You can take part if:

- You have been volunteering with the hospice for more than one month
- You volunteer in a patient facing role (e.g. driver, day therapy, inpatient unit, home care, befriending) rather than behind the scenes (e.g. finance office, shops)

I have enclosed more information about the study if you would like to know more.

If you would like to take part or have a conversation to discuss the project, please get in touch in **one** of the following ways:

1) Call or text: The DClinPsy number will be added when allocated OR 2) Email: h.coleman@lancaster.ac.uk OR
3) Fill in the slip below and give it to your volunteer coordinator or post it back to me using the freepost envelope. I will then contact you.

Yours Sincerely

Helena Coleman

……

The impact on emotional well-being: experiences of being a palliative care volunteer

I am interested in the above research project and would like Helena Coleman to contact me on the details below.
The hospice I volunteer in is:
My telephone number is:
My email address is:

Name_____Signed_____Date_____

Please return this form to your volunteer coordinator if you would like to be contacted regarding participation in this study

Appendix C – Participant Consent Form

Consent Form

The impact on emotional well-being: experiences of being a palliative care volunteer

We are asking if you would like to take part in a research project looking at hospice volunteers' experiences of their role.

Before you consent to participating, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Helena Coleman

	Please initial each statement
1. I confirm that I have read the information sheet and fully understand what is expected of me within this study	☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered.	☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.	☐
4. I understand that audio recordings will be kept until the research project has been examined.	☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.	☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.	☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events.	☐
9. I understand that the researcher will discuss data with their supervisor as needed.	☐
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor.	☐
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.	☐
12. I consent to the transcripts being shared with other researchers.	☐
13. I consent to take part in the above study.	☐

Name of Participant_____ **Signature**_____ **Date** _____

Name of Researcher _____**Signature** _____**Date** _____

Appendix D – Distress Protocol

Distress Protocol

This distress protocol will be used within the interviews to support the lead researcher in identifying and managing distress of participants.

a) Be vigilant for signs of distress or discomfort during the interview.
b) If participants appear to be distressed during the interview:
   - Pause the interview
   - Give the participant the opportunity to discuss their distress (ask questions about what they and thinking and feeling, assess risks to self)
   - Give the participant the option of taking a break or continuing the interview if you deem it appropriate to do so
   - Gove the participant the option of terminating the interview
   - Do not offer to continue the interview if you feel the participant's distress is more than would be expected in an interview about this topic
c) If the participant's distress is more than would be expected:
   - Suggest to the participant that they should contact their regular health provider for support
   - Give the participant information about local support groups that they could access
   - Ask the participant if they would be happy for you to contact them the following working day to check-in with them
   - Notify your research supervisor of recommendations given to the participant
d) If the participant displayed signs of acute emotional distress, in addition to point c) above:
   - Request permission from the participant to contact their regular health provider to inform them of the participant's distress
   - Alternatively, if you deem there is an immediate risk to the participant's safety, or someone else, contact their health provider without their permission and/or dial 999 for assistance

References

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Appendix E – Debrief sheet for researcher

Debrief Sheet for researcher

Debrief to be done at the end of the interview, in person.

1) Thank you for participating.
2) How do you feel after participating?
3) How did you find the interview?
4) Sources of support
5) Do you have any questions about the study?
6) Explain how to contact the lead researcher if there are any questions or concerns relating to participating in this study.
7) Explain what happens next e.g. they do not need to do anything, they will not be contacted for further participation, if they have requested a summary of the results this will be sent to them through the hospice in August 2020.

Appendix F – Debrief sheet for participants

Participant Debrief Sheet

Firstly, I would like to express my thanks for your participation in this project.

Purpose of the project

I did this study to gain an understanding of hospice volunteers' experiences of their role in relation to emotional well-being.

I will type up all the interviews and will pick out important information. This might help us with good practice within hospice settings.

Sources of support

If you require any support following participation in this project, you can contact your line manager. The following recommendations may also be useful:

Samaritans
Phone: 116 123
Website: www.samaritans.org

Cruse Bereavement Helpline
Phone: 0808 808 1677
Website: www.cruse.org.uk

If you have any questions or concerns relating to this project, please contact the lead researcher, Helena Coleman. (Email: h.coleman@lancaster.ac.uk)

What happens next?

You do not need to do anything else and you will not be contacted for further participation in this project. If you have requested to be informed of the results of this study, you will receive a summary of the project on completion, likely to be August 2020.

Appendix G – Interview topic guide

Semi-structured interview

Before the interview starts

- Introduce yourself and thank them for their time
- Explain the study
- Go through the information sheet and consent form with them
- Ask if they have any questions prior to the study starting

Interview Schedule
Key
Bold: Interview questions
Italic: prompts

- **Can you tell me about your role as a volunteer?**
  - *How long have you been volunteering?*
  - *Have you volunteered anywhere else?*
- **Can you tell me about how you became a volunteer?**
  - *What was the process like?*
  - *Did anyone suggest the role to you?*
- **Can you tell me about why you became a volunteer?**
- **What were your initial reactions to becoming a volunteer?**
  - *What did you think the role would be like?*
  - *Did it match these expectations?*
- **Have you had any personal experience of death and dying?**
  - *Have these experiences supported you in your role as a volunteer?*
- **What is it like working with people who are towards the end of their life?**
- **Can you tell me about the good parts of your role as a volunteer?**
  - *Are there any particular experiences that stand out for you?*
- **Can you tell me about the not so good parts to your role?**
  - *Are there any particular things that stand out for you?*
- **Can you tell me about whether or not you feel valued in your role?**
  - *What is the communication like between staff and volunteers?*
- **Can you tell me about any support you have had in your role as a volunteer?**
  - *Are there particular people that support you well?*
  - *What are the important qualities of support?*
  - *Are there people who are not so supportive?*
  - *What is it like receiving support from people?*
- **Have you had any strong thoughts or feelings in relation to your role as a volunteer?**
  - *Both positive and negative*
  - *Are there any particular patients or circumstances that stand out?*
- **How have you managed these strong thoughts and feelings?**
  - *What are you support systems like outside of the hospice?*
- **If you felt unable to manage emotionally in your role, what would you do?**
- **What could the organisation do differently to support you more in your role?**

- **How has your role impacted on you as a person and your life outside of the hospice?**
    - *Has your role impacted on your beliefs or hopes for life and death?*
- **What advice would you give to someone who had just started volunteering in a hospice, based on your experiences?**
- **Is there anything you would like to add about your experiences that we have not covered?**

Appendix H - Faculty of Health and Medicine Research Ethics Committee (FHMREC) ethical approval letter

Applicant: Helena Coleman
Supervisor: Catherine Walshe
Department: Health Research
FHMREC Reference: FHMREC18072

17 May 2019

Dear Helena

Re: The impact on emotional well-being: experiences of being a palliative care volunteer. An interpretative phenomenological analysis.

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

As principal investigator your responsibilities include:

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

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

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC